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Neglect among Adults with Disability and Older People in NSW

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Prepared for:
New South Wales Ageing and Disability Commission

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Acknowledgement of country

We value the cultures, knowledge and practices of Aboriginal and Torres Strait Islander Peoples and how this contributes to quality research. We are committed to not perpetuating harms that have been caused by research on and about Indigenous Peoples. We embrace and honour Indigenous knowledges and continue to learn from Indigenous Peoples where we work.

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Glossary

ACQSC	Aged Care Quality and Safety Commission
ADC	New South Wales Ageing and Disability Commission
Adult with disability	Under the *Ageing and Disability Commissioner Act 2019*, an adult with disability is a person aged 18 and over who has a disability, which includes a long-term physical, psychiatric, intellectual or sensory impairment that, in interaction with various barriers, may hinder the person's full and effective participation in the community on an equal basis with others
Carer	The term 'carer' in this report is used to refer to informal care provided by friends or family, not formal care provided by paid care workers
COPS	NSW Police Force Data System
CSI	Community Supports and Investigations
HCCC	Health Care Complaints Commission
NDISQSC	NDIS Quality and Safeguards Commission
Older person	Under the Ageing and Disability Commissioner Act 2019, an older person is a person who is aged 65 years or over, or aged 50 years or over if an Aboriginal or Torres Strait Islander person
PSOA	Person Subject of Allegation
Person	Adult with disability or older person who was reported to the ADC as being subject to, or at risk of, neglect

Executive summary

Neglect of older people and adults with disability features in around a quarter of all reports to the New South Wales Ageing and Disability Commission (ADC). This research has sought to better understand incidents of neglect by examining reports to the ADC. The ADC commissioned the Social Policy Research Centre to examine patterns of neglect, the roles of agencies and service providers and identify opportunities to better prevent and respond to neglect of older people and adults with disability.

The research involved a rapid review of current literature and analysis of reports of alleged neglect of older people and adults with disability in their families, homes and communities. The ADC provided deidentified databases to the SPRC for quantitative and qualitative analysis. The cases were 1,458 reports made to the ADC which were closed in 2021 and 2022. The research was reviewed and approved by the University of New South Wales Human Research Ethics Committee (IRECS7245).

The literature review identified key themes to address risk and contributory factors to neglect of older people and adults with disability and good practice prevention and intervention strategies. The findings from the literature review highlights the complexity of factors contributing to the neglect of older people and adults with disability. Similar characteristics appear to be associated with the risk of neglect for older people and adults with disability such as high levels of physical and cognitive disability, living alone and living in rental or public housing. Self-neglect has emerged as a growing area of concern internationally particularly in relation to adults with disability.

Research on good practice to enable early intervention and prevention strategies to mitigate the risk of neglect is limited. However, research in the USA in the field of emergency medicine has developed screening tools that may be adapted for use in Australia. Screening tools could be used by health and service practitioners to identify risk and also assess the capacity of the carer to meet needs.

Analysis of neglect reports data from the ADC found factors contributing to neglect at three levels of an ecological model: at an individual, relationship and service system level, with factors at each of those levels interact in people's experiences of neglect.

At an individual level, the research found differences between adults with disability and older people, such that:

Adults with disability are more likely to be

- male
- have an intellectual disability, mental illness, or physical disability
- have domestic violence identified as a risk factor potentially contributing to neglect.

Older people are more likely to be

- female
- have suspected concerns about decision making capacity
- less likely to be using community services
- more likely to have attended hospital.

At a relationship level, analysis of CSI cases found that

- In the majority of cases, the Person was living with the Person Subject of Allegation (PSOA) (75.9%), or the PSOA was their primary carer (70.7%).
- Nearly half of Persons were socially isolated (44.1%)
- Carer stress was thought to play a role in many cases (40.7%)
- Current or historical abuse within the relationship was identified as a concern in more than a third of cases (37.6%).

At a service system level, the analysis found that:

- Two-thirds of adults with disability and over a third of older people in Community Supports and Investigations (CSI) cases were receiving assistance from support services.

More than a third of cases referred to CSI (38.2%) were identified as involving serious neglect. Persons in these cases were less connected to support from services or a PSOA. They were also more likely to have domestic violence identified as a possible contributor to neglect.

The research also found that abuse, isolation and connection to services often co-occurred. Persons who were socially isolated were less likely to be connected to services, and in the majority of cases the PSOA had blocked access to services. Often, too, these cases involved carer stress, current or historic abuse.

Respect for the autonomy of older people and adults with disability to make decisions about their own lives is fundamental at the ADC. At the same time, disability and ill-health can impede people’s decision-making capacity such that they are unable to make informed decisions for themselves and about their care. Additionally, the complexity and fear associated with living with abuse or coercive control can also affect how a Person views, and wishes to respond to, their situation.

This research demonstrated the importance of the involvement of an agency with unique expertise like the ADC in exploring a neglected Person’s wishes in the context of their capacity to make decisions. They can explore whether or not a Person is making an informed decision, investigate the implications of that decision and can help put measures in place to monitor their circumstances and whether or not their neglect becomes worse, as well as changes to their decision-making capacity into the future.

The research has found that the actions of organisations such as aged care and disability support providers, the police and health services have been instrumental in identifying and responding to neglect. However, there is also evidence that their capacity to identify neglect is mixed, as is their capability to respond. The following recommendations outline measures which could support the organisations who have regular contact with older people and adults with disability to more consistently recognise when they are at risk of neglect, and have a clear understanding of how to respond.

Guidance on identifying neglect and risk of neglect

Identifying neglect among older people and adults with disability allows a response to be developed.

The earlier neglect is identified, the sooner action can be taken to address the neglect and improve the lives of older people and adults with disability.

The engagement of many older people and adults with disability with their general practitioner offers an opportunity to identify neglect early. General practitioners also often have good knowledge about their patients and the care which they need and receive. However, general practitioners rarely made reports to the ADC about neglect, despite nearly half of cases of neglect having seen their general practitioner in the previous six months. To improve general practitioner screening for neglect, we recommend:

- Develop a tool, such as that developed by Howe (2021), which flags potential neglect and guides general practitioners to collect information about their patients' wellbeing, care needs, receipt of care and possible neglect. The tool could help general practitioners identify neglect, understand how to respond, and monitor to ensure the situation improves rather than worsens.
- Educate general practitioners about: how to identify and monitor neglect; how neglect might be a feature of abuse or coercive control; the services which can help address neglect; and the role of agencies like the ADC.
- Research to determine levels of understanding about neglect among general practitioners, and their knowledge of how to respond and monitor, and their capacity to do so. This would help ensure the tool and education campaign were appropriate.

Additionally, the fact that more than half of all reports of neglect involve adults with disability or older people who have not seen their general practitioner in the previous year is a concern, especially as this proportion is higher among those experiencing abuse or serious neglect. The tool recommended above could also suggest general practitioners make contact and screen patients who have not had a recent in-person doctor visit. Additionally, inquiring about general practitioner appointments could flag potential neglect for other organisations working with adults with disability or older people.

Service systems measures to prevent and respond to neglect

The research found that ambulance services, hospitals and police were often involved in identifying cases of serious neglect. To improve their capacity to identify and appropriately respond to neglect, we recommend:

- Develop a tool, such as that developed by Howe (2021), which flags potential neglect and guides general practitioners to collect information about their patients' wellbeing, care needs, receipt of care and possible neglect. The tool could help general practitioners identify neglect, understand how to respond, and monitor to ensure the situation improves rather than worsens.
- The tool could also suggest general practitioners make contact and screen patients who have not had a recent in-person doctor visit.
- Educate general practitioners about: how to identify and monitor neglect; how neglect might be a feature of abuse or coercive control; the services which can help address neglect; and the role of agencies like the ADC.
- Organisations working with adults with disability or older people could about their general

practitioner appointments, as this could flag potential neglect.

A duty of care

Analysis of service system responses to neglect shows that many receive support from aged care or disability services, paramedics or hospital staff. Workers in these organisations have a prescribed duty of care to act if they have suspicions or concerns about potential abuse or neglect, and there are many instances of aged care or disability support workers reporting concerns of neglect to the ADC.

It would be beneficial if other workers who may encounter neglect among older people or adults with disability were guided by a similar duty of care. As such, we recommend:

- Working with police and key health workers (outside of NSW Health) to determine the feasibility of introducing a duty of care to act if there are concerns about the wellbeing of older people and adults with disability, including where this is concern about neglect.

Support services for older people and adults with disability

The research found that neglect was more likely to arise in cases where the Persons were not using services. This suggests that increased service usage could reduce incidents of neglect. To improve service usage among people experiencing neglect, we recommend building a robust service system which attends to the complexities of access.

To enable accessible service system to help prevent neglect among adults with disability and older people:

- Consider an education campaign to promote service use to Persons and their carers as a means to maintain independence, including information about service options, costs and discounts. Acknowledge the impact on privacy of paid workers entering the home.
- Ensure that services do promote such independence and, so far as possible, minimise the impact on privacy and the administrative burden of arranging and using services.
- Prioritise building and sustaining trust between service providers and potential clients, both Persons and their carers.
- Consider the use of brokers to discuss service usage in some cases of neglect with Persons or PSOAs who have refused services. Brokerage may facilitate service engagement and better matching of services to a Person’s needs and values.
- Given services can be blocked to enable abuse or as an element of coercive control, do not rely on actions of the PSOA to ensure services are in place. Instead, a broker or other third party should help arrange services and follow up to ensure they remain in place.

In particular, recommendations regarding accessible services for older people and adults with disability, include:

- If a Person is refusing services, explore why. Explore how services might better match with the Person's needs, values, budget, culture, etc. Consider whether abuse or coercive control may be a factor which may affect the Person's willingness to accept support.
- Include a full assessment of a Person's needs, which also includes the needs of others in the household or those who are supposed to be providing care to the Person.

Recommendations regarding accessible services for carers or the PSOA, include:

- Present the receipt of services to carers or PSOAs as a means to ease carer stress, provide breaks from care, and maintain independence of older people and adults with disability.
- Ensure that organising service delivery is not burdensome for carers.
- When assessing the needs of an older person or adult with disability, also explore the needs of others in the household or including carers or PSOAs or others who might provide care to the Person.
- If a carer is blocking access to services explore why. Is it a form of coercive control resulting in social isolation or abuse? Do they need their own supports? Are there other issues that a responsive service system could address?

Data, evaluation and further research

Finally, the research makes recommendations regarding data, evaluation and additional research.

This report primarily focused on cases of more serious neglect which were referred to the CSI. However, it is possible that the Helpline is an important mechanism through which neglect is prevented or addressed before it becomes serious. We recommend:

- Investigating the early intervention impact of the ADC Helpline. This would involve reviewing databases to ensure adequate data is collected and introducing monitoring or follow up in at least some Helpline cases.
- Additional research on ADC data could be conducted with cases that have been reported to the ADC more than once. Longitudinal research with these cases could explore effective interventions, opportunities for intervention which were not taken, where responses have failed and what else is needed in cases with recurrent concern about neglect.

Challenges with data are common in research which draws upon administrative datasets because the primary purpose of the data is not research. The qualitative analysis in this project could have provided more insights if the research team had access to more detailed data. We recommend

- Exploring whether more detailed qualitative data could be shared for research purposes, for example, if researchers were required to submit to security checks.
- The addition of a variable in the dataset on whether a case was handled by the Helpline or CSI or both would facilitate quicker and more accurate analysis of Helpline and CSI cases.

- Currently, cases in which cultural issues are identified as contributing to neglect are mostly limited to cases where there was limited English language skills. There may be additional insights into diverse cultural experiences of neglect in the case files, but these were not well reflected in the datasets. Consider if data on cultural issues could be better captured in the data.

Additional research will help inform many of the strategies to prevent and respond to neglect outlined above. In particular, we recommend:

- Additional research on ADC data could be conducted with cases that have been reported to the ADC more than once. Longitudinal research with these cases could explore effective interventions, opportunities for intervention which were not taken, where responses have failed and what else is needed in cases with recurrent concern about neglect. Research to determine levels of understanding about neglect among general practitioners, and their knowledge of how to respond and monitor, and their capacity to do so. This would help ensure the tool and education campaign were appropriate.
- Undertake research with police and lawyers in order to understand what is behind cases which are referred to police with the outcome ‘doesn’t meet the threshold for criminal neglect’. It is not clear if cases are referred but found not to constitute criminal neglect, or if there are the challenges prosecuting a case against a perpetrator of criminal neglect.

1 Introduction

Neglect of older people and adults with disability in their family, home and community has been an issue of growing concern to the New South Wales Ageing and Disability Commission (ADC). For several years, neglect, which includes failure to meet support needs and medical neglect, has featured in a high proportion of reports to the ADC. Between 1 July 2019 and 30 June 2024, neglect was the third most common type of alleged abuse of older people (after psychological and financial abuse), constituting 21.4% of all allegations relating to older people. For adults with disability, neglect was the second most common type of allegation in this period (after psychological abuse), constituting 25.5% of allegations. While Australia does not have definitive data on the prevalence of neglect, some research reported in the international literature suggests neglect may be the most common form of elder abuse. However, it is likely to be under-reported to authorities.

To better understand incidents of neglect in the community, the ADC commissioned the Social Policy Research Centre to conduct this research. Through a literature review and qualitative and quantitative analysis of reports received by ADC, this project has examined patterns in the neglect of adults with disability and older people, the roles of various agencies, such as service providers, health services and police, and identified opportunities and strategies to better prevent and respond to neglect of older people and adults with disability. Findings will help identify opportunities for targeted education, engagement and awareness activities, and help inform broader conversations and strategies in relation to neglect.

2 Background

As an independent NSW government agency, the Ageing and Disability Commission (ADC) focuses on protecting and promoting the rights of adults with disability and older people and safeguarding them from abuse, neglect, and exploitation in their family, home, and community. The primary focus of the ADC's work is adults with disability and older people who are subject to, or at risk of, abuse, neglect, and exploitation.

In doing so, the ADC (2024c) states, "Our intention is always to improve the safety of the adult, and uphold their rights."

The primary functions of the ADC involve:

- Handling reports about abuse, neglect, and exploitation
- Building community capability to prevent and address abuse
- Overseeing and coordinating the NSW Official Community Visitor (OCV) scheme
- Inquiring into systemic issues and making recommendations to the government (ADC, 2024a)

Between 2019 and 2024, the ADC received 18,896 reports of concern about potential neglect or abuse of adults with disability and older people. Neglect is one of the three most commonly reported types of alleged abuse; the other two are psychological abuse and financial abuse. The main reported allegation about neglect related to failure to meet support needs, medical care, and clothing/food.

Types of neglect that are recorded by the ADC include:

- Failure to meet support needs, for example, when someone who has a duty of care/carer responsibility has intentionally or unintentionally failed to meet the support needs of the Person.
- Clothing (not wearing clothing appropriate for the climate or weather), and food (not having access to sufficient, adequate or appropriate food for their needs).
- Failure to enable the Person to access medical care or treatment.
- Failure to protect from abuse, for example, someone with a duty of care is aware (or would have reasonable grounds to believe) that the Person is subject to, or at risk of, abuse, neglect or exploitation, and has failed to take reasonable steps to protect the Person.
- Failure to provide necessities of life, such as food, water, shelter, medical attention. Failure to provide necessities of life may meet the criminal benchmark of neglect under section 44 of the *Crimes Act 1900* (NSW).
- Misuse of guardianship, where the PSOA is the Person's legally appointed guardian and makes decisions, or fails to make decisions, that are in the interests of the Person.
- Reckless act/ failure to act which has resulted in harm or risk of harm to the Person.
- Failure to provide, or preventing the Person from accessing, adequate shelter.
- Supervisory neglect, which includes a reckless or intentional failure to provide adequate supervision to meet the Person's needs/ prevent harm.

Reports of abuse, neglect, and exploitation can be made to the ADC via telephone, web form, email, in person, and by letter. The majority of contacts with the ADC are dealt with by the telephone Helpline, mainly addressed as early intervention or resolution by providing advice, information, support, and making appropriate referrals (ADC, 2025a). Where early intervention or resolution do not seem possible, the Helpline staff assess whether a matter requires referral to the Community Supports and Investigations (CSI) Unit, which handles reports that are likely to require further involvement and/or investigation by the ADC (ADC, 2025b).

When deciding whether a matter should be referred to the CSI Unit, staff are guided by the ADC Risk and Priority Assessment tool. Cases of highest risk and/or most urgent priority are referred to the CSI. Risk ratings are based on the ADC's assessment, consideration of allegations, the environment (including support networks), and factors relating to the Person and PSOA. The risk rating includes non-financial and financial abuse risk ratings, each of which can be divided into five levels. In relation to non-financial risk, Risk 1 is the highest, indicating a probable risk of death or sexual assault in the near term. The severity progressively decreases through the levels, with Risk 5 representing no probable risk of harm (ADC, 2025a). The priority rating relates to the time frame in which the ADC aims to act on the case, depending on resource availability. Priority is categorized into four levels, with Priority 1 indicating cases that require a response or action in the near term, with a target time of 1 business day. Priority 4 identifies cases in which no anticipated action is required. Daily updating of the priority rating is required so that matters are upgraded or downgraded as needed, as actions are progressed, and information is gathered.

There are a range of ways in which the CSI Unit then responds to reports of neglect, including (depending on the case):

- Gathering additional information from the Person, the PSOA, health providers, community services and others with knowledge of the Person
- Asking police to conduct a welfare check
- Visiting the Person to understand their wishes and circumstances
- Conducting an investigation
- Seeking to improve the Person's circumstances, reduce risks, and address contributory factors to the neglect by working with the Person and other relevant parties to facilitate access to necessary supports, engaging the PSOA in challenging discussions, and educating providers
- Referring the matter to police if it involves potential criminal neglect (ADC, 2025a).

To respond to cases of serious neglect of a Person involving a risk of serious injury or death, ADC staff follow an internal protocol on *Responding to Reports of Serious Neglect*. The Serious Neglect Protocol is activated in response to matters such as pressure sores and sepsis resulting from poorly managed skin integrity, and failure to provide food and water to a Person, both of which may pose a risk of serious harm or death. The ADC manages the immediate risks regardless of whether the case of serious neglect involves self-neglect or neglect by a carer (ADC, 2025c).

In 2023-24, the ADC referred 257 matters that involved potential criminal offences to NSW Police

(ADC, 2024a). The ADC also made 29 other referrals to NSW Police during that period, such as referrals for welfare checks. Not all of the referrals to NSW Police related to alleged neglect.

In 2023-24, the ADC made 204 referrals to other agencies, such as aged care, disability, health, legal and advocacy services.

Neglect of older people and adults with disability in their family, home and community is an issue of increasing concern to the ADC. However, the agency is in a unique position to encourage better understanding of, and responses to, neglect. By building on their existing education and collaborative work, the ADC could improve awareness and prevention of neglect in the community, among aged care and disability services, and by health and justice agencies.

3 Methodology

The research utilised mixed-methods in order to:

- Identify opportunities and strategies to better prevent and respond to neglect of older people and adults with disability
- Identify areas, agencies and groups for targeted education, engagement and awareness activities
- Inform broader conversations and strategies in relation to neglect, including national activities.

The research methods included a literature review and both qualitative and quantitative analysis of neglect reports to the ADC.

3.1 Literature review

The literature review involved a rapid review of relevant Australian and international literature, from across disciplines relevant to neglect, such as health, social work, social policy, disability studies and gerontology. The review focused on:

- risk and contributory factors to neglect of older people and adults with disability, and
- effective prevention and intervention strategies in relation to neglect of older people and adults with disability.

The focus of the review was on neglect of older people and adults with disability in their family, home and community. Although important in the consideration of neglect, material relating to neglect of older people and adults in institutional settings and neglect of children and young people was not included. These issues are the subject of extensive bodies of literature beyond the scope of this review. However, material identified as relevant to the neglect of older people and adults with disability, for example strategies for preventing neglect, was considered.

3.2 Analysis of reports to the ADC

We analysed 1,458 reports to the ADC closed in 2021 and 2022 that involved alleged neglect of older people and adults with disability in their family, home and community. Reports involving alleged neglect by paid staff were excluded. The reports were selected, anonymised and divided into qualitative and quantitative spreadsheets by the ADC.

The quantitative database included data on: type of neglect; risk factors; decision making capacity; demographic information; living arrangements; nature of disability; community services and referrals; ADC actions; and outcomes for the Person and PSOA.

The qualitative database included information about:

- the Person’s circumstances, disability, health and relationships
- factors contributing to the alleged neglect, such as availability or knowledge of services; factors

relating to the PSOA such as blocking services, lack of understanding of the issues, a history of abuse
- factors affecting the response, including the wishes of the Person, lack of knowledge or understanding, cultural factors
- involvement of informal supports, services
- involvement and actions of health services and police
- ADC actions

Most data in the qualitative database were categorical, with free text fields containing short responses providing more detailed insights.

Analysis of ADC data involved both quantitative and qualitative components, as outlined below. As administrative data, kept for the purpose of tracking and responding to alleged neglect, the data provided was not designed for research purposes. This poses some challenges for the analysis. A key limitation in the analysis relates to whether or not an issue is recorded for a case. It is possible that some matters did contribute to neglect, but were not recorded as such, because they did not arise in the ADC exploration of the matter. Language spoken at home provides one example. Many cases were missing data on language spoken at home. It is possible that language may have contributed to neglect in some cases where the data was not recorded. While analysis was able to identify significant associations between the variables recorded in the data, there may also be other factors relevant to cases of neglect, which were either not captured or beyond the scope of the administrative data.

3.2.1 Quantitative analysis

To enable analysis of factors associated with case characteristics and individual situations, reports that were consolidated into another matter were excluded from quantitative analysis (n=52), leaving a total sample of 1,406 cases. The total sample was analysed descriptively, then cases that were handled by the Helpline were compared with those referred to the CSI Unit. Cases that were likely referred to the CSI Unit were identified as those where the ADC's primary action (as recorded in the quantitative dataset) was one of the following: closed after preliminary inquiries (n=215), community support (n=195), investigated (n=35), referred to police (n=28), or referred to other body (n=1). Helpline only cases were identified as those where the ADC's primary action was either early intervention/resolution (n=892) or declined at outset (n=40). Subsequent analyses presented in this report include only those cases that were categorised as being referred to the CSI Unit (n=474). Serious cases of neglect were identified using the following criteria provided by the ADC:

- The Person's condition was 'very unwell' or 'critically unwell' at the time of the report to the ADC, and/or
- The neglect allegations included 'failure to provide necessities of life', and/or
- The case had been referred to the Police, and/or
- The Person died prior to case closure and related to the neglect event(s).

In subsequent analyses, cases were grouped according to key variables of interest and comparative analyses were conducted on demographic and situational variables, reported risk factors, and other contributing factors identified in both quantitative and qualitative datasets provided by the ADC (e.g., service or family member involvement; service and family member actions and responses; factors contributing to the issues and allegations or affecting responses of relevant parties). Initial comparisons were made using chi-squared tests (for categorical variables), Mann-Whitney U tests (for ordinal variables), and independent samples t-tests (for continuous variables). Variables that were statistically significant at a level of $p<.10$ were then block entered into multivariable logistic regression analyses to identify independent relationships between variables and the grouping categories (i.e., when controlling for the effect of other factors). For readability and to ensure clarity of the main results, tables throughout the report only include variables that were found to be statistically significant in multivariable analysis. Full results (including comparisons with all included variables) are provided in the Appendix.

3.2.2 Qualitative analysis

The qualitative analysis focused on cases which were handled by the ADC, as these provided the richest qualitative data. Cases which only involved contact with the helpline were necessarily much briefer and offered fewer insights. For this reason, the qualitative analysis has focused on the more serious cases of neglect, as these are the ones which are referred to the CSI for investigation.

Deidentified qualitative data was provided to the research team as spreadsheets. For this reason, the qualitative data was analysed using Microsoft Excel. The data was de-identified before providing it to the research team, which made understanding some of the details difficult.

Cases were examined using filtering and key words to identify patterns and to better understand the nuances and dynamics of neglect and how agencies respond to neglect. The qualitative data was limited, with most cases providing a few sentences across a few database fields. The most detailed information was a description of the concerns that prompted the report, with short half sentence descriptions about factors contributing to a Person's circumstances and responses by ADC and other organisations. This has limited the insights which could be drawn from the qualitative data, as it was difficult to develop a full picture of many cases. However, the open text fields do provide valuable detail on people's experiences of neglect, why they are experiencing neglect, their relationships to carers and significant others, the role of the PSOA (Person subject of allegation) and how the ADC and other organisations have supported them.

The qualitative analysis has been used in two ways. Firstly, to provide better understanding of findings highlighted by the quantitative analysis. And secondly, to explore issues too complex and nuanced for quantitative analysis, such as self-neglect and the role of the service system.

Although data was provided to the SPRC in a deidentified form, because of the sensitive nature of the material, additional care was taken to ensure that no potentially identifying details are published in this report. For this reason, some details have been changed or left out to make identifying any individual more difficult. For example, sometimes the exact nature of the neglect is not described, or the relationship between the Person and the PSOA has been changed, sometimes two cases have been combined into one scenario. In doing so, care has been taken to ensure that the insights of individual cases are preserved and presented accurately. Pseudonyms have been used in the cases, these were taken from the list of most popular names in NSW from 1952-1959. The pseudonyms were allocated alphabetically through the report.

It is hoped that the qualitative examples contained in the report will be useful for education and awareness activities and to develop policy and practice strategies to better prevent and respond to neglect.

The qualitative and quantitative analysis will be conducted concurrently by different analysts who will liaise throughout the process and discuss emerging findings in preparation for the synthesis and development of recommendations that will feature in the final report.

4 Literature review

This section of the report presents the findings from Phase 2 of the project; the rapid review of Australian and international literature relating to:

- risk and contributory factors to neglect of older people and/or adults with disability, and
- effective prevention and intervention strategies in relation to neglect of older people and/or adults with disability.

These findings are situated within the ecological approach to highlight the multiple interacting factors that impact on neglect of older people and adults with disability.

4.1 Conceptual approach

Ecological approach

Theoretical frameworks can help to understand the interaction between different individual characteristics, relationships and contexts. The ecological approach was developed by Bronfenbrenner as a model of human development (Bronfenbrenner 1979). The model places human development in a broader environmental context containing nested micro, meso and macro systems (Bronfenbrenner 1979). An ecological approach has been effectively applied to the risk and incidence of elder abuse, drawing attention to the importance of social, cultural, policy and economic contexts in which the abuse of individuals occurs (Dean, 2019). There are four inter-related levels in the ecological framework:

- the immediate social environment (e.g. family) (microsystem)
- family relationships and other social support networks (mesosystem)

- the external social environments (exosystem)
- broader cultural values, norms and practices within society (macrosystem) (Dean, 2019)

The ecological framework also has relevance for examining the issue of neglect. Appling an ecological framework to defining neglect, identifying the extent of neglect and the associated risk factors highlights the complex nature of neglect. The framework also illustrates how multiple factors can interact and contribute to neglect. These factors include:

- individual characteristics/risk factors;
- interaction and the quality of the relationship between the Person and perpetrator;
- broader relationships to service systems and policy; and
- wider social and cultural environment.

4.2 Defining neglect in the literature

4.2.1 Types of neglect

In Australia there is no consistent definition of the term neglect of older people and adults with disability (CRE-DH, 2021, Dean 2019). Neglect is commonly referred to as a type of abuse alongside physical, psychological/emotional, economic/financial and sexual abuse (Kaspiew et al., 2019). Definitions of neglect commonly operate at the level of individual characteristics in the ecological framework and do not consider the broader environmental contexts such as service systems, for example, one definition of neglect as a form of abuse encompasses:

> a carer's failure to provide basic necessities such as food, shelter or medical care, or preventing someone else from providing them. A common sign of neglect is poor personal hygiene (Relationships Australia, 2021)

However, neglect is not necessarily limited to carers. More broadly neglect can be defined as:

> the failure to meet a Person's basic needs such as food, housing and essential medical care. (Dean, 2019:7)

Other definitions capture the nature of neglect by including an understanding that the vulnerable person's basic needs are not being met, plus that the perpetrator may or may not be a family member or someone specifically defined as a carer due to meeting the eligibility requirements to receive a government provided carer payment.

> failing to provide someone with such things as food, shelter or medical care. Family members may be responsible for providing such 'necessities of life' and some may receive a social security payment for doing so (ALRC2017:6)

The literature also notes different types of neglect which can include:

- Intentional or unintentional (Beach and Schulz, 2016);

- Passive or active (Nagaratnam and Nagaratnam, 2019:20) or omissions rather than actions (Qu et al., 2021:3); and
- Self-neglect (EAHRU, 2016).

Not all neglect is intentional. Neglect may result from socio-economic issues. Family members may find it financially difficult to cover care costs such as paying for medication, feeding equipment and/or mobility equipment. Financial constraints may affect a family member's ability to pay for services or hire formal carers (Caceres et al., 2017).

A lack of recognition of age-appropriate changes in older people's behaviour and a lack of knowledge and understanding about how to care appropriately for an older person or person with disability can result in neglect (Caceres et al., 2017).

Closely related to intentional or unintentional is active or passive neglect (Nagaratnam and Nagaratnam, 2019:20). 'In active neglect there is an intentional act to withhold basic items or resources necessary for safe living or an omission of caregiving activities' (Jenkins and Davies, 2006: 36). In passive neglect there is a failure to act in undertaking necessary caretaking duties (Jenkins and Davies, 2006: 36).

4.2.2 Prevalence of neglect in Australia and internationally

Older people

Little is known about the prevalence of elder abuse including neglect in Australia (Dean, 2019:7). However, as the population ages, so will the number of older people vulnerable to neglect (Dean, 2019:3). To address this gap in knowledge in Australia, the National Elder Abuse Prevalence Study (NEAPS) was commissioned by the Attorney General's Department as part of the National Plan to Respond to Abuse of Older Australian (Council of Attorneys-General, 2019). The Survey of Older People (2020) which is a nationally representative survey of 7,000 people aged 65 years and over living in the community showed that three per cent of people experienced neglect in the year prior to the survey. This research excluded older people with a cognitive impairment, which may affect the nature of neglect reported. In particular, it appears that some of the neglect reported in NEAPS are less critical/serious than what tends to be reported to the ADC.

A person was deemed to have experienced neglect if they needed support, and a person was supposed to have provided that support, but did not. In the 12 months prior to the conduct of the survey, psychological abuse was most reported (11.7%) by participants followed by 2.9% who had experienced neglect (Qu et al., 2021). Failure to provide routine housework was the most common form of neglect, reported by 80 per cent of people experiencing neglect, followed by an unmet need for assistance with transport (69 per cent) and failing to help with shopping for food or clothes (57 per cent) and a lack of help with meal preparation (52 per cent) (Qu et al., 2021).

Research has found that neglect also occurred in conjunction with other types of abuse (Qu et al., 2021:48-49). Analysis of the National Elder Abuse Prevalence Study found that, of all those who experienced some form of abuse, 10.5 per cent experienced neglect only, while 5.6 per cent experienced neglect in combination with psychological abuse (Qu et al., 2021). Table 1 shows combinations of neglect with other forms of abuse, which were much less common.

Table 1: National Elder Abuse Prevalence Study, combined experiences of abuse and neglect

Abuse types	As % of participants who experienced 2+ types	As % of participants who experienced any form of abuse
Psychological and Neglect	23.3	5.6
Psychological and Physical	20.9	5.0
Psychological and Financial	20.5	4.9
Psychological and Sexual	7.6	1.8
Psychological, Physical and Financial	6.1	1.5
Psychological, Physical and Sexual	4.6	1.1
Psychological, Physical and Neglect	3.6	0.9
Psychological, Financial and Neglect	2.6	0.6
Psychological, Sexual and Neglect	1.9	0.5
Financial and Neglect	1.5	0.4
Psychological, Physical, Sexual, Financial and Neglect	1.5	0.4
Psychological, Physical, Sexual and Financial	1.4	0.3
Sexual and Neglect	1.0	0.2
Psychological, Sexual and Financial	0.9	0.2
Physical and Neglect	0.7	0.2
Sexual and Financial	0.5	0.1
Physical and Sexual	0.4	0.1
Physical and Financial	0.4	0.1
Physical, Sexual and Neglect	0.3	0.1
Psychological, Physical, Financial and Neglect	0.3	0.1
Psychological, Physical, Sexual and Neglect	0.2	0.0

Source Table 5.6: Survey of Older People: Co-occurrence of abuse in the previous 12 months for participants who reported two or more abuse types and participants who reported one type of abuse only (Qu et al., 2021 48)

The prevalence of neglect among CALD older people was similar to non-CALD people, 2.6% and 2.9% respectively (Qu et al., 2021:49).

Another study, the Australian Longitudinal Study of Women's Health conducted in 2008 found that 20% of women aged 70–75 years and 85–90 years experienced neglect (Kaspiew et al., 2016). This is considerably higher than the rate found in the National Elder Abuse Prevalence Study, which although it found rates of neglect were higher among older age groups, even among those aged 85 or more, 11.3% said they had an unmet need for help (Qu et al., 2021:60). Advocare Incorporated (2016) compiled administrative data collected by 12 Australian advocacy organisations. Of 2,717 cases and 12,993 information calls received during 2015/16, 14% related to neglect compared to financial abuse (38%), psychological abuse (36%), physical abuse (9%), social abuse (6%) and sexual abuse (0.3%) (Dean, 2019).

Prevalence rates vary internationally due to different definitions and measures used (Howe et al, 2015-2016). In the US, neglect is the most commonly reported form of abuse (Caceres et al., 2017, Carmen and LoFasso, 2014). Some studies have found far higher rates than reported in the Australian National Elder Abuse Prevalence Study. For example, a study of caregivers and older adults with disability in the USA in 2011 found that unmet need was widespread among older adults requiring care due to disability with 44.3% of care recipients reporting at least 1 unmet need. 38.2% had unmet needs associated with activities of daily living (e.g., wet or soiled clothing) or mobility (e.g., have to stay inside). 14.6% had unmet needs regarding “instrumental activities of daily living” (e.g. medication errors) (Beach and Schulz, 2016:560).

In a Korean study that aimed to examine the prevalence and risk factors associated with self-neglect of older adults with disability who lived alone, 22.8% of older research participants experienced some form of self-neglect. (Minhong and Kyeongmo, 2014:126).

However, lower rates of neglect of older people are also evident in international research. In an international meta-analysis of elder abuse prevalence (Yon, Mikton, Gassoumis, & Wilber, 2017, cited in Dean, 2019:8), 15.7% of older adults (60 years and older) in community settings had experienced some form of abuse in the past 12 months and neglect was experienced by 4.2%. In another study in the US, unmet need for assistance was found in 5.1% of older people living in the community (Acierno, et al. 2010).

Adults with disability

In Australia and internationally there is little data collected that specifically addresses the neglect of adults with disability. The term neglect is often referred to in conjunction with the terms ‘violence’, ‘abuse’, and ‘exploitation’. Older people are also included in research on adults with disability. Similar to older people, prevalence rates are affected by the definition used for the term neglect as well as by how disability is defined.

In Australia, however, in 2022 the Survey of Disability, Ageing and Carers asked people about their experience of different types of abuse. The questions were voluntary and around two thirds of respondents answered at least some of these questions. Of the people with disability, which includes older people with disability, 11 percent had experienced at least one form of abuse or neglect in the last 12 months. The percentage of people with disability who said they had experienced neglect (1.5%) was lower than those who had experienced physical abuse (4.5%) and emotional abuse (9.1%) (ABS, 2022).

Internationally, self-neglect is the primary focus of much of the research literature on neglect among adults with disability. In England, there has been a growth in the number of cases of self-neglect. In a study based on local authority reporting of case numbers, self-neglect was the sixth most common out of 11 forms of adult abuse and neglect (Martineau, 2021). In a study analysing 195 cases involving self-neglect (or a constituent element such as squalor, hoarding, neglect of health and wellbeing, rejection of care and support), Preston-Shoot (2019) found men outnumbered women and that adults over 76 were the largest age group. They also noted that ethnicity was rarely recorded. In an analysis of subsequent years, the dominant age group was 50-59 year olds, largely because of inclusion of people experiencing homelessness in the latter analysis (Preston-Shoot 2021). Self-neglect was the central focus in 64% of cases, implicit in 21% and peripheral in 12% of cases. Preston-Shoot (2019) found refusal of services and lack of self-care were the most prominent forms of self-neglect. Many cases involved AOD or diabetes.

In a multi-country study, Dong and Sun (2022) found that during the COVID-19 outbreak, self-neglect had become a serious public health problem among older adults with disability, as a result of the use of social isolation to control the outbreak. This caused difficulties in people’s lives and exacerbated self-neglect. In Korea, the prevalence of self-neglect prior to the pandemic was found to be 22.8% of older people who lived alone, in Istanbul it was 16.8% of community-dwelling older adults and in the USA it was 19.2% of people over 60 years (Dong and Sun, 2022). In Dong and Sun’s study of older adults with disability in China, the prevalence was found to be as high as 86%, perhaps due to the physical limitations of these adults that makes them more susceptible to self-neglect. However, the isolation resulting from diverse COVID-19 public health approaches may account for the difference in measurement across studies.

Beach and Schulz (2016:562) provide data on adults with disability in the USA (of which older adults, on the primary focus of their study, are a subset). Their comparison data on adults with disability shows that 31.8% had one or more unmet need and 24.9% had unmet need relating to activities of daily living or mobility. On all items of potential unmet need, adults with disability were slightly less likely to experience unmet need compared to older adults with disability.

Summary

In Australia the best data available about neglect of older people is found in the National Elder Abuse Prevalence Study (NEAPS). No equivalent survey is conducted specifically for adults with disability. However, in 2022 the Survey of Disability, Ageing and Carers asked people about their experience of different types of abuse. The statistics currently reported focus on all adults with disability including older people.

Definitions of neglect vary in Australia and internationally. The international evidence on prevalence rates of neglect suggests rates might be similar between adults with disability and older people. However, prevalence rates are influenced by the inconsistency of definitions applied to the analysis leading to varying estimates of the rates of neglect.

Self-neglect is an emerging area of study, especially among adults with disability, where it appears to be the primary focus of neglect studies internationally. As with the definitions of neglect, estimates of prevalence rates largely focus on individual factors and seldom take account of the broader context in which neglect is situated.

4.2.3 Risk and contributory factors to neglect in the community

Older people and adults with disability risk factors

For both older people and people with disability living in the community, age and level of disability can contribute to the risk of neglect. Older people and adults with disability experience physical frailty, chronic health conditions, and cognitive impairments (e.g., dementia), which increase their dependency on others and can lead to vulnerability which in turn can increase the risk of experiencing neglect (Beach and Schulz, 2016). Also, the level or severity of physical and cognitive limitations of older people and people with disability increases the risk of neglect (Dean, 2019). Relatedly, where there are reports of unmet need among older adults who require care, there may be a risk of neglect (Beach and Schulz, 2016).

Australian research has found that several characteristics are associated with increased likelihood of neglect. These characteristics include being a woman, being separated or divorced, owning a home with debt, living in rental accommodation or public housing, being in poor physical or psychological health and low levels of social connections (ALRC, 2017; Dean, 2019; Qu et al., 2021).

Social isolation is a common issue among older adults and adults with disability and is a significant risk factor for neglect. Isolation may result from the loss of social networks, limited mobility, or societal marginalisation (ALRC, 2017; Dean, 2019). Additionally, neglect of older people may also occur when the relationship between older people and their children is not strong. Care responsibilities may be taken on reluctantly, and not fulfilled well (Dean, 2019).

In Australia in terms of the main perpetrators of neglect according to NEAPS survey participants, sons were more likely than daughters (14 compared to 9 per cent) to be the main perpetrators. Forty per cent of perpetrators were living with the survey participant. A quarter of the perpetrators had their own physical health problems and 11 per cent had mental health problems. In terms of the relationship of the perpetrators to the older person, 25 per cent were a partner or spouse, 24 per cent were a son/daughter and around 14 per cent were identified as professional carers or service providers (Qu. et al., 2021).

Internationally, similar risk factors have been found to be associated with neglect. Risk factors identified include living with non-spouse family or friends, living in a non-supervised setting, and being widowed, divorced or separated (Nagaratnam and Nagaratnam, 2019:20).

The characteristics associated with the risk of self-neglect for older people reflect those of neglect more generally. For example, in a multivariate analysis of survey responses from 230 older adults with disability, Dong and Sun (2022) found self-neglect was predicted by low monthly income, more severe disability, depressive symptoms and low social support. There was no association between self-neglect and either marital status, education, gender or other medical conditions. Dong and Sun (2022) found that those most at risk of self-neglect were those needing help with activities of daily living, those with more depressive symptoms and those with poor social support. Interestingly, respondents to the survey did not consider their behaviours to be forms of self-neglect, pointing to the need for better education. A Korean study by Minhong and Kyeongmo (2014) found that living alone, being over 75 years old, poverty, psychiatric illness, physical function impairment, reduced cognitive capability, dementia, cerebrovascular disease, depression, chronic illness, nutritional deficiency, alcohol and substance misuse, lack of social network, or inadequate support services were associated with increased risk of self-neglect.

A study by Braye et al. (2015) in England analysed serious case reviews to understand different types of self-neglect and to identify challenges for the multiple agencies and professionals involved in support and care interventions to address self-neglect. Across several reports, they identified contributory factors relating to frontline practice and client engagement, including lack of person-centred focus, with little attempt to establish trust or cooperation, or to understand individuals' decisions to refuse services, plus missed opportunities to engage with individuals in ways they were prepared to. They also identified failure to assess and record 'capacity' appropriately, with carers' perspectives sometimes replacing the wishes of the individual. However, in other cases insufficient attention was given to learning from carers/family members, resulting in lack of knowledge about individuals' needs or their families' capacity to support them. Braye et al (2015) observed that dilemmas about confidentiality could prevent practitioners from following up issues with family members. This study also identified lost opportunities where services were not responsive, did not reassess need, closed cases prematurely or treated circumstances separately rather than as part of a pattern of behaviour, with practitioners overlooking important points in the case history.

Jenkins and Davies (2006) noted that neglect can arise from activities of daily living that are not visible to other people such as not toileting, dressing, providing nutrition and meeting emotional needs. These may manifest as poor hygiene, nutritional status, untreated injuries and lack of help with selfcare. Less obvious forms of neglect include restricting access to health care, leisure opportunities or social contact (Jenkins and Davies, 2006). Families and carers may not be aware that this is a form of abuse, they may lack knowledge about what is available to individuals, and many older carers of people with disability are themselves in ill health and have disability (Jenkins and Davies, 2006).

Caregiver and other family members related risk factors

Different types of abuse appear to have different patterns of perpetrators. In the case of neglect, perpetrators are much more likely to be living with the neglected person (compared to other types of abuse) (Qu et al., 2021:73). They are also less likely to have problems with drugs, alcohol, gambling, mental health compared to perpetrators of other forms of abuse.

Physical health problems (25%) were the most common problem for perpetrators of neglect. Financial (11%) and mental health (11%) problems the next most common problems in perpetrators of neglect. The main perpetrators had a higher occurrence of problems than perpetrators of other abuse types. These findings suggest that in some cases of neglect, problems such as physical health may contribute to carers being unable to meet care needs rather than being a case of intentional neglect (Qu et al., 2021:74). Carers themselves may be in need of care and support and also have unmet needs. Carers with a disability requiring support from services raises the issue of whether they can be considered perpetrators of neglect.

Informal carers, such as family members, often face substantial stress and strain which can lead to a higher risk of neglect. The National Health and Aging Trends Study and National Study of Caregiving is a population-based survey of caregivers (n = 1,996) and older adult care recipients with disability (n = 1,366) living in the community in the United States. The study found that 44.3 per cent of care recipients reported at least one unmet need for care in the past month (38.2% ADL related, 14.6% IADL related). Younger caregivers, caregiving sons, caregivers not living with care recipients, and having paid caregivers were associated with more unmet needs. For care recipients with two or more unmet needs, caregivers reported higher levels of burden and stress and physical and psychosocial restrictions which could cause them to provide substandard or poor care to older adults, putting the care recipient at risk of neglect (Beach and Schulz, 2016; Beach et al., 2017).

Other factors that can put older people and adults with disability at risk of neglect include competing work and care commitments among caregivers, as well as a lack of respite care for carers (Caceres et al., 2017). Also, carers may lack the necessary skills or resources to provide adequate care, contributing to unintentional neglect (Caceres et al., 2017).

Socioeconomic risk factors

The ecological approach highlights the interaction between individual characteristics, the relationship between the Person and the perpetrator, service systems and the broader social and environmental context. Although socioeconomic risk factors relate to individual characteristics, they are influenced by the wider social context and policy context. In the research, socioeconomic risk can be clustered into two key areas:

Economic constraints: Lack of financial resources can restrict access to essential services and support, exacerbating the risk of neglect which restricts the ability of family and friends to provide appropriate care (Caceres et al., 2017)

Systemic and structural factors: Inadequate community services: The availability and accessibility of medical services community and social services, and links to support networks are factors that mitigate or prevent neglect. Gaps in these services often contribute to neglect in the community (Caceres et al., 2017)

4.2.4 Good practice in prevention and early intervention strategies

Research on good practice in prevention and early intervention strategies to address neglect provides some evidence of the need to look at both the individual characteristics of both the perpetrator and the person and the interaction of these and the wider service systems and policy contexts. Providing training, respite care, and psychological support to informal caregivers can reduce the risk of caregiver burnout and subsequent neglect (Caceres et al., 2017). A study conducted by Ezalina et al., (2019) of primary family caregivers of older people involved a sample of family members who lived with the older person or lived in the same city. The purpose of the study was to examine the effectiveness of the elderly caring model which provided training to increase understanding of health and cognitive conditions and how to respond to prevent neglect. The results showed that the model increased family support and improved the relationships and social activities of the older people, and prevented neglect of the older people in the family (Ezalina et al., 2019).

Older people

Primary or universal interventions that target whole communities or populations, including public education about neglect and training for health professionals about how to respond to neglect, are required. Secondary interventions that target at-risk populations of both older people and adults with disability and perpetrators are also needed. Tertiary interventions that respond to older people and adults with disability when neglect has been identified such as case management, helpline, family care conferences and mediation are also required. Additionally, the provision of community-based resources, increased education regarding care of older people for both caregivers and healthcare professionals, and greater interdisciplinary collaboration were identified as potential solutions to combat neglect.

Several protective factors have been found to mitigate the risk of neglect of older people with disability. These include access to social support and support networks and healthy relationships with family members (Dean, 2019:1). Interventions such as social support to address social isolation and the quality of family and caring relationships can be effective as these risk factors are most open to change with intervention. Also increased support for carers such as housework and respite could alleviate and reduce caregiver stress and decrease the risk of neglect. However, developing good policy and practice responses to neglect are hindered by a lack of evidenced based practice and a lack of a consistent definition of neglect (Dean, 2019).

In the US, a study used a novel approach to identify risk (Howe, 2021). The study trialled the use of a standard disability assessment tool (measuring ADLs and IDALs) and additional questions on whether they want help, whether they get help, and reliability of the help. Screening and risk assessments could be conducted regularly in health care settings such as hospital emergency departments and general practice (Dean, 2019; Nagaratnam and Nagaratnam (2019). For example, The Elder Assessment Instrument (EAI) is suitable for all clinical settings. This is a 41-item screening tool comprising 7 subscales. A person is identified as being at risk of neglect if they want help but do not receive it or the help they are getting is unreliable (Howe, et al., 2021: S352). This definition does not take account of self-neglect.

Lack of community-based resources have also been found to contribute to neglect. Increased education regarding care of older people for both caregivers and healthcare professionals and greater interdisciplinary collaboration were identified as potential solutions to combat neglect. Other strategies to mitigate neglect could include the development and testing of tools in hospitals, GPs and community services to effectively identify risk or the presence of neglect in community hospitals, GPs and community services (Caceres et al., 2017).

Adults with disability

Much of the literature focusing on adults with disability relates to self-neglect. Martineau (2021) notes the importance of time, patience, frequent visiting and rapport in early (1957) studies of elder self-neglect, which resonates with contemporary literature although there is now a much more comprehensive understanding of intervention methods including skill sets, and joint working, with learning arising from Safeguarding Adults Reviews (SAR) in England. The Care Act 2014, section 44, mandates that an SAR is conducted in cases where an adult needing care and support has died or suffered serious harm and where neglect including self-neglect is the suspected cause (Local Government Association 2024).

Analysis conducted by Preston-Shoot focused on the safeguarding actions of different agencies in relation to reports about self-neglect by adults with disability. Preston-Shoot (2019) identifies lessons learned from safeguarding adult reviews and asks what facilitated and disrupted best practice in relation to self-neglect. He finds that recommendations across reviews spanned many areas including staff support, review process, best practice and procedures. Many recommendations related to:

- mental capacity assessments, including the importance of exploring people’s choices and understanding lifestyle choices
- person-centred, relationship-based approaches and different ways to engage with people who are refusing services
- transitions, especially discharge from hospital and assessment of risk and support needs
- referral and assessment
- working together and information sharing
- staffing and resourcing levels (Preston-Shoot, 2019).

Preston-Shoot’s analysis developed the following areas of best practice: In terms of practice with individual adults, the focus of reviews is on making safeguarding personal, including speaking with the adult who self neglects, taking a person-centred approach which should include enquiring about refusal of services/treatment, and having difficult conversations about the impact of individual decisions. More assertive outreach is often needed. Better ‘safeguarding literacy’ was often recommended including about delays in raising concerns and missed opportunities to ensure multiagency working, or poor understanding of procedures or when/how to escalate concerns (Preston-Shoot, 2019).

In terms of organisational factors, recommendations include that commissioners understand the scale of self-neglect and recognise the longevity of work needed to address it and ensure suitable placements. Working environments and practices around closing cases, supervision and senior management oversight were also themes, including ensuring support to staff for complex cases (Preston-Shoot, 2019).

In repeating the 2019 analysis for subsequent years, Preston-Shoot (2021) found safeguarding boards, which aim to help and safeguard adults with care and support needs across a locality in the UK, are not learning from or building on the evidence base when working with people who self-neglect, as safeguarding adult reviews are replicating earlier inquiries and not building knowledge and depth, they are not building on learning that is already available.

Preston-Shoot (2021) found not all recommendations in the safeguarding reviews were SMART (specific, measurable, agreed, realistic and time bound) suggesting that reviews weren't quality assured. In the safeguarding reviews, Preston-Shoot (2021) identified recommendations for better staff support, case allocation and monitoring of workloads, training and supervision; and some reviews recommend better partnership working, including with utility companies, postal services and voluntary organisations reinforcing that adult safeguarding is everyone's business. Recommendations also related to assessments, relational approaches, and review of guidance (Preston-Shoot, 2021).

Summary

The literature review aimed to identify key themes to address risk and contributory factors to neglect of older people and adults with disability and effective prevention and intervention strategies. The findings from the literature review highlight the multiple factors contributing to the neglect of older people and adults with disability. Inconsistent definitions of neglect make it difficult to provide reliable estimates of the prevalence of neglect for older people and adults with disability. In Australia, further analysis of the ABS *Survey of Disability Ageing and Carers* by age could provide better estimates of the risk of neglect for older people and differentiate them from adults with disability.

In the literature, similar characteristics appear to be associated with the risk of neglect for older people and adults with disability such as high levels of physical and cognitive disability which can increase the level of need for support. Living alone and living in rental or public housing appears also to increase risk of neglect. Self-neglect has emerged as a growing area of concern internationally particularly in relation to adults with disability.

Also evident in the literature reviewed is that perpetrators of neglect often display unintentional neglect either due to a lack of knowledge about appropriate care, a lack of resources including time and income and at times due to their own levels of disability or ill health and possibly their own unmet need for care. Carers' capacity to provide support needs to be taken into account when assessing the support needs of the older person or the adult with disability. In relation to the ecological approach these risk factors relate to individual characteristics of the older people, people with disability and their carers. Limited research examines the environmental context and service systems in which neglect occurs.

Research on good practice to enable early intervention and prevention strategies to mitigate the risk of neglect is limited. However, research in the USA in the field of emergency has developed screening tools that may be adapted for use in Australia. Screening tools could be used by health and service practitioners to identify risk and also assess the capacity of the carer to meet needs.

Overall, the review emphasises the need for comprehensive as well as targeted prevention and intervention strategies that distinguishes neglect as a discreet form of abuse rather than employing the commonly used ‘catch all phrase’ of abuse and neglect in the research and the development of prevention and early intervention strategies.

The literature review has provided a framework for the analysis of ADC reports data, presented in the remainder of this report. After outlining the methodology in the following section, we then present our research findings exploring factors contributing to neglect in different layers in the ecological framework depicted above. In doing so, we contribute to filling a gap in existing research about neglect by going beyond individual characteristics to explore a person’s relationships and their connection to the service system.

5 Findings

5.1 Sample description

The following table outlines Person demographics within the whole sample of 1406 cases, and compares those cases that were likely handled by the Helpline only with those that were likely referred to the CSI Unit. As would be expected, it shows that reports of neglect that are escalated to the CSI Unit are more serious and more likely to be multifaceted. Cases handled by the CSI Unit more often involved a Person with more challenging health conditions or disability, had more significant core activity limitations and concerns about the Person's decision-making capacity.

Throughout the remainder of the report, analysis focuses on CSI cases. This is because data on Helpline-only cases is incomplete due to the nature of Helpline interactions, which only collect data as needed to address concerns. CSI cases, which involve more detailed inquiries, offer more complete data for analysis.

Table 2: Person demographics

	Total sample (n=1,406) n (%)	Helpline only cases (n=932) n (%)	CSI cases (n=474) n (%)
Person status:*			
Adult with disability	349 (24.8)	182 (19.5)	167 (35.2)
Older Person	532 (37.8)	426 (45.7)	106 (22.4)
Older Person with disability	525 (37.3)	324 (34.8)	201 (42.4)
Gender:			
Female	873 (62.1)	583 (62.6)	290 (61.2)
Male	533 (37.9)	349 (37.4)	184 (38.8)
Aboriginal status:*			
Aboriginal	50 (3.6)	25 (2.7)	25 (5.3)
Not Aboriginal	324 (23.0)	201 (21.6)	123 (25.9)
Not stated	679 (48.3)	482 (51.7)	197 (41.6)
Unknown	353 (25.1)	224 (24.0)	129 (27.2)
Language other than English*	134 (9.5)	64 (6.9)	70 (14.8)
Disability:			
None*	532 (37.8)	426 (45.7)	106 (22.4)
Neurological*	417 (29.7)	219 (23.5)	198 (42.8)

Physical*	236 (16.8)	123 (13.2)	113 (23.8)
Intellectual*	141 (10.0)	60 (6.4)	81 (17.1)
Mental health	126 (9.0)	77 (8.3)	49 (10.3)
Other cognitive	110 (7.8)	71 (7.6)	39 (8.2)
Autism	70 (5.0)	40 (4.3)	30 (6.3)
Sensory	54 (3.8)	32 (3.4)	22 (4.6)
Community services[1] *	711 (50.6)	451 (48.4)	260 (54.9)
Person's condition/presentation at the time of report to ADC[2]:*			
Needs not met	287 (20.4)	197 (21.1)	90 (19.0)
Signs of neglect	786 (55.9)	534 (57.3)	252 (53.2)
Poor condition	153 (10.9)	76 (8.2)	77 (16.2)
Very unwell	49 (3.5)	30 (3.2)	19 (4.0)
Critically unwell	42 (3.0)	24 (2.6)	18 (3.8)
Unknown	89 (6.3)	71 (7.6)	18 (3.8)
Usual level of functioning[3]:*			
No core activity limitation	127 (9.0)	76 (8.2)	51 (10.8)
Core activity limitation	317 (22.5)	216 (23.2)	101 (21.3)
Mild limitation	41 (2.9)	29 (3.1)	12 (2.5)
Moderate limitation	79 (5.6)	55 (5.9)	24 (5.1)
Severe limitation	203 (14.4)	130 (13.9)	73 (15.4)
Profound limitation	407 (28.9)	231 (24.8)	176 (37.1)
Unknown	232 (16.5)	195 (20.9)	37 (7.8)
Concerns about decision-making capacity[4]:*			
Yes	522 (37.1)	290 (31.1)	232 (48.9)
Suspected	121 (8.6)	101 (10.8)	20 (4.2)
Has decision making support (if concerns about capacity)*	190 (36.4)	66 (22.8)	124 (53.4)

* Statistically significant difference between groups. Note: cases with missing data have been excluded from percentage calculations.

[1] In the context of the ADC, community services comprise aged care and/or disability services.

[2] See Appendix B for detailed explanation of each of these categories.

[3] Refers to the Person's usual level of functioning with the core activities of communication, self-care, and mobility.

[4] Refers to whether concerns had been identified about the Person's decision-making capacity by any party.

Across the whole sample, most reports were made in relation to older people (37.8%) or older people with disability (37.3%), with comparatively fewer regarding adults with disability (24.8%). Helpline only cases were most likely in relation to older people (45.7%), while CSI cases were most likely in relation to older people with disability (42.4%). Compared to Helpline only cases, CSI cases were more likely to be in relation to Aboriginal people (5.3% vs. 2.7%) or people who spoke a language other than English (14.8% vs. 6.9%), although there were large proportions of cases where cultural and language information were unknown, particularly in Helpline only cases. Among CSI cases, there were larger proportions of people with neurological, physical, or intellectual disabilities than among Helpline only cases. Persons in CSI cases were more likely to be receiving community services than Helpline only cases (54.9% vs. 48.4%). People in CSI cases were reported to have more significant core activity limitations (e.g., 37.1% had profound limitations vs. 24.8% of Helpline only cases). Concerns about decision making capacity were more commonly reported among CSI cases (48.9%) than among Helpline only cases (31.1%) and where there were concerns about this capacity, Persons in CSI cases were more likely to have decision making support (53.4%) than Helpline only cases (22.8%).

Most people lived with the PSOA (71.0%), and this was more common among CSI cases (75.9%) than Helpline only cases (68.5%). Compared to Helpline only cases, people in CSI cases were more likely to live with their family or spouse (26.0% vs. 16.7%), or children (8.7% vs. 2.6%), and were less likely to live alone (11.0% vs. 19.9%). Most people lived in their own home (81.8%), though this was less common among CSI cases (74.6%) than among Helpline only cases (86.2%). CSI cases were more likely to live in community or social housing (17.1%) than Helpline cases (7.6%).

Table 3. Person living situation

	Total sample (n=1,406) n (%)	**Helpline only cases (n=932) n (%)**	**CSI cases (n-474) n (%)**
Person lives with:			
PSOA*	993 (71.0)	634 (68.5)	359 (75.9)
Family/spouse*	278 (19.9)	155 (16.7)	123 (26.0)
Alone*	236 (16.9)	184 (19.9)	52 (11.0)
Children[1] *	65 (4.6)	24 (2.6)	41 (8.7)
Others	30 (2.1)	18 (1.9)	12 (2.5)
Person lives in: *			
Own home	897 (81.8)	592 (86.2)	305 (74.6)
Community/social housing	122 (11.1)	52 (7.6)	70 (17.1)
Retirement village	24 (2.2)	19 (2.8)	5 (1.2)
Granny flat	11 (1.0)	6 (0.9)	5 (1.2)
Separate residence on family property	6 (0.5)	2 (0.3)	4 (1.0)
Residential care	4 (0.4)	0	4 (1.0)
Other	32 (2.9)	16 (2.3)	16 (3.9)
Accommodation management:*			

Person owns or leases	1,036 (73.7)	726 (78.5)	310 (66.2)
Family owns or leases	261 (18.6)	149 (16.1)	112 (23.9)
Other party owns or leases	96 (6.8)	50 (5.4)	46 (9.8)

* Statistically significant difference between groups. Note: cases with missing data have been excluded from percentage calculations.

[1] In this table, 'children' refers to children and young people aged under 18 years.

The following table shows PSOA demographics for the whole sample, Helpline only cases, and CSI cases. Across the whole sample, there was an even distribution of PSOA gender (47.7% female, 47.0% male, 1.3% other genders, 4.1% unknown). There was a higher proportion of male PSOAs in CSI cases (51.1%) than in Helpline only cases (45.0%). PSOAs in CSI cases were also more likely to speak a language other than English (5.1% vs. 2.4%) and to be the Person's primary carer (70.7% vs. 63.5%). Compared to those in Helpline only cases, PSOAs in CSI cases were less likely to be the Person's child (41.4% vs. 51.8%) and more likely to be their parent (18.6% vs. 9.1%). Similar proportions of PSOAs in each group were the Person's spouse/partner (21.3% of CSI cases, 20.7% of Helpline only cases).

Table 4. PSOA demographics

	Total sample (n=1,406) n (%)	**Helpline only cases (n=932) n (%)**	**CSI cases (n=474) n (%)**
Gender:*			
Female	670 (47.7)	454 (48.7)	216 (45.6)
Male	661 (47.0)	419 (45.0)	242 (51.1)
Other	18 (1.3)	16 (1.7)	2 (0.4)
Unknown	57 (4.1)	43 (4.6)	14 (3.0)
Language other than English*	46 (3.3)	22 (2.4)	24 (5.1)
Primary carer:*			
Yes	927 (65.9)	592 (63.5)	335 (70.7)
No	294 (20.9)	207 (22.2)	87 (18.4)
Not disclosed	23 (1.6)	21 (2.3)	2 (0.4)
Unknown	162 (11.5)	112 (12.0)	50 (10.5)
Relationship to Person:*			
Relative:	961 (68.3)	629 (67.5)	332 (70.0)
Child	*679 (48.3)*	*483 (51.8)*	*196 (41.4)*
Parent	*173 (12.3)*	*85 (9.1)*	*88 (18.6)*
Sibling	*61 (4.3)*	*29 (3.1)*	*32 (6.8)*

Other relative	*48 (3.4)*	*32 (3.4)*	*16 (3.4)*
Spouse/partner	294 (20.9)	193 (20.7)	101 (21.3)
Friend	51 (3.6)	37 (4.0)	14 (3.0)
Community member	15 (1.1)	6 (0.6)	9 (1.9)
Ex-foster carer	2 (0.1)	1 (0.1)	1 (0.2)
Unknown/Not disclosed	37 (2.6)	33 (3.5)	4 (0.8)
Other	46 (3.3)	33 (3.5)	13 (2.7)

* Statistically significant difference between groups. Note: cases with missing data have been excluded from percentage calculations.

5.2 Individual factors

Differences between people with disability and those without disability experiencing neglect

Among ADC reports of neglect handled by CSI, people with disability were more likely than those with no reported disability to live in regional areas (59.4% vs. 39.8%) and were more likely to have at least one chronic or terminal condition (77.4% vs. 50.0%), regardless of whether or not they were also older. Concerns about the Person's decision-making capacity were also more common among people with disability than those with no disability (57.6% vs. 18.9%) and the Person was more likely to live with the PSOA (77.9% vs. 68.9%). The PSOA was more likely to be the Person's sibling when the Person had a reported disability (8.2% vs. 1.9%). It is also worth noting that the PSOA was less likely to be the Person's child (35.9% vs. 60.4%) and more likely to be their parent (23.9% vs. 0%) when the Person had a reported disability, however, these did not remain statistically significant in the multivariable analysis. The Person's mental health was more commonly identified as a risk factor among people with disability than among those with no disability (14.5% vs. 2.8%).

Table 5. Independent differences between people with and without reported disability

	People with no disability (n=106) n (%)	**People with disability (n=368) n (%)**
Area of residence:		
Metropolitan	62 (60.2)	147 (40.6)
Regional	41 (39.8)	215 (59.4)
Person health needs:[1]		
No chronic/terminal condition	34 (32.1)	52 (14.1)
1-2 chronic health conditions	44 (41.5)	238 (64.7)
3-4 chronic health conditions	4 (3.8)	34 (9.2)
5+ chronic health conditions	1 (0.9)	6 (1.6)

Terminal condition	4 (3.8)	7 (1.9)
Not known	19 (17.9)	31 (8.4)
Concerns about Person's decision-making capacity:		
No/Unknown	79 (74.5)	143 (38.9)
Suspected	7 (6.6)	13 (3.5)
Yes	20 (18.9)	212 (57.6)
Person lives with PSOA	73 (68.9)	286 (77.9)
PSOA relationship:		
Partner/spouse	23 (21.7)	78 (21.2)
Relative	69 (65.1)	263 (71.5)
Child	64 (60.4)	132 (35.9)
Parent	0	88 (23.9)
Sibling	2 (1.9)	30 (8.2)
Risk factors:		
Mental health	3 (2.8)	53 (14.5)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

[1] Refers to the Person's usual health needs. 'Chronic' conditions refer to persistent and long-lasting health conditions (e.g., diabetes, epilepsy, heart disease). 'Terminal' conditions refer to conditions for which the Person was receiving palliative care or had been advised were terminal (e.g., end stage cancer, kidney failure).

Differences between adults with disability and older people experiencing neglect

This section identifies differences between adults with disability (aged 18-64 years) and older people (including older people with disability). Compared to adults with disability, older people were less likely to be male (31.6% vs. 52.1%) and were less likely to have an intellectual disability, mental illness, or physical disability. There was no significant difference between groups in terms of confirmed concerns about the Person's decision-making capacity; however, there were *suspected* concerns in a larger proportion of cases involving older people (6.2% vs. 0.6%). Among cases involving older people, the PSOA was less likely to be a sibling (3.6% vs. 12.6%) and domestic violence was less likely to be identified as a risk factor (9.2% vs. 17.0%). Older people were less likely to have community services involved (43.6% vs. 75.4%), however, they were more likely to have had hospital services involved within the previous six months (41.4% vs. 28.7%).

Table 6. Independent differences between older people with and adults with disability

	Adults with disability (n=167) n (%)	Older people (n=307) n (%)
Person gender:		

	Adults with disability (n=167) n (%)	Older people (n=307) n (%)
Female	80 (47.9)	210 (68.4)
Male	87 (52.1)	97 (31.6)
Person receiving community services	126 (75.4)	134 (43.6)
Concerns about Person's decision-making capacity:		
No/Unknown	76 (45.5)	146 (47.6)
Suspected	1 (0.6)	19 (6.2)
Yes	90 (53.9)	132 (46.3)
Disability:		
None	0	106 (34.5)
Neurological	59 (35.3)	139 (45.3)
Physical	59 (35.3)	54 (17.6)
Intellectual	74 (44.3)	7 (2.3)
Mental health	27 (16.2)	22 (7.2)
Other cognitive	20 (12.0)	19 (6.2)
Autism	30 (18.0)	0
Sensory	8 (4.8)	14 (4.6)
Health services involved (past 6 months):		
Hospital	48 (28.7)	127 (41.4)
PSOA relationship:		
Child	7 (4.2)	189 (61.6)
Parent	87 (52.1)	1 (0.3)
Sibling	21 (12.6)	11 (3.6)
Risk factors:		
History of domestic violence	28 (17.0)	28 (9.2)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

Factors associated with high support needs

In more than half of CSI cases, the Person had either severe or profound core activity limitations (16.7% severe, 40.3% profound). Higher support needs were independently associated with the Person's being reported to be in worse condition (i.e., more likely to be 'very unwell' or 'critically unwell'). Higher support needs were also independently associated with neurological and other cognitive disability, and concerns about the Person's decision-making capacity. People with higher support needs were more likely to be socially isolated and were less likely to experience neglect in relation to clothing or food.

Factors associated with serious cases of neglect

Using the criteria outlined in the Methodology (section 0), 38.2% of CSI cases were identified as being 'serious' cases of neglect. In cases of serious neglect, the Person was less likely to be receiving community services (44.8% vs. 61.1%) and the PSOA was less likely to be identified as a source of informal support prior to the report to the ADC (75.1% vs. 85.3%). In serious cases, the type of neglect reported was less likely to be failure to meet support needs (65.2% vs. 77.1%). Serious cases of neglect were independently associated with identifying domestic violence as a risk factor (18.3% vs. 7.9%).

Table 7. Factors independently associated with serious cases of neglect

	Less serious cases (n=293) n (%)	**Serious neglect (n=181) n (%)**
Person receiving community services	179 (61.1)	81 (44.8)
Informal supports involved:		
PSOA	250 (85.3)	136 (75.1)
Type of neglect:		
Failure to meet support needs	226 (77.1)	118 (65.2)
Risk factors:		
History of domestic violence	23 (7.9)	33 (18.3)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

The following account describes Alison's experience, an example of serious neglect which was thought to have contributed to death. Like many cases of serious neglect, Alison was an older woman who had no contact with services prior to being admitted to hospital. She had not been seeing a health practitioner, nor were paid services attending to her at home or in the community. Similar to many cases of serious neglect among older people or adults with disability, Alison was not receiving support from the PSOA.

> A hospital worker contacted the ADC to report concern about neglect and abuse of an older woman, Alison, who had recently been admitted. Alison had arrived at hospital very frail and in poor condition showing severe signs of neglect. She had multiple pressure wounds, delirium, hypertension and was very malnourished. It was reported that prior to being admitted to hospital, Alison had lain in bed shaking and unable to move for days, covered in urine and faeces. Alison subsequently died while still in hospital, which led to concern that she had died due to the PSOA's failure to provide the necessities of life leading to death.
>
> The ADC referred the matter to the police who investigated potential grievous bodily harm by neglect. After Alison's death, the case was also referred to the coroner. The ADC offered to provide information and assistance to the coroner as needed.
>
> Prior to admission to hospital, Alison had been living with one of her children, the PSOA. She was not in contact with any health services and nor did she have any paid

> support services, at home or in the community.

Another example of serious neglect relates to an older woman, Barbara, living alone with no support:

> A health care worker found Barbara alone in her home, in a state of collapse after trying to reach the front door. Barbara was weak and dehydrated and had not taken medication for a serious medical condition. She may have been without food or water. She could not remember how long it had been since she had eaten a meal, but it was days. She was immediately taken to hospital.
>
> Barbara had been hospitalised earlier in the year. and at that time, she had been discharged on the understanding she would live with her daughter. No services were arranged prior to her being discharged. Unfortunately, Barbara returned to living on her own, and because of her condition, was unable to arrange services herself. No-one else organised services for her. The ADC identified that no follow up seemed to have occurred at that time to ensure appropriate safeguards were put in place for Barbara.
>
> At the time of the report to the ADC, Barbara had been found by a health care worker who was concerned about her, and had requested a welfare check by the police. The police reported that there were no concerns. Still concerned, the health care worker asked police to conduct a second welfare check, but they refused. Worried, the worker undertook a house visit herself with a colleague.
>
> The ADC commenced an investigation following the report. At that time, Barbara was remaining in hospital and awaiting placement in residential aged care.

Both these examples demonstrate the vulnerability of individuals with little or no sources of support, either from carers, family, friends or paid services. With little oversight by others, serious neglect developed unchecked. In both cases, it was health care workers who noticed the neglect and initiated steps to change the Person’s circumstances.

The second case, regarding Barbara, shows the risk of failing to notice and respond to neglect or a risk of neglect. An older woman with a serious health condition was discharged from hospital on the understanding she would live with family. However, no services were put in place, and no follow up was done to ensure that services had been arranged. This appears to have been a missed opportunity to prevent neglect.

The importance of services in preventing and responding to neglect, including health care services, police, and aged care or NDIS services, are explored in the section, *Service system responses to neglect,* below.

5.2.1 Summary and implications

The data outlined in this section highlight differences in demographics and relationship situations between adults with disability compared to older people. It is worth noting that higher support needs were associated with factors such as specific types of disability (i.e., neurological and other cognitive) and being socially isolated. Further, serious cases of neglect were associated with decreased involvement from community services and a history of domestic violence. These associations reflect an ecological understanding of neglect, including the importance of considering broader relationship, social, and service system contexts when considering appropriate intervention or preventative measures.

This section has outlined the demographic profile of the sample, as well as features of the Person's relationship with the PSOA, social situation, and engagement with formal services. Of note, people with disability were more highly represented among cases referred to the CSI team than those handled by the Helpline, suggesting a greater need for investigation and targeted intervention in reports involving people with disability. It is also worth noting that while only a small proportion of Persons were identified as Aboriginal, in nearly three-quarters of cases, Aboriginal status was unknown or not stated. There is potential scope for ensuring this information is more routinely collected to ensure culturally appropriate responses to allegations of neglect. Approximately half of the cases handled by the CSI Unit had concerns regarding the Person's decision-making capacity, yet the Person had decision-making support in only half of those cases.

Importantly, the data points to the importance of an ecological understanding of neglect, in which people who experience neglect are connected to other people and systems of support. These will be explored in the follow sections, but here we highlight a few key learnings:

Hospitals provide a key opportunity for identification or prevention of neglect among older people – particularly when there are suspected concerns about decision making capacity (not necessarily confirmed concerns). This is particularly the case for people who do not receive support from services or from a family member or friend.

There are potentially opportunities for a broader range of health service providers to identify potential neglect. This is particularly the case for adults with disability, who were more likely to be engaged with a wider group of health professionals. Appointments with health practitioners are opportunities to explore the care that people receive and to raise concern if a Person's condition or lack of support suggests they are at risk of neglect.

People who experience serious neglect are less likely to have access to support from family or friends or from formal services. Community education for adults with disability, older people and their networks could highlight the benefits of support services, the advantages to connecting with services early, before it becomes difficult to manage without support, so that systems of support are in place if they should need them.

The review of the literature showcased screening tools developed in the USA which could be adapted for use in Australia. Such a tool could draw upon the above individual factors to help practitioners to identify people who could be at risk of neglect.

5.3 Relationship factors

This section explores the relationships between adults with disability and older people with others, to better understand the role those relationships play in protecting people from neglect, or placing them at risk of neglect. This section includes discussion of social isolation, and the risks posed by not having relationships with carers, family, friends and neighbours. It then discusses cases of neglect in which the PSOA is experiencing stress associated with providing care, and/or has their own health or disability care needs. Finally, this section examines cases of neglect in which abuse is also a concern.

5.3.1 Carer health needs & carer stress

The review of current research literature presented in section 4 found that some perpetrators of neglect do so because of their own health or disability and need for care. When reports about neglect are made to the ADC, the agency considers whether carer stress or the health or disability of the PSOA could be a factor. This section presents analysis of cases where carer stress was flagged as a possible issue.

Carer stress was identified as a relevant factor in a large minority of CSI cases (40.7%). Carer stress was independently associated with the Person's condition not being as poor (e.g., only 4.3% were 'very unwell' or 'critically unwell' vs. 10.8% of cases with no carer stress). Carer stress was also associated with the PSOA being the primary carer (81.9% vs. 63.0%) and the Person being socially isolated (55.4% vs. 36.3%). Among cases where carer stress was a factor, a larger proportion of Persons had recent hospital or medical contact that may have affected the response (15.0% vs. 4.6%) and the health literacy of the Person and/or PSOA was more likely to be a factor contributing to the issues (19.7% vs. 8.5%).

Table 8. Factors independently associated with carer stress

	No carer stress (n=281) n (%)	Carer stress (n=193) n (%)
Person condition:		
Needs not met	46 (17.2)	44 (23.4)
Signs of neglect	147 (54.9)	105 (55.9)
Poor	46 (17.2)	31 (16.5)
Very unwell	13 (4.9)	6 (3.2)
Critically unwell	16 (6.0)	2 (1.1)
Person isolated	102 (36.3)	107 (55.4)
PSOA primary carer	177 (63.0)	158 (81.9)
Factors contributing to issues/allegations:		
Person and/or PSOA health literacy	24 (8.5)	38 (19.7)
Factors affecting the response:		
Recent hospital/medical contact	13 (4.6)	29 (15.0)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

The qualitative data includes many instances where neglect appeared to be occurring because the PSOA was unable to provide adequate care. Very often, these were cases where a couple was ageing together, and both members of the couple were facing challenges with their health and disability as a result of ageing. For example,

> A report was made to the ADC regarding concerns about neglect of a friend, Carol, an older woman who lived with her husband, Craig. Their daughter visited every fortnight and brought food. However, Carol had severe dementia and was not eating because she worried about the safety of the food.
>
> There was concern that the husband, the PSOA, was not providing appropriate care for his wife. Craig had multiple health issues himself and was reported to say, "I can't take care of myself, why should I care for her?" Nonetheless, Craig cooked, drove, did grocery shopping and took his wife to medical appointments. The house was tidy.
>
> But there were concerns that Craig was often angry and yelled at his wife. In addition, it became apparent that her struggles with eating had lasted many years. At the time of the report, she had lost a lot of weight and was very thin.
>
> Carol was admitted to hospital because of multiple health concerns. While in hospital, Carol was connected to the hospital social worker, who was investigating appropriate supports for her to remain living at home.

In this case, Carol was not receiving the care she needed at home because her husband also needed support services, and, as such, was unable to meet all her care needs.

There were other cases in which the PSOA was struggling, but not as a result of ageing. These cases tended to be more diverse and challenging than those involving ageing couples. It was difficult in the analysis to identify typical cases. In some cases, adults with disability were living with a parent or parents. In these cases, sometimes the parents were overwhelmed by caring responsibilities and struggling to cope, and as a result the adults with disability were not provided adequate care support or supervision. Sometimes this was because of the parents' own health or disability challenges. Sometimes there appeared to be a struggle over the adult with disability's independence and different expectations between the adult with disability and their parents about how they could live safely while also having opportunities for independence. Sometimes the parent was abusive towards the adult with disability, and neglect appeared to be an element of the abuse. Often, multiple factors were in play.

The following is an example where the PSOA's caring responsibilities and own health needs were relevant factors in the neglect of Daniel, an adult with disability.

> The ADC was contacted by a paid worker at a disability service provider because of concern about Daniel's home environment. It was reported that at home, Daniel had no access to running water, no working shower, a bucket was used instead of a toilet, no electricity, and the fridge had been broken for a long time.
>
> Daniel had an intellectual disability, had high support needs and needed occasional assistance with decision making. He was living with his mother, Daisy (the PSOA), and two adult siblings, both of whom also had disability.

> It was reported that Daisy had refused services for her children inside the home but accepted disability support services provided off site. Daniel had attended these for many years.
>
> Daniel had previously lived in supported independent living, but this was "not right for him". He moved back in with his mother while awaiting alternative supported independent living accommodation.
>
> Daisy was described as "presenting as having an undiagnosed mental health condition", plus was experiencing grief following the death of a close family member. In addition, as a retiree, there was concern she had insufficient finances to maintain the property in good condition for her family.

In this case, the PSOA was responsible for the care of her three adult children, all of whom had disabilities. In addition, she possibly had her own challenges with mental health. The ADC was able to respond to the needs of the Person as well as the PSOA, by connecting the Person to alternative accommodation and introducing new services for the PSOA.

However, most other cases were much more complicated. Sometimes these involved adults living with a partner and sometimes they involved drug or alcohol use among both partners. In other instances, the PSOA was a sibling or friend or neighbour. Often both the Person and the PSOA had challenges due to their physical health, mental health or disability. As one example,

> A paid worker contacted the ADC with concerns about abuse and neglect of Eddie, an older man with neurological disability. Eddie was living with his wife, Elaine, the PSOA. His daughter also provided support.
>
> The reporter was concerned that physical assault had occurred in the past and was continuing. Eddie himself contacted police to report that his wife was not providing him with appropriate care. His wife reportedly became extremely distressed at police involvement and subsequently assaulted him again.
>
> Eddie, Elaine and their daughter all had diagnosed disabilities which involved cognitive impairment, and which required support. The reporter suggested that the family had a long history of dysfunction and family violence.
>
> The family had longstanding connections to their general practitioner. Their daughter took her father to their doctor for treatment, but when the general practitioner suggested respite or additional services, she refused.

These cases demonstrate the significance of a PSOA's levels of stress or own health needs to neglect of older people and adults with disability. When responding to alleged neglect, the ADC typically explores whether carer stress or unmet needs of the carer may be a contributing factor and can help facilitate supports for the PSOA and other family members if this is needed. Often this is the case. This demonstrates the need for other organisations with a role in identifying and responding to neglect to also be attuned to the capacity of a nominated carer to actually provide that care, and whether or not additional services might be needed by several family members.

5.3.2 Abuse

Neglect often co-occurs with abuse. In fact, in 37.6% of CSI cases, current or historical abuse within the relationship was identified as a concern. Cases involving current or historical abuse were more likely to be identified as cases of serious neglect (47.2% vs. 32.8%). Abusive relationships were independently associated with the Person being socially isolated (60.7% vs. 34.1%), being less likely to live in their own home (66.2% vs. 79.8%) rather than other housing situations such as social housing, a retirement village, granny flat or separate residence on family property. The PSOA was male in a larger proportion of cases involving abuse (60.7% vs. 45.3%), a history of family dysfunction was more likely to be identified as a risk factor (30.9% vs. 17.7%), and the PSOA was more likely to have refused help or to act (41.0% vs. 12.5%). The Person's views or wishes were more likely to be identified as factors affecting the response in cases of abuse (55.6% vs. 39.9%), however concerns for the Person's decision-making capacity were less prevalent (39.9% vs. 54.4%).

Table 9. Factors independently associated with current or historical abuse in the relationship

	No history of abuse (n=296) n (%)	**Current or historical abuse (n=178) n (%)**
Person isolated	101 (34.1)	108 (60.7)
Concerns about Person's decision-making capacity:		
No/Unknown	121 (40.9)	101 (56.7)
Suspected	14 (4.7)	6 (3.4)
Yes	161 (54.4)	71 (39.9)
Person lives in own home (as opposed to residential care, granny flat, retirement village etc)	201 (79.8)	104 (66.2)
PSOA gender:		
Female	151 (51.0)	65 (36.5)
Male	134 (45.3)	108 (60.7)
Other	2 (0.7)	0
Unknown	9 (3.0)	5 (2.8)
Risk factors:		
History of family dysfunction	17.7%	30.9%
Factors affecting the response:		
Person's views/wishes	118 (39.9)	99 (55.6)
PSOA refused help/refused to act	37 (12.5)	73 (41.0)
Serious neglect	97 (32.8)	84 (47.2)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

Qualitative data demonstrates the challenges of abusive relationships which involve neglect. This case relates to Fay, an older woman who appeared to be experiencing financial abuse and being restrained by being locked in a room.

> At the time of the report, Fay was grieving the loss of her husband who had died a few months earlier. She lived with her son, Frank, the PSOA. Her daughter, who lived elsewhere and did not visit, received the Carer Allowance. Fay had no access to her own money.
>
> A paramedic made a report to the ADC when called to the property to attend to Fay. She had a chronic health condition but hadn't taken medication recently. As a result, her health was so poor that she was rushed to hospital by ambulance. Both Fay and her son said Frank usually gave Fay her medication, but that she had been refusing of late due to her grief. Frank had stopped trying to give her the medication – he explained his mum was 'in a bad place and didn't want to'. The paramedic reported that Fay was confused and had memory issues.
>
> While the house was clean, Fay was in a room that had a lock on the outside of the door, which made the paramedic concerned she could be locked in. Her clothes were slightly unclean.
>
> The paramedic also contacted the police, but the police were unsure of how to respond. The ADC advised the paramedic to inform the police that there was concern for 'not meeting support needs as a carer and neglect'. The paramedic was going to contact the police again.
>
> The ADC worked with the hospital to develop an appropriate discharge plan and monitored to ensure safeguards and services were in place.

This woman's medication had been neglected, which led to serious health issues and necessitated being taken by ambulance to the hospital emergency department. Plus, there were concerns she was experiencing financial abuse and being locked in a room. However, the issue of neglect with regards to medication was complicated by her grief and refusal to accept medication.

Another case provides an example of abuse and neglect of Glen, a young adult with disability.

> A disability support worker contacted the ADC with concerns about abuse and neglect of Glen, a young man living with his parents and siblings. Glen had an intellectual disability.
>
> The young man's siblings also had disabilities and the reporter indicated that his mother likely had a mental illness. The household was described as volatile and the relationship between Glen and his mother as 'toxic'. Family members reportedly yelled at and pushed each other. Investigations found the family had a long history with child protection authorities, including allegations of sexual abuse between siblings.
>
> Glen and his siblings all received NDIS services and Glen regularly attended day programs. A cleaner looked after the house. Glen's father was opposed to supported independent living and his mother would not discuss it for fear of upsetting the father.

> The reporter was concerned that Glen was remaining in incontinence pads for extended periods. The file states “PSOA handed wipes to Person after 3 days to clean himself and stated, ‘What sort of an idiot doesn't clean himself’”.

The above is an example of a case in which neglect occurred in combination with abuse. The family was facing multiple challenges and had been for many years. Prior to Glen reaching adulthood, the family had long been in contact with child protection services due to serious concerns about the wellbeing of the children. The parents were not supportive of Glen moving into supported independent living and had agreed to support to improve family relationships and to address concerns about the young man’s personal care.

Neglect often occurs with abuse and can be part of a pattern of abuse perpetrated by the PSOA towards the Person. This points to the importance of organisations and practitioners, if identifying possible abuse in a relationship with an older person or adult with disability, also exploring whether neglect is occurring in the relationship, as the neglect may be less apparent in the first instance. Similarly, the opposite is necessary. If someone presents as potentially experiencing neglect, it is important to explore if some form of abuse may also be occurring.

In a large minority of cases involving neglect and abuse, the PSOA has refused support or refused to act to address neglect. This highlights the importance of responding to neglect through the direct involvement of services or other agencies, rather than relying on the PSOA to facilitate supports, for example, prior to hospital discharge. Follow up is required to ensure supports remain in place or are expanded as needed. Finally, it is important to consider that concerns about the Person’s decision-making capacity were lower in neglect cases in which current or historic abuse was also a factor. In many cases, the Person’s own wishes affected the response to neglect. This reinforces the importance of taking abuse or potential abuse into account when addressing neglect. It is important, for example, that the Person can communicate their wishes in private, away from the PSOA, that they feel that disagreeing with the PSOA’s wishes is a safe option, and that the Person understands the range of options available to them and how they can be supported to live safely. The reasons the PSOA or the Person might refuse support should also be explored (see Section 5.5 where this issue is explored in more detail).

5.3.3 Social isolation

People who are socially isolated are at greater risk of neglect, and greater risk of that neglect being more serious. ADC databases contain information on whether or not there were indications a Person was socially isolated. This may not be total isolation, but having little to no contact with the community, family or friends (outside of the PSOA), and little to no involvement in any social activities. There were indications that the Person was socially isolated in 44.1% of CSI cases. People who were isolated were more likely to experience some form of core activity limitation (92.6% vs. 85.1%) and experienced more significant limitations in their daily functioning (e.g., 70.9% experienced severe or profound limitations, compared to 46.4% of those with no indication of social isolation). People who were isolated were also less likely to have any involvement from aged care, disability, or health services, and were less likely to receive informal support from their family. Social isolation was also associated with the PSOA preventing the Person's access to services (66.0% vs. 38.9%), carer stress (51.2% vs. 32.5%), and current or historical abuse in the relationship between the PSOA and Person (51.7% vs. 26.4%). Cases of social isolation were also associated with indications that the PSOA did not know what to do in response to the Person's condition (19.1% vs. 5.7%).

Table 10. Factors independently associated with Person being socially isolated

	Person not isolated (n=265) n (%)	**Person socially isolated (n=209) n (%)**
Person functioning:		
No limitation	37 (14.9)	14 (7.4)
Any core activity limitation	211 (85.1)	175 (92.6)
Core activity limitation	*83 (33.5)*	*18 (9.5)*
Mild core activity limitation	*3 (1.2)*	*9 (4.8)*
Moderate core activity limitation	*10 (4.0)*	*14 (7.4)*
Severe core activity limitation	*25 (10.1)*	*48 (25.4)*
Profound activity limitation	*90 (36.3)*	*86 (45.5)*
Formal services involved:		
No disability or aged care services	89 (33.6)	87 (41.6)
Health services involved:		
GP	122 (46.0)	84 (40.2)
Hospital	100 (37.7)	75 (35.9)
Community	49 (18.5)	35 (16.7)
Other medical	26 (9.8)	18 (8.6)
Other	38 (14.3)	8 (3.8)
Informal supports involved:		
Family	127 (47.9)	70 (33.5)
Factors contributing to issues/allegations:		
PSOA preventing access to services	103 (38.9)	138 (66.0)
Carer stress	86 (32.5)	107 (51.2)
Current/historical abuse	70 (26.4)	108 (51.7)
Factors affecting the response:		
PSOA did not know what to do	15 (5.7)	40 (19.1)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

This suggests that being socially connected helps people and their carers to connect to support services, to manage the stress which can arise from providing care, and to understand how to care for people with disability or health conditions. However, an ability to be socially connected is possibly harder for those with more significant limitations on their daily functioning. For those who are in relationships where there may be current or historical experiences of abuse, social isolation may also be associated with a Person being denied access to services or social connections by the PSOA. (These issues are explored in greater detail in Section 5.5.5 below.)

5.3.4 Summary and implications

Relationships between older people and adults with disability, their partners, families, friends and communities are important considerations in cases of neglect. In keeping with the ecological framework presented in the literature review, the role of relationships is connected to the Person's own condition and to the broader service system.

This section has shown that the wellbeing of the PSOA is a significant consideration in cases of neglect. Very often, the PSOA has their own health or disability challenges, multiple caring responsibilities, and can experience carer stress. For this reason, any organisation or practitioner that might identify potential neglect, should look to the needs of the PSOA as well as the Person when considering how to respond.

In addition, cases in which carers are stressed tend to involve less serious neglect. This suggests that the risk of neglect may start to show first in the carer, through carer stress. Therefore, being attuned to carers' wellbeing could help prevent neglect, either by stopping neglect from developing in the first place or intervening before it becomes more serious. Ideally, whenever an older person or adult with disability is identified as needing support from a carer, support services and health services should check to see if the carer needs support and assistance – not only with their own health, but also to avoid being overwhelmed by their caring responsibilities. In addition, this finding points to the importance of respite to provide carers with a break to reduce carer stress.

Many cases of neglect also involve abuse. This finding also points to the importance of considering an older person or adult with disability's relationships where there are concerns of neglect. It is possible that the PSOA may not be a safe person, and inquiries should be made to determine if abuse is also occurring. Conversely, people who are experiencing abuse may also be neglected, so possible neglect should be explored if there are concerns about abuse.

Finally, this section shows that social isolation is associated with greater risk of neglect. Importantly, the finding that social isolation is associated with increased functional limitations provides an opportunity for early intervention. Despite the challenges that functional limitations pose, ensuring that older people and adults with disability have opportunities for regular social contact with extended family, friends and community members could help them to avoid isolation. Moreover, these additional connections may also identify neglect should it start to occur. These connections need to be through formal services but could be informal social gatherings. The finding that social isolation often also occurs in a context of abuse is explored in more detail in Section 5.5.

Together these findings point to the need for organisations who have regular contact with older people and adults with disability to consider their relationships. For example, if health services, including general practitioners, identify a patient has increasing functional limitations, it could help highlight emerging neglect and a need for services or change in circumstances to ensure they can live without neglect. There is especial need for organisations and policy to consider carers and their needs, as well as those of older people and adults with disability. Finally, the co-occurrence of neglect with abuse, particularly in cases of serious neglect and social isolation suggests a need for organisations to explore whether neglect might be an element in an abusive situation.

5.4 Service system factors

This section explores the role of the service system in identifying and responding to neglect – the outer layer of the ecological framework presented in the literature review. It first explores access to services among adults with disability and older people, including use of services among older people and people with disability, use of services among people with dementia, and differences between urban and rural areas. It then presents analysis from ADC data on responses to neglect by NDIS and aged care services, health services, and police.

5.4.1 Access to services

Use of services

Approximately two-thirds of adults with disability in the CSI cases were receiving support from disability services and 37.5% of older people were receiving support from aged care services.

Among adults with disability, receiving disability services was independently associated with having a neurological or other cognitive disability. When people with disability were receiving disability services, isolation was less likely to be identified as a risk factor (8.2% vs. 36.4%) and carer stress was more likely to be identified as a contributing factor to the issues (58.6% vs. 26.8%). While a history of domestic violence was less likely to be identified as a risk factor among cases where the Person was using disability services (12.7% vs. 25.5%), current or historical abuse was more likely to identified as a factor contributing to the allegations (46.8% vs. 28.6%). This may in part be a result of past histories of domestic violence not being identified or reported previously, due to not being recognised or because any reported abuse was a recent occurrence. The issue of the PSOA blocking access to services as part of an abusive situation is explored in more detail in Section 5.5.5.

Table 11. Factors independently associated with receiving disability services among adults with

disability

	Person not receiving disability services (n=56) n (%)	Person receiving disability services (n=111) n (%)
Disability:		
Neurological	13 (23.2)	46 (41.1)
Other cognitive	3 (5.4)	17 (15.3)
Factors contributing to issues/allegations:		
Carer stress	15 (26.8)	65 (58.6)
Current/historical abuse	16 (28.6)	52 (46.8)
Risk factors:		
Social isolation	20 (36.4)	9 (8.2)
History of domestic violence	14 (25.5)	14 (12.7)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. This analysis excludes older people with disability as they receive aged care services. Cases with missing data have been excluded from percentage calculations.

Similarly, over a third of older people were using aged care services. Those receiving aged care services were older on average than those who were not (82.9 years vs. 79.2 years). Isolation was less likely to be identified as a risk factor among people receiving aged care services (7.0% vs. 18.2%) and there was less likely to be any indication that the wishes of the Person affected the response (38.3% vs. 54.7%), which may be due to duty of care responsibilities of aged care services (i.e., circumstances dictating that duty of care outweighs the Person's wishes). The Person's condition was worse among those not receiving any aged care services (e.g., 13.0% were 'very unwell' or 'critically unwell', compared to 3.6% of those receiving aged care services), however, this difference was not statistically significant when controlling for other variables.

Table 12. Factors independently associated with receiving aged care services among older people

	Person not receiving aged care services (n=192) n (%)	Person receiving aged care services (n=115) n (%)
Age: Mean (SD)	79.2 (9.8)	82.9 (8.6)
Person receiving community services	54 (28.1)	80 (69.6)
Risk factors:		

	Person not receiving aged care services (n=192) n (%)	Person receiving aged care services (n=115) n (%)
Social isolation	35 (18.2)	8 (7.0)
Factors affecting the response:		
Person's views/wishes	105 (54.7)	44 (38.3)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

Access to services was a significant issue among older people with dementia. A delay in accessing services was identified as a contributing factor in a larger proportion of cases involving older people with dementia than those involving older people without dementia (14.1% vs. 6.8%). This difference remained significant when controlling for other variables, including concerns about the Person's decision-making capacity. Delays in service access included delays related to service system capacity (e.g., services not having capacity to provide support), provider or practitioner actions (e.g., not following up on referrals in a timely manner), and the actions of the Person, PSOA, or family (e.g., not acting on referrals in a timely manner). In cases involving older people with dementia, it is worth noting that the delays in accessing services were mostly due to actions of the Person, PSOA, or family (10.1% of cases involving older people with dementia), as opposed to service system capacity (3.0% of cases involving older people with dementia).

Table 13. Factors independently associated with dementia (among older people)

	No dementia (n=207) n (%)	Dementia (n=99) n (%)
Concerns about Person's decision-making capacity:		
No/Unknown	128 (61.8)	18 (18.2)
Suspected	14 (6.8)	5 (5.1)
Yes	65 (31.4)	76 (76.8)
Person lives in own home	127 (71.3)	73 (83.0)
Factors contributing to issues/allegations:		
Delay in service access	14 (6.8)	14 (14.1)
Risk factors:		
Self-neglect	9 (4.3)	10 (10.1)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

Access to services in regional and rural areas

Health, aged care and disability services are not as prevalent in rural and regional locations as they are in major capital cities. The Australian Institute of Health and Welfare (2024) reports that outside urban areas, there is a higher rate of hospitalisations that could have potentially been prevented if there had been an earlier intervention. Potentially preventable hospitalisations are even higher in remote areas. This may be connected to the availability of fewer health professionals per head of population in rural/regional areas (AIHW, 2024) and access to a small pool of NDIS providers in regional and rural areas (National Rural Health Alliance, 2023).

In ADC data, however, access to services was generally not significantly different between regional and urban areas. The only significant difference was in relation to community health services (e.g., community nurses, allied health). These services were involved in a larger proportion of cases in regional areas than urban areas (21.9% vs. 12.0%). This difference remained significant when controlling for other variables. Other significant differences between cases from regional and urban areas included language (24.4% of Persons in urban areas spoke a language other than English, compared to 7.0% of Persons from regional areas) and mental ill health (identified among 14.4% of Persons from urban areas, compared to 7.4% of Persons from regional areas). While the majority of Persons in all geographical areas were receiving informal support from the PSOA, this was less common in regional areas than in urban areas (76.2% vs. 87.6%). The Person's chronic health issues were identified as a risk factor in a larger proportion of cases from regional areas than urban areas (36.2% vs. 21.6%).

Table 14. Factors independently associated with living in regional areas (vs. metropolitan)

	Metropolitan (n=209) n (%)	**Regional (n=256) n (%)**
Language other than English	51 (24.4)	18 (7.0)
Disability:		
Mental health	30 (14.4)	19 (7.4)
Health services involved:		
Community	25 (12.0)	56 (21.9)
Informal supports involved:		
PSOA	183 (87.6)	195 (76.2)
Risk factors:		
Chronic health issues	45 (21.6)	92 (36.2)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

Analysis of the qualitative data did not reveal further differences between cases located in rural/regional and urban areas. The analysis investigated comments regarding access to services, PSOA blocking services, carer stress, comments regarding the Person's own wishes, and any closing comments when provided.

Blocking access to services

Among CSI cases, there were indications that the PSOA was blocking or preventing the Person's access to services in 50.8% of cases. The PSOA was the Person's primary carer in 79.7% of these cases (a larger proportion than cases where service access was not blocked, 61.4%). Compared to cases where there were no indications of the PSOA blocking service access, a larger proportion of cases where the PSOA was blocking service access were in regional areas (59.7% vs. 50.2%) and a larger proportion reported indications of the Person being socially isolated (57.3% vs. 30.5%). Concerns about the Person's decision-making capacity were reported in a larger proportion of cases where the PSOA was blocking service access (53.9% vs. 43.8%). Carer stress contributed to the situation in a larger proportion of cases where the PSOA was blocking service access (51.0% vs. 30.0%) and historical or current abuse in the relationship was also more common in cases where the PSOA was blocking service access (45.6% vs. 29.2%). Analysis of the qualitative data reveals that blocking services by the PSOA was often regarded as a form of coercive control. Among other cases where potential abuse was not flagged as a concern, it was also commonly noted that the PSOA blocking services could be coercive behaviour.

Table 15. Factors independently associated with PSOA blocking services

	PSOA not blocking services (n=233) n (%)	**PSOA blocking services (n=241) n (%)**
Area of residence:		
Metropolitan	113 (49.8)	96 (40.3)
Regional	114 (50.2)	142 (59.7)
Person isolated	71 (30.5)	138 (57.3)
Concerns about Person's decision-making capacity:		
No/Unknown	123 (52.8)	99 (41.1)
Suspected	8 (3.4)	12 (5.0)
Yes	102 (43.8)	130 (53.9)
PSOA primary carer	143 (61.4)	192 (79.7)
Factors contributing to issues/allegations:		
Carer stress	70 (30.0)	123 (51.0)
Current/historical abuse	68 (29.2)	110 (45.6)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

5.4.2 Service system responses to neglect

Community support services

Aged care, disability and other services are prevalent in the lives of many older people and adults with disability who experience neglect. Paid workers for aged care and disability services often make reports to the ADC about concerns that a Person might be experiencing neglect. At times, these services are among the few people who attend in person at the home of Persons who might experience neglect. Moreover, the NDIS Code of Conduct (2019) and the Code of Conduct for Aged Care place a duty of care to prevent and respond to abuse and neglect of people receiving services, including from neglect in their own homes by other people.

Unfortunately, there was little evidence about the actions of aged care or disability services in the data. However, it was evident that a primary role for these services regarding neglect is one of noticing and reporting a concern, to ADC or to their service provider, and in facilitating additional supports if it is determined that these are needed. For example,

> A report was made about Helen, a woman with significant intellectual disability who was attending a day program several days each week. Helen lived with her mother who was also identified as potentially having an intellectual disability. Staff at the day program became concerned that the Helen was malnourished with constant diarrhoea and made a report to the ADC. The ADC commenced an investigation, consulted with the Helen, her mother and general practitioner. They determined that additional services would be beneficial, but that such discussions had not been taking place between the NDIS provider, Helen and her mother.

A similar example with aged care services:

> An older man, Ian, was observed to have lice, be very dirty with old clothes, long nails, and was reportedly being left in wet continence aids all night. Ian had significant memory loss and high care needs. The PSOA was his daughter, who did not live with him. She believed that her father could manage his own personal care, which was not the view of the aged care day centre he attended several days each week. Ian previously had cleaning services, but they refused to return, and his home was in bad condition.
>
> Staff from the day centre made a report to the ADC, who investigated. Ian's GP indicated that the PSOA was a 'big hearted person' who had multiple caring responsibilities. Health services visited Ian and conducted a review, determining that he functioned well at home.
>
> The ADC worked with the PSOA to facilitate discussion with service providers and to make changes in her father's home. Ian started attending the day centre 5 days per week. Staff there agreed to continue to monitor his condition, and to re-report to the ADC if there were further concerns.

While services are clearly important in supporting adults with disability and older people with their day-to-day care needs, they have a significant secondary role in identifying, and potentially responding to, neglect. As services with routine contact with adults with disability and older people, they may have opportunities to identify and respond to neglect at an early point. Such opportunities are less likely to be available to other organisations like hospitals and police, who tend to become involved in more serious cases.

Health

Like workers in aged care and disability services, health care workers also have a duty of care to identify and respond to abuse among older people (NSW Health, 2023). Although a range of health services are involved in many cases of neglect, it is most often hospital staff, including social workers, and ambulance officers who are recorded in ADC files as taking action with regards to potential neglect.[1]

Ambulance officers, when called out to an emergency situation, sometimes contact the ADC to seek advice or report potential neglect. For example,

> An ambulance was called to attend to an older woman, Janet, after a fall. The ambulance officer contacted the ADC, having observed signs of neglect. The ambulance officer noticed possible fractures, considerable bruising, pressure sores and skin burnt as a result of Janet sitting in her own urine and faeces. She was unable to walk and struggled to communicate.
>
> Janet was living with her husband and son. Although the family appeared very caring, the ambulance officer was concerned that Janet was being neglected. She had not eaten for several days, the house was unclean, and she did not appear to have accessed appropriate medical care when needed.
>
> The family attended a local General Practitioner who, when interviewed by the ADC, said they were unaware of Janet's circumstances.
>
> Janet was admitted to hospital, where staff provided medical care and assisted with arranging alternative accommodation and services.

The above example is typical of a case in which an ambulance officer contacts the ADC. In this case, CSI worked with agencies to determine if there was possible criminal neglect that would warrant referral to police.

Also of note in this case is the involvement of the local general practitioner. Although seeing the family, the general practitioner was unaware of possible neglect, despite the poor state of health of the older woman. Analysis of all ADC cases in which neglect had been considered by health services without ADC prompting identified only one that had been raised by a general practitioner. However, just under half of Persons had seen their general practitioners in the previous six months, sometimes these including home visits. The qualitative data suggests that others may have been connected to

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[1] The dataset included who made the report to the ADC. The options were: a family member, a neighbour, the Person themselves. It included an option of 'paid worker', which appeared to be used for any paid worker in the health sector, or aged care or disability service, general practitioner, etc. Sometimes, in conjunction with other data fields, it was possible to determine that the paid worker was a health worker, and sometimes that they were an ambulance officer. However, this level of detail was not routinely available.

general practitioners, even if they had not had a recent appointment.

The low proportion of cases in which adults with disability or older persons had seen their general practitioner in the last six months also suggests that there would be benefit in general practitioners being attune to these patients making fewer appointments than might be needed. Involvement of a general practitioner was even lower among cases of serious neglect (39.2%) and cases where there was current or historical abuse (37.1%). Failing to see a general practitioner regularly could be flag for concern for neglect and/or abuse.

Finally, this case highlights the role of hospitals in arranging services and residential aged care when required. Often hospitals also cared for older people as patients while they were waiting to secure aged care or disability services or residential aged care.

In other cases, hospital staff initiate the exploration of potential neglect regarding a patient named Keith.

> An older man, Keith, was admitted to hospital following an alleged assault by one of his adult children who he lived with. In addition to concern about the assault, hospital workers were worried Keith was being neglected because he did not have an appropriate living situation. During a period of renovation, Keith was described as “living in a 'bunker' with exposed wires, no windows and a toilet and basin and a bed all in one room.” He had also not received medical treatment for a swollen and painful foot.
>
> In response, the hospital arranged for Keith to live in residential care for the duration of the renovation. They also made a report to the police.

In the above case, hospital staff arranged new services for Keith, including alternative accommodation while his home accommodation was unsafe.

In another cases, hospital staff contact other agencies with concerns about neglect. For example,

> A paid worker contacted the ADC with concerns about Larry, an older person they believed was being locked in a room by the PSOA for several months. Upon being admitted to hospital [for reasons unknown], Larry was reported to say he didn’t feel safe at home.
>
> The ADC investigated and met with Larry while they were in hospital. Larry denied he had been locked in their room or otherwise prevented from leaving. While Larry refused further assistance from the ADC, hospital staff also contacted public housing authorities regarding the concerns, who supported him to move into new housing. Larry was also working with a hospital social worker to put additional supports in place.

In this case, although Larry did not want support from the ADC and denied they were being neglected or abused, he was able to move into a new home with the assistance of public housing authorities and put new support services in place.

In some instances, hospital staff do not recognise or respond to neglect on their own, only doing so when it is suggested by the ADC. Quantitative analysis was conducted to explore patterns in cases when health services considered whether a Person might be experiencing neglect (with or without prompting from the ADC) compared to those when health services did not consider whether a Person might be experiencing neglect. In cases where health services considered neglect, over half involved a Person who experienced profound core activity limitations (54.4%), compared to 38.1% of those cases where health services did not consider neglect. Health services were less likely to consider neglect when the Person was receiving disability services (11.3% vs. 33.8%) but were more likely to consider neglect in cases where the PSOA was the Person's spouse/partner (36.6% vs. 22.6%). Given evidence presented earlier (Section *Carer health needs and carer stress*) that carer stress can be an early indication of neglect before a Person develops serious functional limitations, this suggests that perhaps hospital staff could benefit from education about signs of neglect.

Table 16. Factors independently associated with health services considering whether a Person maybe experiencing neglect

	Health services did not consider neglect (n=133) n (%)	Health services did consider neglect (n=71) n (%)
Person functioning:		
No limitation	17 (13.5)	4 (5.9)
Core activity limitation	14 (11.1)	9 (13.2)
Mild limitation	4 (3.2)	1 (1.5)
Moderate limitation	10 (7.9)	1 (1.50
Severe limitation	33 (26.2)	16 (23.5)
Profound limitation	48 (38.1)	37 (54.4)
Formal services involved:		
Disability (any)	45 (33.8)	8 (11.3)
PSOA relationship:		
Partner/spouse	30 (22.6)	26 (36.6)

Note: This table only displays variables showing a statistically significant difference in multivariable analysis. Full comparisons are provided in the Appendix. Cases with missing data have been excluded from percentage calculations.

Police

This section considers the role of police in identifying and responding to neglect. Often police become involved when a matter is referred by other parties. So this section first explores which organisations involve police before examining how police respond to neglect.

Referrals to police by other parties

Of the 474 cases which were handled by CSI, 139 cases of alleged neglect were referred to the police

(29.3%). Of these, almost half (n=62; 44.6%) were referred to the police by the ADC and over a third (n=49; 35.3%) were referred because there were concerns that the case could involve criminal neglect. Further, in half of the cases referred to police (n=70; 50.4%), current or historical abuse in the relationship was identified as a relevant factor (compared to 32.2% of cases that were not referred to police). The only other factor that was independently associated with cases being referred to police (by the ADC or any other party) was domestic violence as a risk factor (identified in 21.0% of referred cases; n=29, compared to 8.1% of cases that were not referred).

As noted above, in addition to neglect, current or historic abuse from the PSOA was also a concern in half of the cases referred to the police. Most often this was current abuse (n=58; 41.7%), in 12.9% (n=18) it was historic abuse, and in 6 cases (4.3%) there were concerns about both historic and current abuse. In 49.6% of cases involving alleged neglect (n=69) referred to police there were no concerns flagged about abuse.

Police made inquiries in 51.1% of the referred cases (n=71) and investigated 28.8% (n=40). The police took no action in 22.3% of referred cases (n=31). It was reported that the matter did not meet the criminal threshold in 27.3% of referred cases (n=38) and that the PSOA acted in line with the Person's wishes in 3.6% of referred cases (n=5). Qualitative data offered little additional insights about why police determined there was insufficient evidence to proceed with further action or charges.[2]

Most often, when police were involved, they conducted a welfare check or investigated, usually by speaking with the Person and/or the PSOA. Typically, these did not lead to any further action. Most often, the police reported finding nothing of concern, or the Person or PSOA denied the allegations, and the matter was not pursued further. Occasionally, the Person or the PSOA denied the police access to the property. And occasionally, the Person did not wish to seek an AVO or charges. Often in the database these cases are labelled as 'matter did not meet the criminal threshold', but it is difficult to determine if this is because there was no crime, or because the evidence was not strong enough for a conviction.

Following case explores Maureen's experience. Although there were concerns Maureen might be experiencing neglect as well as abuse, Maureen told police that she was not at risk, and clearly declared her wish to remain with her husband.

> Emergency services received a medi-alert call indicating that Maureen was in fear of a potential physical assault by her husband. Maureen had an acquired brain injury and had experienced a stroke. As a result, she had partial paralysis and slurred speech but was able to communicate given time.
>
> The police had been called out to the Maureen's home previously and noted a history of domestic violence and coercive control, although no action had been taken. The police attended again in response to the medi-alert. Maureen reported that her

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[2] For example, in 7 cases the Person did not provide evidence to support the allegation. (Database records indicate, for example, "Person did not disclose physical abuse incidents between him and PSOA" or "Nil further action due to Person's unwillingness to speak with Police"). In 3 cases the Person denied the police access to their premises. In 3 cases the PSOA denied the allegation of neglect or abuse.

> husband did not provide her with food, medication or other support, and there were too few services in the home. In this instance, too, the police took no further action, as Maureen indicated to them that she was okay and that she felt safe.
>
> To the ADC, Maureen stated repeatedly that she wished to stay in her current situation and current relationship.

Here the police reported that they took no action because Maureen insisted she felt safe. It was not clear from the data who made the report to the ADC, but it is possible that it was police. In some instances, although the police take no further action, they contribute to a collective undertaking by several different services or agencies. For example,

> A community member contacted the ADC with concerns about their elderly neighbour, Narelle. They reported that Narelle was living alone and in squalor, with only monthly visits from the PSOA who was drawing a Carer Pension.
>
> At the ADC's request, police conducted a welfare check. They attended Narelle's home and determined that there was no evidence of neglect, but did say that Narelle was in need of additional services.
>
> Narelle was transferred to hospital for treatment, where it was agreed they would stay until safe to return home. In the meantime, the ADC spoke with the PSOA, who agreed to resume services into Narelle's home.

Here the ADC responded to the report by the community member and coordinated a multifaceted response. The police conducted a welfare check and reported back to the ADC that they felt additional services in the Person's home would be useful. The hospital, in addition to providing medical care, allowed the Person to remain in hospital until services were in place to support them at home. The PSOA, in liaison with the ADC, arranged those additional services.

5.4.3 Summary and implications

About one third of adults with disability and older people were using services in cases where there were serious concerns about neglect that were looked into by the CSI. Given the seriousness of these cases, and that many conclude by putting additional services in place, it seems likely that greater service use could help reduce neglect, not least because aged care and disability support services often report neglect.

Proactive responses of services to ensure clients take up and maintain services could help prevent neglect. Where clients have stopped using services, learning why and what could be done to address any issues could be beneficial. Those who have access to services, but have not taken them up, should be contacted and supported to start using services. Aged care packages which are not being used could help identify those who could benefit from service support. Evidence that a carer has stopped someone else's services should prompt follow up to understand if carer stress is also an issue, and/or if abuse might also be a factor. The issue of why services are not being used is explored further in the following Section 5.5.

Although other research has found that there are fewer services in regional and rural areas, in the ADC data there was no significant difference in use of services based on location. However, older people with dementia were particularly likely to be less connected to services, often due to the actions or choices of the Person, the PSOA or their families. This suggests a need for additional support for older people in this situation to ensure that the services they need are in place prior to their dementia worsening.

Workers in aged care and disability support services have a duty of care which requires them to act if they have suspicions or concerns about abuse or neglect of service users. NSW Health staff have a similar duty towards identifying and responding to abuse among older people and adults with disability, and guidance regarding domestic and family violence including neglect. The adaption and implementation of such a duty of care to other organisations and their staff, for example housing authorities, community and allied health services who might have contact with adults with disability or older people could help address neglect.

Ambulance officers and hospital staff play an important role in identifying neglect, then arranging additional services, and providing a safe place to care for older people, in particular, while alternative accommodation in residential aged care is secured. However, the findings suggest that there is a need for education and protocols to guide hospital staff to identify neglect and act upon it, because although hospital staff do consider the possibility of neglect in many cases, they 'they do not always take steps to appropriately respond, using a person-centred approach. It is not clear from ADC databases why neglect is considered in some cases and not others. Nor is it clear how effectively or appropriately hospitals respond to neglect when the ADC is not involved. Hospital social workers offer an important internal resource for hospital staff in identifying and responding to neglect, as well as a valuable source of information about how hospital staff understand neglect.

Elsewhere in the health system, it was notable that general practitioners, despite having contact with just under half of older people and adults with disability experiencing neglect, rarely made reports to the ADC. It would be useful to better understand levels of knowledge about neglect and pathways to address neglect among general practitioners. In addition, general practitioners might help identify neglect by reconnecting with adults with disability or older people who have not recently made an appointment. This is in keeping with AIFS (2024) who recommended funding for GPs to include making an assessment of whether or not an older person is socially isolated and needs support to access services.

Police act as another important group of workers who may identify neglect. They have a significant role conducting welfare checks when there is concern about the welfare of an older person or adult with disability. Moreover, they can investigate criminal neglect and lay charges. However, police involvement rarely leads to charges being laid, but it is not clear why in the ADC databases. It would be useful to better understand neglect and the law, the understandings and priorities of police, and barriers to successfully prosecuting cases of criminal neglect.

5.5 Cross cutting issues

As will already be apparent, in each case of neglect, there are multiple factors that interact at an individual, relationship and service system level. This report has presented key factors of neglect at each of the three levels in the ecological framework. However, some experiences of neglect involve cross cutting issues, in which individual, relationship and service system factors are interacting. This section explores some of those cross-cutting issues: decision making capacity and autonomy, cases of self-neglect, and how a service system might provide accessible and appropriate services to all adults with disability and older people who need them.

5.5.1 Autonomy and decision-making capacity

There can be a tension between respecting or facilitating a Person's autonomy and trying to discern their capacity for decision making when treatment or support from services is refused or when choosing to remain living in circumstances of neglect.

This was a common challenge. In many CSI cases, there were concerns about the Person's decision-making capacity. This was particularly the case among those with disability, among whom there was concern about their decision-making capacity of more than half (57.6%). Among people with no disability, there were concerns about decision making capacity in around one fifth of cases (18.9%).

The following examples illustrate how a Person can be living in circumstances that put them at risk of neglect but wish to remain in their current situation.

> Pam was living with her father, the PSOA, and his partner. Pam had an acquired brain injury and could express her own views. Pam had a NDIS package and attended day activities and respite. The PSOA appeared to be making decisions and showed excessive /coercive control over the Person. Pam was not receiving care during the night as the PSOA had cancelled the services. Pam made it clear that she wanted to continue to live with her father.

In the example below, Rose, an older woman, lived with the PSOA who was exerting coercive control and preventing her from accessing services.

> Rose was living with her adult child, the PSOA. Rose had limited mobility and needed support with domestic tasks, personal care and shopping. Rose received some community services and had been assessed as eligible for a Level 3 aged care package. A support worker reported that the PSOA appeared to be trying to stop services and exhibiting coercive control by monitoring Rose's phone calls, isolating her and pressuring her to take money out of her bank account. Despite these circumstances, Rose did not want to change her living situation.

The following case illustrates the challenges faced when trying to balance the agency of the Person and their decision-making capacity, particularly in circumstances where their decision can impact on their wellbeing:

> A sibling contacted the ADC with concern about neglect of their brother, Shane, who they suspected of having dementia and hoarding behaviour. Shane's health and home

> environment had begun to deteriorate after his wife had died. At the time of the report, Shane did not have access to running water and had been buying water daily. There was also no working stove, television or heating/cooling in the house. The sibling thought their brother did not understand the severity of his circumstances. After being unable to contact their brother by phone, the sibling contacted police. Police conducted a welfare check and determined that there were no issues of concern, observing that Shane felt that his situation was fine, and he did not need any help. However, Shane had no family living close by and no support from services.

The above cases illustrate how multiple factors at the individual and service system levels interact and contribute to a Person being at risk of neglect. It can be difficult for agencies with limited resources and experience identifying and dealing with neglect to make informed assessments of the Person's situation and their need for decision making support and refer to appropriate supports. There can be a number of reasons why a Person may not be able to express a desire to change their living situation. However, leaving their current situation may not always be the appropriate option to address neglect. The involvement of agencies with the skills and expertise in neglect such as the ADC can be important in such cases.

5.5.2 Self-neglect

Cases of self-neglect often involve a Person making their own decisions about refusing support or being unable to make decisions and act regarding their own care. Self-neglect was a strong theme in the research and was evident in a number of cases. In the qualitative data, most of the Persons reported in cases of self-neglect had at least 1-2 chronic health conditions along with a disability. Most of the cases reported that the Person was socially isolated and access to formal services varied. Many of the cases of reported self-neglect had no formal services and were not aware of available support. A small number were living with others but were not receiving formal services. The following cases of self-neglect illustrate how social isolation, the desire to remain living independently, and a service system with limited resources interact and contribute to creating an environment where people are at risk of self-neglect.

In this case, an older woman, Tracy, desired to remain independent without outside help, but this had led to self-neglect. A lack of knowledge about how services can help to support a Person to remain at home may also have been a contributing factor.

> An ambulance officer who treated Tracy at home reported to the ADC concerns that she was at risk of self-neglect. Although Tracy had no evident chronic conditions, she had limited ability to undertake core activities such as taking care of her personal hygiene and meal preparation. Tracy was reported to be proud and did not want to accept services. Tracy was referred for a medical treatment review. The ADC organised a family meeting with Tracy to discuss how to support her wish to remain at home, including access to services and supports.

In this case, as in the earlier case, although services had initially been refused by the Person, through discussion they were persuaded to accept services, in this case, in order that Tracy could continue to live in her own home.

In the case below, social isolation meant that the Person's health and wellbeing remained unchecked and seriously deteriorated.

> A neighbour contacted the ADC regarding concerns about the welfare of Vic, a man in his late 80's. The neighbour stated that she had never seen family or support workers visit Vic in the years she had lived there. Vic appeared incoherent when speaking and was wearing dirty clothing and had been seen pacing up and down the driveway. There were indications that Vic did not realise the severity of their circumstances and had a reduced ability to engage with the healthcare system and professionals. The ADC referred the matter to the police for a welfare check. Following the welfare check, Vic was admitted to hospital and assessed by the social worker. The social worker advised the ADC that Vic would be moving to a residential care facility.

Following the report by a neighbour, the ADC arranged a welfare check which ultimately resulted in a move to residential care. Earlier intervention and support from health and social services may have prevented or delayed the serious health deterioration and neglect experienced by this older person.

These cases demonstrate the importance of service providers and community members taking action when they have concerns about neglect. This need will only increase as the Australian population continues to age. These cases also demonstrate that even when older people or adults with disability state that they wish to continue to live in their current circumstances and do not want support services, that sometimes a sensitive conversation with an organisation or practitioner that takes an informed and supportive approach may assist someone to accept services.

5.5.3 Cultural factors contributing to neglect

The Person in 14.8% of CSI cases spoke a language other than English at home, while this data was missing for a quarter of cases (27%). A handful of these cases where the Person spoke a language other than English were marked as potentially involving cultural issues contributing to the alleged neglect.

Closer examination of the small number of cases identified as involving cultural factors revealed that most of these were related to language, specifically resulting from limited English which made communication difficult and caused problems with identifying issues of concern. The need for an interpreter was noted as creating barriers to accessing support.

In most of these cases, the Person had informal support. In just under half of the cases, carer stress was identified as a contributing factor resulting in the carer struggling to meet the basic needs of the Person. In many of the reported cases there were indications that the PSOA was blocking or preventing the Person's access to services.

In only a few cases was cultural background or beliefs clearly noted as contributing to neglect. The following example demonstrates the interplay of cultural beliefs and family history leading to a Person’s basic needs not being met.

> Wendy was a young person with disability who lived in a household with her family. There were indications of historical and current abuse and neglect. Wendy appeared undernourished and was reportedly not being fed by her family. A neighbour had witnessed Wendy being hit and locked out of the family home. The PSOA was reported to believe that that mental illness was contagious and so had restricted Wendy’s social activities. Wendy did not have access to her money and there were varying accounts as to why Wendy was not receiving services. Despite these circumstances, Wendy had no concerns about her situation and denied any allegations of abuse.

In this case, it appears that cultural understandings about mental illness were a factor affecting the PSOA’s treatment of Wendy; particularly, the PSOA’s belief that they were protecting the community from a contagion by restricting Wendy’s social contact.

In the next example, the multiple factors including cultural background that contribute to neglect are evident.

> An older person, Yvonne, was admitted to hospital due to extreme pressure wounds and other health issues. Yvonne also had advanced dementia. Yvonne’s daughter, who had limited English, had previously sought advice from the general practitioner regarding treatment of pressure wounds. However, the daughter indicated that Yvonne had refused treatment. A neighbour had contacted the ambulance service after Yvonne’s daughter had asked for help and the neighbour saw the seriousness of the Yvonne’s condition.

Here, the PSOA’s knowledge of how to care for her parent was limited and her language skills affected her ability to seek support in their care. In addition, she may have had limited understanding of the seriousness of Yvonne 's condition prior to hospitalisation.

Data about cultural factors which contributed to neglect was limited, and much of it related to language. Language issues could affect a Person and the PSOA’s capacity to provide appropriate care, and to understand and engage with services or hospitals. Other factors that could act to block access to and use of support may relate to visa status or, for recent arrivals, knowledge of available services. However, deeper cultural factors are likely to be an issue in many more cases, but they may present subtly. It would be good to explore in more detail about how cultural factors contribute to neglect.

5.5.4 Appropriate services

When a Person refuses services, sometimes that may be because they are refusing a specific type of service, or because services have not worked well for them in the past.

The data has provided indications that Persons and PSOAs are sometimes wary of services or do not like the idea of using services. In Section 5.4.1, analysis showed that half of all CSI cases involved the PSOA blocking access to services. In addition, in cases where there was delayed access to services, these were more commonly the result of actions by the Person, PSOA or other family members than because there were no services available.

In many cases where the PSOA was blocking services, it was thought to be a sign of coercive control. However, there were other cases where blocking services was not thought to be a potential sign of abuse. Most often the reasons for blocking services in these circumstances was not clear but a handful of cases provide insights. Sometimes the PSOA was worried about the cost of services. For example, this case relates to two older people Alan and Amanda, husband and wife, who were living together and both had care needs.

> Alan, the PSOA, refused My Aged Care or anyone helping him and his wife, Amanda...Alan indicated he was let down by services "he has been down this road was badly let down". He explained that services that were offered were not fully subsidised and he doesn't want any more bills.

Several others were also worried about service fees and declined services to avoid the cost. In addition, in the case above, the PSOA had reportedly 'been let down' by services before. Another case involved someone for whom supported independent living had been "not right" and had returned to their family home while waiting other accommodation.

In another case, it was reported that services were seen as interfering and thought to be low quality:

> Both Brad and Belinda, the PSOA, reportedly did not like too much intervention from services, were not satisfied with the quality of support from some service providers. Brad stated that previous trust with service providers was broken when service providers spoke to the general practitioner, despite Brad wanting confidentiality.

In another case, a family refused services after their daughter experienced a fall in respite:

> Since the COVID-19 lockdown, Carmel's family had not allowed services back into the home or re-engaged with any former workers. Carmel is an adult with disability and is cared for by her parents, the co-PSOAs. Carmel has profound limitations undertaking any activities and her level of functioning had declined significantly since she had a fall while in respite. Carmel's mother expressed feeling guilty about taking up the offer of respite and appeared to be struggling to meet her care needs.

This mother felt she could no longer trust services with her daughter's care, even though she seemed to be struggling to meet her daughter's needs herself.

While others also seemed to want to avoid services coming into their home. For example, in one case, an older person refused services, saying their adult child could meet their care needs, but in fact the child was an adult with disabilities and care needs of their own. In another, it was noted that "Dianne, the PSOA, kept her son Dennis, an adult with disabilities, at home as Dianne was lonely." While in another, an older person, Elizabeth, was offered domestic assistance under Commonwealth Home Support Programme in 2019, but the PSOA rejected the referral indicating they were not ready to accept service supports.

For nearly all these cases, there were notes to say that not accessing sufficient services was not due to lack of knowledge or awareness, inability to obtain services, delays in accessing services, or not being supported to access services.

However, in many of these cases, involvement of the ADC or other agencies did result in additional services. We do not know how long those services remained in place or how satisfactory people found them. But the fact that the involvement of a third party facilitated service use, suggests that there is a role for brokers to facilitate access to services, explain how they work and what they can offer, highlight the challenges of continuing without services, and help address concerns that people may have about accepting services.

Although differences between cases located in rural/regional and urban areas were not strong in our analysis, there are nonetheless, fewer services available outside of major cities. The Australian Institute of Health and Welfare (2024), for example, has found that there tend to be fewer health professionals per head of population in regional and rural areas. It is possible that a lack of choice among service providers could contribute to the decisions of Persons and PSOAs to refuse to use services, as they may not feel they could find services that truly meet their needs.

Research by the Australian Institute of Family Studies regarding access to services among socially isolated older people suggests reframing the way services are presented to older people so as to emphasise their role in supporting independence (Stevens et al., 2024). It is possible that sensitive discussions with the ADC and other agencies may result in greater service uptake among people who have refused services by taking such an approach and focusing on how adults with disability and older people can be more independent by drawing upon support from the service system.

In addition, adults with disability and older people need access to quality services that are delivered respectfully and in ways that are responsive to their needs. If community members lack confidence in the quality of services, they may not wish to use them (Commissioner for Senior Victorians, 2020).

5.5.5 Abuse and coercive control as factors in social isolation and blocked access to services

In addition, there were cases in which blocking access to services appeared to be an element of abuse and coercive control. For example, in this case, failure to fill a prescription alerted a hospital worker to potential abuse and neglect.

> A hospital health worker contacted the ADC with concerns relating to the neglect and abuse of Fred, a 68-year-old man admitted due to health problems related to severe pain. When the hospital worker first spoke with Fred, he disclosed his wife (the PSOA) prevents him from attending appointments and has previously blocked medical care. Fred was prescribed anti-depressants however the PSOA told the pharmacist that he did not need the prescription. She also said they could not afford healthcare.
>
> The reporter was concerned that the PSOA was verbally abusive and used coercive control. Fred’s grandson also lived in the home and was also described as controlling, as well as using illicit substances. When asked, the PSOA stated that her husband was not neglected regarding his basic needs.

> Health workers made a plan to assess Fred as well as meet with him privately to confirm his wishes and determine what ongoing supports could be put into place.

In the above case, hospital staff raised concerns that Fred was being stopped from accessing the health care he needed by the PSOA. Moreover, they were concerned that this occurred because the PSOA was abusive and controlling, and so tried to ensure Fred was supported to express his wishes privately.

In the following case, too, blocking access to services was thought to be a form of coercive control of an adult with disability.

> Geoff had an Intellectual Disability and mental illness. He lived with his father whose physical health was declining and also needed support. Geoff's mother, Gail, used to care for him and manage the household finances but Gail had recently moved into residential care. A family member had contacted the ADC to report that Geoff was undernourished, had too little clothing or furniture, and no consistent access to food or support. The family member also reported that Geoff's father, the PSOA, had financially abused him and was withholding funds from Geoff. The reporter said that the PSOA had cancelled most support services for Geoff without consulting him. The reporter also noted that Geoff was adamant that he wanted to continue to live with his father.

The above case shows that the PSOA was unable to meet Geoff's needs and had actively blocked access to support. This example underscores the importance of following up with the Person if services are cancelled, to determine if blocking services is a means of enabling neglect or a form of abuse in itself.

Another example describes Heather's experiences of abuse and neglect:

> A family member contacted the ADC with concerns about neglect of an older woman, Heather, who had limited mobility, a hearing impairment and was also experiencing cognitive decline.
>
> Heather was living in her own home with her son, the PSOA. The PSOA was the primary carer. Heather's daughter previously contributed to her care by shopping for groceries and preparing food, but she is no longer welcomed by the PSOA.
>
> The PSOA had also refused support services. It was reported that PSOA had stated "no one is going to come in because I'm doing it". The family member believed that the PSOA was neglecting his mother and committing psychological abuse. The family member was also concerned that the PSOA was motivated to live with Heather in order to gain from her financially.
>
> Heather's husband had passed away and she was still grieving for him. This meant she didn't want to go anywhere or see anyone. Heather was also reported as not wanting any assistance at home, stating, "I do not have any problems and do not want people to come here" and "I don't feel the need for seeing anyone as I am fine."
>
> The family member reported that she smelt of urine, her bedding was not frequently changed and her home was in poor condition. Her food was inadequate, sometimes

> so old it had caused food poisoning. Nor was the PSOA assisting the Heather with regular showers.

Here, the PSOA refused any support from aged care services or from Heather's daughter. In addition, Heather also reportedly refused services herself. However, this position was likely influenced by her grief following her husband's death, and the abuse and coercive control she was experiencing from the PSOA.

5.5.6 Summary and implications

This section has shown that cases involving concerns about balancing respect for autonomy with concerns about a Person's decision-making capacity, or where a Person appears to be making decisions detrimental to their own wellbeing require a sensitive and careful response. In such cases, the involvement of organisations like the ADC provides skills and experience in managing these matters that other organisations may not have. By successfully negotiating with Persons and PSOA in such matters, it may be possible to prevent neglect from worsening.

This section has also found that community members and neighbours play an important role in identifying cases of self-neglect, especially when the Persons involved are not receiving support services and have limited social contact. A public education campaign which encourages community members to act on concerns of neglect could alert more people to the pathways available to respond to neglect, such as contacting the ADC or a local service provider.

Cases where Persons or PSOAs have refused services have been resolved by the ADC or other organisations working with them to arrange services. This suggests that brokerage could help explain the benefits of services for maintaining independence and connect people to appropriate services or to find services better matched with their needs.

Education among older people and adults with disability could improve understanding that services can help them to maintain their independence and live in their own homes with dignity.

However, there is evidence blocking access to services can be an element of abuse or coercive control, in which the PSOA refuses to allow others support a person they are neglecting. Sometimes, the person themselves also says that they do not wish for services, however, this response needs to be understood in a context of abuse. Efforts to address neglect by putting services in place, or reinstating services, should not rely solely on actions of the PSOA, given that the PSOA may be actively blocking services. Other approaches should be explored, and follow up undertaken, to ensure that services are started, sustained and revised as needed.

6 Conclusion and recommendations

Neglect of older people and adults with disability occurs in highly diverse and complex circumstances. Sometimes it happens when people are isolated from friends and family and unable or unwilling to use support services, sometimes when a couple are ageing together and cannot provide adequate care for each other, sometimes when carers are overwhelmed by care responsibilities and fail to provide appropriate care, and sometimes in combination with abuse, when neglect is another manifestation of the abuse. Often, multiple elements occur together, so that when concerns about neglect are reported to the ADC there is a multifaceted puzzle to piece together.

This report has analysed 1458 cases of neglect made to the ADC closed in 2021 and 2022, using both quantitative methods to reveal broad patterns in the data and to highlight key factors associated with neglect, and with qualitative methods investigating particular cases in detail.

The report has presented findings at three levels of an ecological model, describing individual factors associated with neglect, relationship factors and service system factors. However, none of these levels could fully describe neglect on its own. Instead, the analysis has demonstrated that factors at each of those levels interact in people's experiences of neglect.

This final concluding section brings together key findings from the report to develop conclusions and recommendations on how neglect might be prevented and ways in which neglect could be addressed.

6.1 Risk factors for neglect

At an individual level, analysis of ADC data has revealed key differences between adults with disability and older people in cases where there is alleged neglect.

Adults with disability who are alleged victims of neglect are more likely to be male, and to have an intellectual disability, mental illness, or physical disability compared to older people. They are also more likely to have domestic violence identified as a risk factor potentially contributing to neglect.

On the other hand, older people who are alleged victims of neglect are more likely to be female and more likely to have suspected concerns about decision making capacity. They are also less likely to be using community services but more likely to have attended hospital.

Importantly, analysis of the case data points to the importance of Persons' relationships with the PSOA and social isolation, as well as service use for their experiences of neglect. In most CSI cases (75.9%), the Person was living with the PSOA or the PSOA was their primary carer (70.7%). In nearly half, they were socially isolated. Approximately two-thirds of adults with disability and over a third of older people in CSI cases were receiving assistance from support services.

More than a third of cases referred to CSI (38.2%) were identified as involving serious neglect. Persons in these cases were less connected to support from services or a PSOA. They were also more likely to have domestic violence identified as a possible contributor to neglect.

Carer stress was thought to play a role in the alleged neglect of many CSI cases (40.7%). Often, in these cases, the Person was also reliant on the PSOA as the primary carer, and isolated socially. This occurred among older couples where both were experiencing the effects of ageing, and also in situations where carers were overwhelmed by other care responsibilities or own health needs.

Current or historical abuse within the relationship was identified as a concern in more than a third of CSI cases (37.6%). These cases were more likely to have a history of family dysfunction and current or historical abuse. In cases also potentially involving abuse, the PSOA was more likely to be male and to have refused help/ refused to act. In these cases, the Person was more likely to be socially isolated and their wishes were also often identified as contributing to the response. Importantly, there was less likely to be concern about the Person's decision-making capacity.

Social isolation was a factor in nearly half of all CSI cases (44.1%). People with higher support needs were more likely to be socially isolated. Persons who were isolated were more likely to be experiencing some form of core activity limitation, and to have those limitations be more profound. They were less often connected to services, and in the majority of cases the PSOA had blocked access to services. Often, too, these cases involved carer stress, current or historic abuse, or the response was affected by the PSOA not understanding how to respond to the Person's condition.

The remainder of the conclusion presents recommendations about how better to identify, prevent and respond to neglect, with a particular focus on level of communities, community services and governments.

6.2 Decision making capacity and autonomy

Respect for the autonomy of older people and adults with disability to make decisions about their own lives is fundamental at the ADC. At the same time, disability and ill-health can impede people's decision-making capacity such that they are unable to make informed decisions for themselves and about their care. Additionally, the complexity and fear associated with living with abuse or coercive control can also affect how a Person views, and wishes to respond to, their situation.

Concerns about a Person's decision-making capacity are common in ADC reports. Moreover, the dataset provides evidence of some of the challenges in responding to neglect when a Person maintains that they do not want their circumstances to change. There are examples when organisations such as service providers, the police or hospitals accept a Person's refusal to use services or their wish to stay in circumstances of neglect. While sometimes this is the right response, sometimes it is not. Evidence in the database suggests particular sensitivity by the ADC when handling such cases to delicately balance a Person's right to autonomy and to make their own decisions with the right to live free from abuse. In such cases, involvement of an agency like the ADC which can investigate is valuable.

Analysis of the qualitative data demonstrates the importance of the involvement of an agency with unique expertise like the ADC in exploring a neglected Person's wishes in the context of their capacity to make decisions, and an understanding of the possibility that the Person may be living in an abusive situation. They can explore whether or not a Person is making an informed decision, investigate the implications of that decision and can help put measures in place to monitor their circumstances and whether or not their neglect becomes worse, as well as changes to their decision-making capacity into the future.

However, other organisations should also be supported to adopt person centred care, and explore issues of decision making capacity. Education or guidance developed for hospital staff, general practitioners and aged care or disability service providers, could guide exploration of a Person's views and wishes. Also, it could include ways to help them determine whether the person may need decision making support and the kinds of decision-making supports that are available (see Section 6.3).

6.3 Service system measures to prevent and respond to neglect

The research has found that the actions of organisations such as aged care and disability support providers, the police and health services have been instrumental in identifying and responding to neglect. However, there is also evidence that their capacity to identify neglect is mixed, as is their capability to respond. The following recommendations outline measures which could support the organisations who have regular contact with older people and adults with disability to more consistently recognise when they are at risk of neglect, and have a clear understanding of how to respond.

Guidance on identifying neglect and risk of neglect

Identifying neglect among older people and adults with disability allows a response to be developed. The earlier neglect is identified; the sooner action can be taken to address the neglect and improve the lives of older people and adults with disability.

The engagement of many older people and adults with disability with their general practitioner offers an opportunity to identify neglect early. General practitioners also often have good knowledge about their patients and the care which they need and receive. However, general practitioners rarely made reports to the ADC about neglect, despite nearly half of cases of neglect having seen their general practitioner in the previous six months. To improve general practitioner screening for neglect, we recommend:

- Develop a tool, such as that developed by Howe (2021), which flags potential neglect and guides general practitioners to collect information about their patients' wellbeing, care needs, receipt of care and possible neglect. The tool could help general practitioners identify neglect, understand how to respond, and monitor to ensure the situation improves rather than worsens.
- Educate general practitioners about: how to identify and monitor neglect; how neglect might be a feature of abuse or coercive control; the services which can help address neglect; and the role of agencies like the ADC.

Additionally, more than half of all reports of neglect involve adults with disability or older people who had not seen their general practitioner in the previous year. This finding is of note, especially as this proportion is higher among those experiencing abuse or serious neglect. The tool recommended above could also suggest general practitioners make contact and screen patients who have not had a recent in-person doctor visit. Additionally, asking adults with disability or older people about their general practitioner appointments could flag potential neglect for other organisations working with these groups.

The research has shown that hospitals and police were often involved in identifying cases of serious neglect. These include welfare checks conducted by police, investigations by police where there were concerns of criminal neglect, and treatment by hospitals of people who had developed serious health conditions as a result of neglect. At times, their involvement was critical in ensuring that neglect did not continue. However, there was also evidence that police officers and hospital workers did not always proactively consider neglect and did not always understand how to respond. As such, we recommend:

- The development of guidance or tools for hospitals and police which could help identify neglect and provide information on how to respond. These could draw upon findings in this report on factors associated with neglect, not only at an individual level, but also at the level of a Person's relationships (including abuse) and engagement with support services.

A duty of care

Analysis of service system responses to neglect shows that many receive support from aged care or disability services, paramedics or hospital staff. Workers in these organisations have a prescribed duty of care to act if they have suspicions or concerns about potential abuse or neglect, and there are many instances of these workers reporting concerns of neglect to the ADC. As service providers who see older people and people with disability regularly, sometimes weekly or even daily, aged care and disability service workers often can have a good knowledge of changes in a Person's wellbeing and circumstances. This places them in a position to respond early. While paramedics and hospital staff are more likely to be in a position to identify neglect, including serious neglect, that is already occurring.

NSW Health workers have a duty of care to identify and respond to abuse among older people and people with disability, and are also guided by the NSW Health *Integrated Prevention and Response to Violence, Abuse and Neglect Framework*. However, there is evidence that hospital staff do not always proactively consider neglect.

It would be beneficial if other workers who may encounter neglect among older people or adults with disability were guided by a similar duty of care, such as police, community transport providers, and other health workers including allied health. We recommend:

- Working with police and key health workers to determine the feasibility of introducing a duty of care to act if there are concerns about the wellbeing of older people and adults with disability, including where this is concern about neglect.

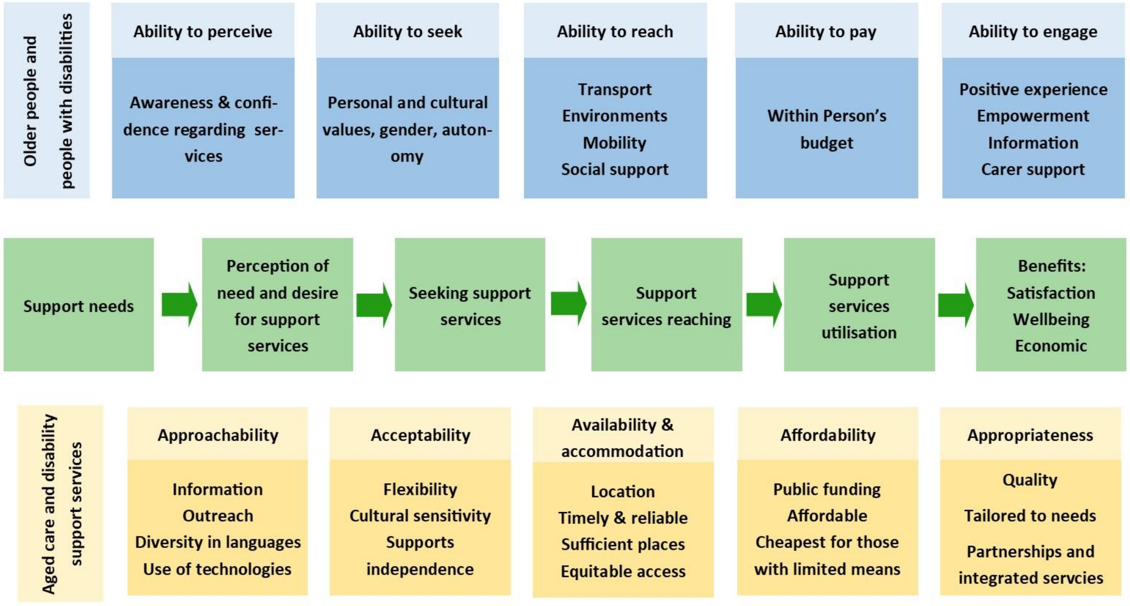
6.4 Support services for older people and adults with disability

The research found that neglect often occurs in situations where older people or adults with disability are not using support services. Use of services has several benefits regarding neglect. Support workers often identify neglect among older people and adults with disability, so the more people who have connections with support workers, the more cases of neglect may be identified and addressed. In addition, the service itself can help address some of the elements of neglect, for example, by attending to someone’s personal care needs if they cannot themselves and no carer is assisting them.

People’s use of services is affected by multiple factors. Very often, in CSI cases, a Person was not using services because they had been stopped by the PSOA, while the Person themselves also sometimes refused services. While there was little information in the ADC databases on why services were declined, there were indications for some that this related to concerns about cost, loss of autonomy and services not meeting their needs. Often, in such cases, after concerns about neglect and the services which might be useful had been discussed with the Person or the PSOA by the ADC or by hospital staff like social workers, they agreed to start or increase their service use.

In other cases, not being connected to services was a factor in an abusive situation, in which services were blocked as part of social isolation or coercive control. In these cases, exploring the reasons why services were not in place, or had been stopped, could help identify neglect and associated abuse.

Figure 1: A model for accessible ageing and disability services



Adapted from Levesque, Harris & Russell, 2013 (CC BY) and Archambault, Cote & Raynault, 2020 (CC BY).

Therefore, improved service usage is a means to prevent neglect and respond to neglect. Frameworks through which to understand the dimensions of engagement between community members and services have been developed for health and early education and care. The framework above has been adapted from a similar framework for health services (Levesque, et al., 2013) and a study of accessible Australian early education and care services (Skattebol, et al., 2021). We recommend considering some of the enablers of service usage using this framework.

To improve service usage among people experiencing neglect, we recommend building a robust service system which attends to the many facets of access outlined in Section 4.1. Services should be:

- Approachable – adults with disability and older people should know what kinds of services are available and how they might connect with them to initiate service use.
- Acceptable – services should be provided in a way that suits the needs of adults with disability and older people, they should be responsive to the needs of service users, flexible and culturally appropriate, and support independence.
- Available and accommodating – by having places readily available and being conveniently located and provided in a timely manner. Access should be equitable for all adults with disability and older people.
- Affordable – regardless of means, adults with disability and older people should be able to afford services, and understand the costs and discounts available to them.
- Appropriate – appropriate services are of a high quality. They are person centred, and tailored to the needs of each service user. Quality services engage in partnerships with other services and agencies to aid access to a wide range of supports.

To enable accessible service system to help prevent neglect among adults with disability and older people:

- Consider an education campaign to promote service use to Persons and their carers as a means to maintain independence, including information about service options, costs and discounts. Acknowledge the impact on privacy of paid workers entering the home.
- Ensure that services do promote such independence and, so far as possible, minimise the impact on privacy and the administrative burden of arranging and using services.
- Prioritise building and sustaining trust between service providers and potential clients, both Persons and their carers.
- Consider the use of brokers to discuss service usage in cases of neglect with Persons or PSOAs who have refused services. Brokerage may facilitate service engagement and better matching of services to a Person's needs and values.
- Given services can be blocked to enable abuse or as an element of coercive control, do not rely on actions of the PSOA to ensure services are in place. Instead, a broker or other third party should help arrange services and follow up to ensure they remain in place.

In particular, recommendations regarding accessible services for older people and adults with disability, include:

- If a Person is refusing services, explore why. Explore how services might better match with the Person's needs, values, budget, culture, etc. Consider whether abuse or coercive control may be a factor which may affect the Person's willingness to accept support.
- Include a full assessment of a Person's needs, which also includes the needs of others in the household or those who are supposed to be providing care to the Person.

Recommendations regarding accessible services for carers or the PSOA, include:

- Present the receipt of services to carers or PSOAs as a means to ease carer stress, provide breaks from care, and maintain independence of older people and adults with disability.
- Ensure that organising service delivery is not burdensome for carers.
- When assessing the needs of an older person or adult with disability, also explore the needs of others in the household or including carers or PSOAs or others who might provide care to the Person.
- If a carer is blocking access to services explore why. Is it a form of coercive control resulting in social isolation or abuse? Do they need their own supports? Are there other issues that a responsive service system could address?

Ultimately, a high quality service system that can flexibly meet the needs of older people and adults with disability should provide quality, affordable, timely, culturally appropriate care, and so be able to engage more adults with disability and older people, and reduce incidents of neglect and ensure earlier responses to cases of neglect.

6.5 Data, evaluation and further research

The analysis in this report has focused on cases of more serious neglect which were referred to the CSI. However, the ADC's Helpline also responds to many reports of neglect without the need for CSI involvement. It is possible that the Helpline is an important mechanism through which neglect is prevented or addressed before it becomes serious. However, the data provided for this project did not indicate outcomes of helpline reports. We recommend:

- Investigating the early intervention impact of the ADC Helpline. This would involve reviewing databases to ensure adequate data is collected and introducing monitoring or follow up in at least some Helpline cases.
- Additional research on ADC data could be conducted with cases that have been reported to the ADC more than once. Longitudinal research with these cases could explore effective interventions, opportunities for intervention which were not taken, where responses have failed and what else is needed in cases with recurrent concern about neglect.

Analysis for this research was limited by the data available. Challenges with data are common in research which draws upon administrative datasets, such as this one, because the primary purpose of the data is not for research. Sensitive material, like that contained in ADC data regarding experiences of neglect also require care in order to protect the identities of people whose data is being used for research. Nonetheless, the qualitative analysis in this project could have provided more insights if the research team had access to more detailed data, for example, case files. We recommend exploring whether more data could be shared, for example, if researchers were required to submit to security checks.

Other data issues to consider include:

- The addition of a variable in the dataset on whether a case was handled by the Helpline or CSI or both would facilitate quicker and more accurate analysis of Helpline and CSI cases.
- Currently, cases in which cultural issues are identified as contributing to neglect are mostly limited to cases where there was limited English language skills. There may be additional insights into diverse cultural experiences of neglect in the case files, but these were not well reflected in the datasets. Consider if data on cultural issues could be better captured in the data.

Additional research could inform many of the strategies to prevent and respond to neglect outlined above. In particular, we recommend:

- Additional research on ADC data could be conducted with cases that have been reported to the ADC more than once. Longitudinal research with these cases could explore effective interventions, opportunities for intervention which were not taken, where responses have failed and what else is needed in cases with recurrent concern about neglect.
- Research to determine levels of understanding about neglect among general practitioners, and their knowledge of how to respond and monitor, and their capacity to do so. This would help ensure the tool and education campaign were appropriate.
- Undertake research with police and lawyers in order to understand what is behind cases which are referred to police with the outcome ‘doesn’t meet the threshold for criminal neglect’. It is not clear if cases are referred but found not to constitute criminal neglect, or if there are the challenges prosecuting a case against a perpetrator of criminal neglect.

The data provided limited insights into the kinds of actions that aged care and disability support services take, with the exception of making reports to the ADC or working with the ADC to improve support services. It is possible, but not known, if and how these organisations respond to neglect when the ADC is not involved. We recommend:

- Research with disability support services and aged care services to better understand how they understand their duty of care with regards to neglect and how they respond to neglect. Such research may provide insights into when it is appropriate for organisations to respond to neglect without the involvement of the ADC and when ADC involvement is needed.

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Appendix A: Literature review method

The literature search in academic databases was restricted to academic literature over the last

decade published between 2014 and 2024. Although the literature dates back longer, the identification and retrieval of other relevant older literature could be captured through the analysis of existing review studies.
The databases used in use literature search were:

- the Social Sciences Citation Index (for sociological and economic studies),
- Medline and PsycINFO (for health and psychology related studies), and
- Scopus, the largest abstract and citation database of peer-reviewed literature across science and technology, medicine, business and social sciences.
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The key words used in the search included ‘neglect’ combined using Boolean operators with target population related keywords, such as ‘elder’ or ‘older person’ and ‘disability’ or ‘disabled’. The focus of the research was on evidence from the home and community.

The initial search of the databases yielded over 2000 articles. Commonly the term neglect was paired with the term abuse, which resulted in the large volume of published material. To contain the search, articles that only contained the term neglect were included. Initially articles were screened based on title and abstract. A more focused review of the abstract was conducted to locate research that focused only on neglect and/or differentiated between the prevalence and risk factors associated with different types of abuse including neglect. The selection process yielded 26 studies which were included in the review.

Appendix B: Definitions

Person’s condition/presentation at the time of the report to the ADC:

- ‘Needs not met’ = included where the Person’s basic support needs were not met (such as a lack of support services, and inadequate help to meet their mobility, communication, health needs) but they were not yet showing signs of neglect.
- ‘Signs of neglect’ = the Person was starting to show signs of potential neglect (such as stained clothing, unwashed, not having any food or money)
- ‘Poor condition’ = included where the Person was covered in faeces, was unwashed, had matted hair, had no or threadbare/filthy clothing, had untreated medical issues
- ‘Very unwell’ = the Person required medical assistance and likely hospital admission to avoid becoming critically unwell (such as dehydrated, malnourished, high grade pressure areas)
- ‘Critically unwell’: the Person was in a life or death condition requiring urgent medical assistance and hospital admission (such as unconscious, seriously dehydrated/ malnourished, sepsis)

Appendix C: Additional tables

Table 17. Comparison of people with disability vs. people with no disability (CSI cases only)

	People with no disability n (%)	People with disability n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	82.6 (9.0)	60.9 (24.1)	<.001	N/A*
Person gender:			.07	1.55 (0.83-2.94)
Female	73 (68.9)	217 (59.0)		
Male	33 (31.1)	151 (41.0)		
Area of residence:			<.001	2.09 (1.16-3.76)
Metropolitan	62 (60.2)	147 (40.6)		
Regional	41 (39.8)	215 (59.4)		
Aboriginal	5 (4.7)	20 (5.4)	.77	-
Language other than English	21 (19.8)	49 (13.3)	.10	-
Person receiving community services	44 (41.5)	216 (58.7)	<.01	1.04 (0.52-2.06)
Person condition:			.36	-
Needs not met	20 (19.4)	70 (19.8)		
Signs of neglect	54 (52.4)	198 (56.1)		
Poor	14 (13.6)	63 (17.8)		
Very unwell	7 (6.8)	12 (3.4)		
Critically unwell	8 (7.8)	10 (2.8)		
Person functioning:			<.01	1.05 (0.92-1.19)
No limitation	18 (19.6)	33 (9.6)		
Core activity limitation	23 (25.0)	78 (22.6)		
Mild limitation	2 (2.2)	10 (2.9)		
Moderate limitation	8 (8.7)	16 (4.6)		
Severe limitation	15 (16.3)	58 (16.8)		
Profound limitation	26 (28.3)	150 (43.5)		
Person health needs:			<.001	1.79 (1.19-2.67)
No chronic/terminal condition	34 (32.1)	52 (14.1)		
1-2 chronic health conditions	44 (41.5)	238 (64.7)		
3-4 chronic health conditions	4 (3.8)	34 (9.2)		
5+ chronic health conditions	1 (0.9)	6 (1.6)		
Terminal condition	4 (3.8)	7 (1.9)		
Not known	19 (17.9)	31 (8.4)		
Person isolated	47 (44.3)	162 (44.0)	.95	-
Concerns about Person's decision-making capacity:			<.001	

	People with no disability n (%)	People with disability n (%)	*p*-value	aOR (95% CI)
No/Unknown	79 (74.5)	143 (38.9)		Ref.
Suspected	7 (6.6)	13 (3.5)		2.46 (0.73-8.24)
Yes	20 (18.9)	212 (57.6)		7.71 (3.88-15.32)
Disability:				
None	106 (100)	0	<.001	N/A*
Neurological	0	198 (53.8)	<.001	N/A*
Physical	0	113 (30.7)	<.001	N/A*
Intellectual	0	81 (22.0)	<.001	N/A*
Mental health	0	49 (13.3)	<.001	N/A*
Other cognitive	0	39 (10.6)	<.001	N/A*
Autism	0	30 (8.2)	<.01	N/A*
Sensory	0	22 (6.0)	.01	N/A*
Formal services involved:				
Disability (any)	1 (0.9)	138 (37.5)	<.001	N/A*
In-home	0	97 (26.4)	<.001	N/A*
Other	1 (0.9)	58 (15.8)	<.001	N/A*
Aged care (any)	39 (36.8)	81 (22.0)	<.01	N/A*
In-home	32 (30.2)	69 (18.8)	.01	N/A*
Other	9 (8.5)	17 (4.6)	.12	-
None	56 (52.8)	120 (32.6)	<.001	0.63 (0.32-1.23)
Health services involved:				
GP	47 (44.3)	159 (43.2)	.84	-
Hospital	43 (40.6)	132 (35.9)	.38	-
Community	15 (14.2)	69 (18.8)	.28	-
Other medical	8 (7.5)	36 (9.8)	.49	-
Other	3 (2.8)	43 (11.7)	<.01	3.43 (0.89-13.28)
Informal supports involved:				
PSOA	91 (85.8)	295 (80.2)	.19	-
Family	48 (45.3)	149 (40.5)	.38	-
Friends	6 (5.7)	14 (3.8)	.40	-
Neighbour	9 (8.5)	17 (4.6)	.12	-
Person lives with PSOA	73 (68.9)	286 (77.9)	.06	2.13 (1.05-4.33)
Person lives in own home	61 (71.8)	244 (75.3)	.50	-
PSOA gender:			.82	-
Female	46 (43.4)	170 (46.2)		
Male	57 (53.8)	185 (50.3)		
Other	0	2 (0.5)		
Unknown	3 (2.8)	11 (3.0)		
PSOA relationship:				

	People with no disability **n (%)**	**People with disability** **n (%)**	***p*-value**	**aOR (95% CI)**
Partner/spouse	23 (21.7)	78 (21.2)	.91	-
Relative	69 (65.1)	263 (71.5)	.21	-
Child	64 (60.4)	132 (35.9)	<.001	0.73 (0.39-1.33)
Parent	0	88 (23.9)	<.001	N/A*
Sibling	2 (1.9)	30 (8.2)	.02	10.28 (1.16-91.00)
PSOA primary carer	64 (60.4)	271 (73.6)	<.01	1.13 (0.59-2.13)
Type of neglect:				
Failure to meet support needs	72 (67.9)	272 (73.9)	.22	-
Medical care	32 (30.2)	123 (33.4)	.53	-
Clothing/food	17 (16.0)	62 (16.8)	.84	-
Failure to provide necessities of life	12 (11.3)	24 (6.5)	.10	-
Factors contributing to issues/allegations:				
PSOA preventing access to services	50 (47.2)	191 (51.9)	.39	-
Carer stress	37 (34.9)	156 (42.4)	.17	-
Current/historical abuse	45 (42.5)	133 (36.1)	.24	-
Health literacy	9 (8.5)	53 (14.4)	.11	-
Delay in service access	9 (8.5)	34 (9.2)	.81	-
Risk factors:				
Dementia	17 (16.0)	84 (23.0)	.12	-
Chronic health issues	27 (25.5)	112 (30.7)	.30	-
History of family dysfunction	19 (17.9)	88 (24.1)	.18	-
Social isolation	15 (14.2)	57 (15.6)	.71	-
Mental health	3 (2.8)	53 (14.5)	<.01	5.63 (1.48-21.38)
History of domestic violence	8 (7.5)	48 (13.2)	.12	-
Squalor and/or hoarding	9 (8.5)	47 (12.9)	.22	-
Self-neglect	5 (4.7)	28 (7.7)	.29	-
Factors affecting the response:				
Person’s views/wishes	55 (51.9)	162 (44.0)	.34	-
Parties did not realise severity	15 (14.2)	87 (23.6)	.07	2.06 (0.92-4.65)
Recent hospital/medical contact	11 (10.4)	31 (8.4)	.46	-
PSOA did not know what to do	14 (13.2)	41 (11.1)	.81	-
PSOA refused help/refused to act	26 (24.5)	84 (22.8)	.76	-
Serious neglect	47 (44.3)	134 (36.4)	.14	-

* N/A indicates variable was excluded from multivariable analysis

Table 18. Comparison of older people vs. adults with disability (CSI cases only)

	Adults with disability n (%)	Older people n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	38.1 (15.2)	80.6 (9.5)	<.001	N/A*
Person gender:			<.001	
Female	80 (47.9)	210 (68.4)		Ref.
Male	87 (52.1)	97 (31.6)		0.93 (0.22-0.69)
Area of residence:			.30	-
Metropolitan	68 (41.7)	141 (46.7)		
Regional	95 (58.3)	161 (53.3)		
Aboriginal	6 (3.6)	19 (6.2)	.23	-
Language other than English	15 (9.0)	55 (17.9)	<.01	1.54 (0.67-3.52)
Person receiving community services	126 (75.4)	134 (43.6)	<.001	0.28 (0.14-0.55)
Person condition:			.10	-
Needs not met	39 (24.2)	51 (17.3)		
Signs of neglect	85 (52.8)	167 (56.6)		
Poor	28 (17.4)	49 (16.6)		
Very unwell	4 (2.5)	15 (5.1)		
Critically unwell	5 (3.1)	13 (4.4)		
Person functioning:			.66	-
No limitation	21 (13.5)	30 (10.6)		
Core activity limitation	27 (17.4)	74 (26.2)		
Mild limitation	5 (3.2)	7 (2.5)		
Moderate limitation	11 (7.1)	13 (4.6)		
Severe limitation	27 (17.4)	46 (16.3)		
Profound limitation	64 (41.3)	112 (39.7)		
Person health needs:			.18	-
No chronic/terminal condition	40 (24.0)	46 (15.0)		
1-2 chronic health conditions	87 (52.1)	195 (63.5)		
3-4 chronic health conditions	13 (7.8)	25 (8.1)		
5+ chronic health conditions	4 (2.4)	3 (1.0)		
Terminal condition	5 (3.0)	6 (2.0)		
Not known	18 (10.8)	32 (10.4)		
Person isolated	66 (39.5)	143 (46.6)	.14	-
Concerns about Person's decision-making capacity:			<.01	
No/Unknown	76 (45.5)	146 (47.6)		Ref.
Suspected	1 (0.6)	19 (6.2)		37.57 (2.19-644.29)
Yes				

	Adults with disability n (%)	Older people n (%)	*p*-value	aOR (95% CI)
	90 (53.9)	132 (46.3)		0.76 (0.42-1.39)
Disability:				
None	0	106 (34.5)	<.001	N/A*
Neurological	59 (35.3)	139 (45.3)	.04	1.08 (0.59-1.97)
Physical	59 (35.3)	54 (17.6)	<.001	0.21 (0.11-0.39)
Intellectual	74 (44.3)	7 (2.3)	<.001	0.03 (0.01-0.07)
Mental health	27 (16.2)	22 (7.2)	<.01	0.20 (0.07-0.57)
Other cognitive	20 (12.0)	19 (6.2)	.03	0.51 (0.20-1.33)
Autism	30 (18.0)	0	<.001	N/A*
Sensory	8 (4.8)	14 (4.6)	.91	-
Formal services involved:				
Disability (any)	111 (66.5)	28 (9.1)	<.001	N/A*
In-home	74 (44.3)	23 (7.5)	<.001	N/A*
Other	53 (31.7)	6 (2.0)	<.001	N/A*
Aged care (any)	5 (3.0)	115 (37.5)	<.001	N/A*
In-home	3 (1.8)	98 (31.9)	<.001	N/A*
Other	3 (1.8)	23 (7.5)	<.01	N/A*
None	37 (22.2)	139 (45.3)	<.001	1.18 (0.60-2.34)
Health services involved:				
GP	64 (38.3)	142 (46.3)	.10	-
Hospital	48 (28.7)	127 (41.4)	<.01	1.84 (1.02-3.33)
Community	27 (16.2)	57 (18.6)	.51	-
Other medical	18 (10.8)	26 (8.5)	.41	-
Other	22 (13.2)	24 (7.8)	.06	0.97 (0.38-2.49)
Informal supports involved:				
PSOA	128 (76.6)	258 (84.0)	.05	1.76 (0.84-3.68)
Family	61 (36.5)	136 (44.3)	.10	-
Friends	5 (3.0)	15 (4.9)	.33	-
Neighbour	0	26 (8.5)	<.001	N/A*
Person lives with PSOA	131 (78.4)	228 (74.5)	.34	-
Person lives in own home	104 (73.2)	201 (75.3)	.65	-
PSOA gender:			.02	
Female	92 (55.1)	124 (40.4)		Ref.
Male	69 (41.3)	173 (56.4)		1.25 (0.70-2.22)
Other	1 (0.6)	1 (0.3)		0.19 (0.01-4.12)
Unknown	5 (3.0)	9 (2.9)		0.37 (0.07-1.98)
PSOA relationship:				
Partner/spouse	34 (20.4)	67 (21.8)	.71	-
Relative	123 (73.7)	209 (68.1)	.21	-

	Adults with disability n (%)	**Older people n (%)**	***p*-value**	**aOR (95% CI)**
Child	7 (4.2)	189 (61.6)	<.001	N/A*
Parent	87 (52.1)	1 (0.3)	<.001	N/A*
Sibling	21 (12.6)	11 (3.6)	<.001	0.33 (0.11-0.99)
PSOA primary carer	119 (71.3)	216 (70.4)	.84	-
Type of neglect:				
Failure to meet support needs	111 (66.5)	233 (75.9)	.03	1.45 (0.79-2.68)
Medical care	60 (35.9)	95 (30.9)	.27	-
Clothing/food	27 (16.2)	52 (16.9)	.83	-
Failure to provide necessities of life	9 (5.4)	27 (8.8)	.18	-
Factors contributing to issues/allegations:				
PSOA preventing access to services	86 (51.5)	155 (50.5)	.83	-
Carer stress	80 (47.9)	113 (36.8)	.02	0.69 (0.38-1.27)
Current/historical abuse	68 (49.7)	110 (35.8)	.29	-
Health literacy	24 (14.4)	38 (12.4)	.54	-
Delay in service access	15 (9.0)	28 (9.1)	.96	-
Risk factors:				
Dementia	2 (1.2)	99 (32.4)	<.001	N/A*
Chronic health issues	59 (35.8)	80 (26.1)	.03	0.82 (0.44-1.51)
History of family dysfunction	46 (27.9)	61 (19.9)	.05	0.75 (0.39-1.45)
Social isolation	29 (17.6)	43 (14.1)	.31	-
Mental health	27 (16.4)	29 (9.5)	.03	1.40 (0.54-3.64)
History of domestic violence	28 (17.0)	28 (9.2)	.01	0.24 (0.11-0.52)
Squalor and/or hoarding	24 (14.5)	32 (10.5)	.19	-
Self-neglect	14 (8.5)	19 (6.2)	.36	-
Factors affecting the response:				
Person's views/wishes	68 (40.7)	149 (48.5)	.08	1.14 (0.64-2.06)
Parties did not realise severity	43 (25.7)	59 (19.2)	.23	-
Recent hospital/medical contact	13 (7.8)	29 (9.4)	.55	-
PSOA did not know what to do	19 (11.4)	36 (11.7)	.11	-
PSOA refused help/refused to act	44 (26.3)	66 (21.5)	.45	-
Serious neglect	57 (34.1)	124 (40.4)	.18	-

* N/A indicates variable was excluded from multivariable analysis

Table 19. Comparison serious vs. less serious cases of neglect (CSI cases only)

	Less serious cases n (%)	Serious neglect n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	64.9 (23.9)	66.5 (23.1)	.46	-
Person gender:			.74	-
Female	181 (61.8)	109 (60.2)		
Male	112 (38.2)	72 (39.8)		
Area of residence:				-
Metropolitan	130 (45.1)	79 (44.6)	.91	
Regional	158 (54.9)	98 (55.4)		
Aboriginal	13 (4.4)	12 (6.6)	.30	-
Language other than English	40 (13.7)	30 (16.6)	.38	-
Person receiving community services	179 (61.1)	81 (44.8)	<.01	0.56 (0.35-0.89)
Person condition:			<.001	N/A*
Needs not met	62 (22.3)	28 (15.7)		
Signs of neglect	172 (61.9)	80 (44.9)		
Poor	44 (15.8)	33 (18.5)		
Very unwell	0	19 (10.7)		
Critically unwell	0	18 (10.1)		
Person functioning:			.30	-
No limitation	27 (10.0)	24 (14.4)		
Core activity limitation	68 (25.2)	33 (19.8)		
Mild limitation	5 (1.9)	7 (4.2)		
Moderate limitation	15 (5.6)	9 (5.4)		
Severe limitation	42 (15.6)	31 (18.6)		
Profound limitation	113 (41.9)	63 (37.7)		
Person health needs:			.18	-
No chronic/terminal condition	47 (16.0)	39 (21.5)		
1-2 chronic health conditions	177 (60.4)	105 (58.0)		
3-4 chronic health conditions	30 (10.2)	8 (4.4)		
5+ chronic health conditions	5 (1.7)	2 (1.1)		
Terminal condition	3 (1.0)	8 (4.4)		
Not known	31 (10.6)	19 (10.5)		
Person isolated	123 (42.0)	86 (47.5)	.24	-
Concerns about Person's decision-making capacity:			.38	-
No/Unknown	134 (45.7)	88 (48.6)		
Suspected	10 (3.4)	10 (5.5)		
Yes				

	Less serious cases n (%)	Serious neglect n (%)	*p*-value	aOR (95% CI)
	149 (50.9)	83 (45.9)		
Disability:				
None	59 (20.1)	47 (26.0)	.14	-
Neurological	127 (43.3)	71 (39.2)	.38	-
Physical	75 (25.6)	38 (21.0)	.25	-
Intellectual	54 (18.4)	27 (14.9)	.32	-
Mental health	34 (11.6)	15 (8.3)	.25	-
Other cognitive	29 (9.9)	10 (5.5)	.09	0.58 (0.26-1.31)
Autism	19 (6.5)	11 (6.1)	.86	-
Sensory	15 (5.1)	7 (3.9)	.53	-
Formal services involved:				
Disability (any)	96 (32.8)	43 (23.8)	.04	0.81 (0.38-1.71)
In-home	68 (23.2)	29 (16.0)	.06	N/A*
Other	39 (13.3)	20 (11.0)	.47	-
Aged care (any)	82 (28.0)	38 (21.0)	.09	0.86 (0.41-1.81)
In-home	68 (23.2)	33 (18.2)	.20	-
Other	17 (5.8)	9 (5.0)	.70	-
None	94 (32.1)	82 (45.3)	<.01	1.10 (0.55-2.21)
Health services involved:				
GP	135 (46.1)	71 (39.2)	.14	-
Hospital	106 (36.2)	69 (38.1)	.67	-
Community	56 (19.1)	28 (15.5)	.31	-
Other medical	26 (8.9)	18 (9.9)	.70	-
Other	27 (9.2)	19 (10.5)	.65	-
Informal supports involved:				
PSOA	250 (85.3)	136 (75.1)	<.01	0.52 (0.31-0.89)
Family	123 (42.0)	74 (40.9)	.81	-
Friends	12 (4.1)	8 (4.4)	.87	-
Neighbour	14 (4.8)	12 (6.6)	.39	-
Person lives with PSOA	220 (75.3)	139 (76.8)	.72	-
Person lives in own home	194 (77.3)	111 (70.3)	.11	-
PSOA gender:			.04	
Female	147 (50.2)	69 (38.1)		Ref.
Male	135 (46.1)	107 (59.1)		1.48 (0.97-2.25)
Other	2 (0.7)	0		N/A*
Unknown	9 (3.1)	5 (2.8)		0.66 (0.19-2.27)
PSOA relationship:				
Partner/spouse	59 (20.1)	42 (32.2)	.43	-
Relative	211 (72.0)	121 (66.9)	.23	-

	Less serious cases n (%)	Serious neglect n (%)	*p*-value	aOR (95% CI)
Child	117 (39.9)	79 (43.6)	.43	-
Parent	58 (19.8)	30 (16.6)	.38	-
Sibling	21 (7.2)	11 (6.1)	.65	-
PSOA primary carer	219 (74.7)	116 (64.1)	.01	0.80 (0.50-1.28)
Type of neglect:				
Failure to meet support needs	226 (77.1)	118 (65.2)	<.01	0.61 (0.38-0.96)
Medical care	92 (31.4)	63 (34.8)	.44	-
Clothing/food	41 (14.0)	38 (21.0)	.05	1.40 (0.82-2.39)
Failure to provide necessities of life	0	36 (19.9)	<.001	N/A*
Factors contributing to issues/allegations:				
PSOA preventing access to services	151 (51.5)	90 (49.7)	.70	-
Carer stress	126 (43.0)	67 (37.0)	.20	-
Current/historical abuse	94 (32.1)	84 (46.4)	<.01	1.45 (0.92-2.27)
Health literacy	34 (11.6)	28 (15.5)	.23	-
Delay in service access	22 (7.5)	21 (11.6)	.13	-
Risk factors:				
Dementia	66 (22.7)	35 (19.4)	.41	-
Chronic health issues	85 (29.1)	54 (30.0)	.86	-
History of family dysfunction	63 (21.6)	44 (24.4)	.48	-
Social isolation	36 (12.4)	36 (20.0)	.03	1.60 (0.92-2.79)
Mental health	37 (12.7)	19 (10.6)	.48	-
History of domestic violence	23 (7.9)	33 (18.3)	<.01	2.23 (1.19-4.18)
Squalor and/or hoarding	31 (10.7)	25 (13.9)	.29	-
Self-neglect	22 (7.6)	11 (6.1)	.55	-
Factors affecting the response:				
Person's views/wishes	126 (43.0)	91 (50.3)	.29	-
Parties did not realise severity	58 (19.8)	44 (24.3)	.48	-
Recent hospital/medical contact	24 (8.2)	18 (9.9)	.62	-
PSOA did not know what to do	31 (10.6)	24 (13.3)	.62	-
PSOA refused help/refused to act	58 (19.8)	52 (28.7)	.07	

* N/A indicates variable was excluded from multivariable analysis

Table 20. Comparison of cases where Person was socially isolated vs. not socially isolated (CSI cases only)

	Person not isolated n (%)	Person socially isolated n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	63.6 (25.0)	67.8 (21.4)	.07	1.00 (.99-1.02)
Person gender:			.12	-
Female	154 (58.1)	136 (65.1)		
Male	111 (41.9)	73 (34.9)		
Area of residence:			.49	-
Metropolitan	121 (46.4)	88 (43.1)		
Regional	140 (53.6)	116 (56.9)		
Aboriginal	16 (6.0)	9 (4.3)	.40	-
Language other than English	38 (14.3)	32 (15.3)	.77	-
Person receiving community services	153 (57.7)	107 (51.2)	.16	-
Person condition:			.85	-
Needs not met	43 (16.9)	47 (23.4)		
Signs of neglect	154 (60.4)	98 (48.8)		
Poor	46 (18.0)	31 (15.4)		
Very unwell	9 (3.5)	10 (5.0)		
Critically unwell	3 (1.2)	15 (7.5)		
Person functioning:			<.001	1.17 (1.04-1.30)
No limitation	37 (14.9)	14 (7.4)		
Core activity limitation	83 (33.5)	18 (9.5)		
Mild limitation	3 (1.2)	9 (4.8)		
Moderate limitation	10 (4.0)	14 (7.4)		
Severe limitation	25 (10.1)	48 (25.4)		
Profound limitation	90 (36.3)	86 (45.5)		
Person health needs:			.51	-
No chronic/terminal condition	53 (20.0)	33 (15.8)		
1-2 chronic health conditions	165 (62.3)	117 (56.0)		
3-4 chronic health conditions	17 (6.4)	21 (10.0)		
5+ chronic health conditions	4 (1.5)	3 (1.4)		
Terminal condition	4 (1.5)	7 (3.3)		
Not known	22 (8.3)	28 (13.4)		
Concerns about Person's decision-making capacity:			.30	-
No/Unknown	123 (46.4)	99 (47.4)		
Suspected	8 (3.0)	12 (5.7)		
Yes	134 (50.6)	98 (46.9)		

	Person not isolated n (%)	Person socially isolated n (%)	*p*-value	aOR (95% CI)
Disability:				
None	59 (22.3)	47 (22.5)	.95	-
Neurological	104 (39.2)	94 (45.0)	.21	-
Physical	61 (23.0)	52 (24.9)	.64	-
Intellectual	55 (20.8)	26 (12.4)	.02	0.68 (0.30-1.51)
Mental health	28 (10.6)	21 (10.0)	.85	-
Other cognitive	19 (7.2)	20 (9.6)	.35	-
Autism	20 (7.5)	10 (4.8)	.22	-
Sensory	14 (5.3)	8 (3.8)	.46	-
Formal services involved:				
Disability (any)	84 (31.7)	55 (26.3)	.20	-
In-home	54 (20.4)	43 (20.6)	.96	-
Other	38 (14.3)	21 (10.0)	.16	-
Aged care (any)	72 (27.2)	48 (23.0)	.30	-
In-home	62 (23.4)	39 (18.7)	.21	-
Other	13 (4.9)	13 (6.2)	.53	-
None	89 (33.6)	87 (41.6)	.07	2.04 (1.17-3.54)
Health services involved:				
GP	122 (46.0)	84 (40.2)	.20	-
Hospital	100 (37.7)	75 (35.9)	.68	-
Community	49 (18.5)	35 (16.7)	.62	-
Other medical	26 (9.8)	18 (8.6)	.66	-
Other	38 (14.3)	8 (3.8)	<.001	0.19 (0.07-0.55)
Informal supports involved:				
PSOA	218 (82.3)	168 (80.4)	.60	-
Family	127 (47.9)	70 (33.5)	<.01	0.51 (0.30-0.85)
Friends	14 (5.3)	6 (2.9)	.20	-
Neighbour	13 (4.9)	13 (6.2)	.53	-
Person lives with PSOA	191 (72.1)	168 (80.8)	.03	1.46 (0.77-2.76)
Person lives in own home	166 (73.5)	139 (76.0)	.56	-
PSOA gender:			.73	-
Female	119 (44.9)	97 (46.4)		
Male	139 (52.5)	103 (49.3)		
Other	1 (0.4)	1 (0.5)		
Unknown	6 (2.3)	8 (3.8)		
PSOA relationship:				
Partner/spouse	48 (18.1)	53 (25.4)	.06	1.08 (0.47-2.47)
Relative	190 (71.7)	142 (67.9)	.38	-
Child	100 (37.7)	96 (45.9)	.07	1.42 (0.64-3.19)

	Person not isolated **n (%)**	**Person socially isolated** **n (%)**	***p*-value**	**aOR (95% CI)**
Parent	57 (21.5)	31 (14.8)	.06	0.75 (0.27-2.10)
Sibling	22 (8.3)	10 (4.8)	.13	-
PSOA primary carer	181 (68.3)	154 (73.7)	.20	-
Type of neglect:				
Failure to meet support needs	187 (70.6)	157 (75.1)	.27	-
Medical care	87 (32.8)	68 (32.5)	.95	-
Clothing/food	40 (15.1)	39 (18.7)	.30	-
Failure to provide necessities of life	15 (5.7)	21 (10.0)	.07	1.66 (0.63-4.37)
Factors contributing to issues/allegations:				
PSOA preventing access to services	103 (38.9)	138 (66.0)	<.001	2.26 (1.33-3.86)
Carer stress	86 (32.5)	107 (51.2)	<.001	1.56 (1.17-2.08)
Current/historical abuse	70 (26.4)	108 (51.7)	<.001	2.31 (1.32-4.06)
Health literacy	21 (7.9)	41 (19.6)	<.001	1.24 (0.91-1.68)
Delay in service access	20 (7.5)	23 (11.0)	.19	-
Risk factors:				
Dementia	59 (22.5)	42 (20.1)	.52	-
Chronic health issues	70 (26.7)	69 (33.0)	.14	-
History of family dysfunction	51 (19.5)	56 (26.8)	.06	1.44 (0.78-2.63)
Social isolation	29 (11.1)	43 (20.6)	<.01	N/A*
Mental health	31 (11.8)	25 (12.0)	.97	-
History of domestic violence	25 (9.5)	31 (14.8)	.08	1.58 (0.71-3.51)
Squalor and/or hoarding	35 (13.4)	21 (10.0)	.27	-
Self-neglect	21 (8.0)	12 (5.7)	.34	-
Factors affecting the response:				
Person’s views/wishes	112 (42.3)	105 (50.2)	.09	0.99 (0.58-1.68)
Parties did not realise severity	41 (15.5)	61 (29.2)	<.001	1.30 (0.66-2.54)
Recent hospital/medical contact	14 (5.3)	28 (13.4)	<.01	1.11 (0.46-2.72)
PSOA did not know what to do	15 (5.7)	40 (19.1)	<.001	2.53 (1.09-5.87)
PSOA refused help/refused to act	36 (13.6)	74 (35.4)	<.001	1.75 (0.92-3.33)
Serious neglect	95 (35.8)	86 (41.1)	.24	-

* N/A indicates variable was excluded from multivariable analysis

Table 21. Comparison of cases with indications of carer stress vs. no carer stress (CSI cases only)

	No carer stress n (%)	Carer stress n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	66.7 (23.0)	63.5 (24.2)	.15	-
Person gender:			.71	-
Female	170 (60.5)	120 (62.2)		
Male	111 (39.5)	73 (37.8)		
Area of residence:			.78	-
Metropolitan	123 (44.4)	86 (45.7)		
Regional	154 (55.6)	102 (54.3)		
Aboriginal	15 (5.3)	10 (5.2)	.94	-
Language other than English	47 (16.7)	23 (11.9)	.15	-
Person receiving community services	142 (50.5)	118 (61.1)	.02	1.13 (0.65-1.96)
Person condition:			.02	0.69 (0.53-0.90)
Needs not met	46 (17.2)	44 (23.4)		
Signs of neglect	147 (54.9)	105 (55.9)		
Poor	46 (17.2)	31 (16.5)		
Very unwell	13 (4.9)	6 (3.2)		
Critically unwell	16 (6.0)	2 (1.1)		
Person functioning:			<.001	1.09 (0.97-1.21)
No limitation	37 (14.6)	14 (7.7)		
Core activity limitation	73 (28.7)	28 (15.3)		
Mild limitation	8 (3.1)	4 (2.2)		
Moderate limitation	12 (4.7)	12 (6.6)		
Severe limitation	31 (12.2)	42 (23.0)		
Profound limitation	93 (36.6)	83 (45.4)		
Person health needs:			.59	-
No chronic/terminal condition	56 (19.9)	30 (15.5)		
1-2 chronic health conditions	166 (59.1)	116 (60.1)		
3-4 chronic health conditions	22 (7.8)	16 (8.3)		
5+ chronic health conditions	3 (1.1)	4 (2.1)		
Terminal condition	7 (2.5)	4 (2.1)		
Not known	27 (9.6)	23 (11.9)		
Person isolated	102 (36.3)	107 (55.4)	<.001	1.81 (1.08-3.05)
Concerns about Person's decision-making capacity:			.04	
No/Unknown	145 (51.6)	77 (39.9)		Ref.
Suspected	11 (3.9)	9 (4.7)		1.97 (0.62-6.20)

	No carer stress **n (%)**	**Carer stress** **n (%)**	***p*-value**	**aOR (95% CI)**
Yes	125 (44.5)	107 (55.4)		1.40 (0.86-2.28)
Disability:				
None	69 (24.6)	37 (19.2)	.17	-
Neurological	113 (40.2)	85 (44.0)	.41	-
Physical	69 (24.6)	44 (22.8)	.66	-
Intellectual	42 (14.9)	39 (20.2)	.14	-
Mental health	28 (10.0)	21 (10.9)	.75	-
Other cognitive	19 (6.8)	20 (10.4)	.16	-
Autism	19 (6.8)	11 (5.7)	.64	-
Sensory	15 (5.3)	7 (3.6)	.38	-
Formal services involved:				
Disability (any)	64 (22.8)	75 (38.9)	<.001	1.50 (0.79-2.82)
In-home	41 (14.6)	56 (29.0)	<.001	N/A*
Other	26 (9.3)	33 (17.1)	.01	N/A*
Aged care (any)	69 (24.6)	51 (26.4)	.65	-
In-home	60 (21.4)	41 (21.2)	.98	-
Other	13 (4.6)	13 (6.7)	.32	-
None	123 (43.8)	53 (27.5)	<.001	0.77 (0.42-1.41)
Health services involved:				
GP	124 (44.1)	82 (42.5)	.72	-
Hospital	113 (40.2)	62 (32.1)	.07	0.63 (0.38-1.02)
Community	44 (15.7)	40 (20.7)	.16	-
Other medical	22 (7.8)	22 (11.4)	.19	-
Other	29 (10.3)	17 (8.8)	.59	-
Informal supports involved:				
PSOA	214 (76.2)	172 (89.1)	<.001	1.86 (0.94-3.68)
Family	127 (45.2)	70 (36.3)	.05	0.97 (0.60-1.57)
Friends	15 (5.3)	5 (2.6)	.14	-
Neighbour	15 (5.3)	11 (5.7)	.87	-
Person lives with PSOA	202 (72.1)	157 (81.3)	.02	1.12 (0.63-2.00)
Person lives in own home	177 (73.8)	128 (75.7)	.65	-
PSOA gender:			.16	-
Female	118 (42.0)	98 (50.8)		
Male	151 (53.7)	91 (47.2)		
Other	2 (0.7)	0		
Unknown	10 (3.6)	4 (2.1)		
PSOA relationship:				
Partner/spouse	55 (19.6)	46 (23.8)	.27	-
Relative	192 (68.3)	140 (72.5)	.33	-
Child	117 (41.6)	79 (40.9)	.88	-

	No carer stress n (%)	Carer stress n (%)	*p*-value	aOR (95% CI)
Parent	41 (14.6)	47 (24.4)	<.01	1.86 (0.98-3.55)
Sibling	22 (7.8)	10 (5.2)	.26	-
PSOA primary carer	177 (63.0)	158 (81.9)	<.001	1.98 (1.09-3.59)
Type of neglect:				
Failure to meet support needs	191 (68.0)	153 (79.3)	<.01	1.69 (0.98-2.91)
Medical care	95 (33.8)	60 (31.1)	.54	-
Clothing/food	49 (17.4)	30 (15.5)	.59	-
Failure to provide necessities of life	23 (8.2)	13 (6.7)	.56	-
Factors contributing to issues/allegations:				
PSOA preventing access to services	118 (42.0)	123 (63.7)	<.001	1.59 (0.96-2.63)
Current/historical abuse	95 (33.8)	83 (43.0)	.04	1.12 (0.66-1.89)
Health literacy	24 (8.5)	38 (19.7)	<.001	2.08 (1.00-4.32)
Delay in service access	22 (7.8)	21 (10.9)	.26	-
Risk factors:				
Dementia	61 (21.9)	40 (20.8)	.79	-
Chronic health issues	75 (26.9)	64 (33.3)	.13	-
History of family dysfunction	58 (20.8)	49 (25.5)	.23	-
Social isolation	45 (16.1)	27 (14.1)	.54	-
Mental health	37 (13.3)	19 (9.9)	.27	-
History of domestic violence	34 (12.2)	22 (11.5)	.81	-
Squalor and/or hoarding	36 (12.9)	20 (10.4)	.41	-
Self-neglect	26 (9.3)	7 (3.6)	.02	0.59 (0.22-1.59)
Factors affecting the response:				
Person's views/wishes	136 (48.4)	81 (42.0)	.39	-
Parties did not realise severity	54 (19.2)	48 (24.9)	.03	1.04 (0.55-1.95)
Recent hospital/medical contact	13 (4.6)	29 (15.0)	<.001	2.71 (1.12-6.56)
PSOA did not know what to do	20 (7.1)	35 (18.1)	<.001	1.55 (0.74-3.28)
PSOA refused help/refused to act	54 (19.2)	56 (29.0)	.04	0.78 (0.43-1.44)
Serious neglect	114 (40.6)	67 (34.7)	.20	-

* N/A indicates variable was excluded from multivariable analysis

Table 22. Comparison of cases with current or history of abuse within relationship vs. no history of abuse (CSI cases only)

	No history of abuse n (%)	Current or historical abuse n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	66.9 (24.1)	63.1 (22.5)	.10	-
Person gender:			.12	-
Female	173 (58.4)	117 (65.7)		
Male	123 (41.6)	61 (34.3)		
Area of residence:			.36	-
Metropolitan	136 (46.6)	73 (42.2)		
Regional	156 (53.4)	100 (57.8)		
Aboriginal	14 (4.7)	11 (6.2)	.49	-
Language other than English	53 (17.9)	17 (9.6)	.01	0.51 (0.25-1.06)
Person receiving community services	159 (53.7)	101 (56.7)	.52	-
Person condition:			.06	N/A*
Needs not met	51 (18.1)	39 (22.4)		
Signs of neglect	152 (53.9)	100 (57.5)		
Poor	54 (19.1)	23 (13.2)		
Very unwell	10 (3.5)	9 (5.2)		
Critically unwell	15 (5.3)	3 (1.7)		
Person functioning:			.19	-
No limitation	36 (13.2)	15 (9.1)		
Core activity limitation	77 (28.2)	24 (14.6)		
Mild limitation	8 (2.9)	4 (2.4)		
Moderate limitation	8 (2.9)	16 (9.8)		
Severe limitation	29 (10.6)	44 (26.8)		
Profound limitation	115 (42.1)	61 (37.2)		
Person health needs:			.13	-
No chronic/terminal condition	50 (16.9)	36 (20.2)		
1-2 chronic health conditions	180 (60.8)	102 (57.3)		
3-4 chronic health conditions	27 (9.1)	11 (6.2)		
5+ chronic health conditions	3 (1.0)	4 (2.2)		
Terminal condition	8 (2.7)	3 (1.7)		
Not known	28 (9.5)	22 (12.4)		
Person isolated	101 (34.1)	108 (60.7)	<.001	2.24 (1.32-3.81)
Concerns about Person's decision-making capacity:			<.01	
No/Unknown	121 (40.9)	101 (56.7)		Ref.
Suspected				

	No history of abuse n (%)	Current or historical abuse n (%)	*p*-value	aOR (95% CI)
Yes	14 (4.7)	6 (3.4)		0.22 (0.05-0.93)
	161 (54.4)	71 (39.9)		0.49 (0.29-0.83)
Disability:				
None	61 (20.6)	45 (25.3)	.24	-
Neurological	128 (43.2)	70 (39.3)	.40	-
Physical	71 (24.0)	42 (23.6)	.92	-
Intellectual	49 (16.6)	32 (18.0)	.69	-
Mental health	25 (8.4)	24 (13.5)	.08	1.44 (0.65-3.20)
Other cognitive	25 (8.4)	14 (7.9)	.82	-
Autism	24 (8.1)	6 (3.4)	.04	0.34 (0.11-1.12)
Sensory	16 (5.4)	6 (3.4)	.31	-
Formal services involved:				
Disability (any)	75 (25.3)	64 (36.0)	.01	1.58 (0.85-2.89)
In-home	56 (18.9)	41 (23.0)	.28	-
Other	27 (9.1)	32 (18.0)	<.01	N/A*
Aged care (any)	82 (27.7)	38 (21.3)	.12	-
In-home	73 (24.7)	28 (15.7)	.02	0.83 (0.44-1.60)
Other	13 (4.4)	13 (7.3)	.18	-
None	113 (38.2)	63 (35.4)	.54	-
Health services involved:				
GP	140 (47.3)	66 (37.1)	.03	0.71 (0.42-1.18)
Hospital	117 (39.5)	58 (32.6)	.13	-
Community	58 (19.6)	26 (14.6)	.17	-
Other medical	28 (9.5)	16 (9.0)	.86	-
Other	30 (10.1)	16 (9.0)	.68	-
Informal supports involved:				
PSOA	245 (82.8)	141 (79.2)	.34	-
Family	128 (43.2)	69 (38.8)	.34	-
Friends	14 (4.7)	6 (3.4)	.48	-
Neighbour	20 (6.8)	6 (3.4)	.12	-
Person lives with PSOA	222 (75.0)	137 (77.4)	.56	-
Person lives in own home	201 (79.8)	104 (66.2)	<.01	0.42 (0.24-0.73)
PSOA gender:			<.01	
Female	151 (51.0)	65 (36.5)		Ref.
Male	134 (45.3)	108 (60.7)		2.32 (1.37-3.94)
Other	2 (0.7)	0		N/A*
Unknown	9 (3.0)	5 (2.8)		1.70 (0.33-8.77)
PSOA relationship:				
Partner/spouse	46 (15.5)	55 (30.9)	<.001	1.37 (0.69-2.73)

	No history of abuse n (%)	Current or historical abuse n (%)	*p*-value	aOR (95% CI)
Relative	224 (75.7)	108 (60.7)	<.01	N/A*
Child	132 (44.6)	64 (36.0)	.06	0.60 (0.31-1.16)
Parent	61 (20.6)	27 (15.2)	.14	-
Sibling	20 (6.8)	12 (6.7)	.99	-
PSOA primary carer	210 (70.9)	125 (70.2)	.87	-
Type of neglect:				
Failure to meet support needs	221 (74.7)	123 (69.1)	.19	-
Medical care	103 (34.8)	52 (29.2)	.21	-
Clothing/food	47 (15.9)	32 (18.0)	.55	-
Failure to provide necessities of life	22 (7.4)	14 (7.9)	.86	-
Factors contributing to issues/allegations:				
PSOA preventing access to services	131 (44.3)	110 (61.8)	<.001	1.32 (0.76-2.29)
Carer stress	110 (37.2)	83 (46.6)	.04	1.18 (0.71-1.99)
Health literacy	41 (13.9)	21 (11.8)	.52	-
Delay in service access	27 (9.1)	16 (9.0)	.96	-
Risk factors:				
Dementia	69 (23.5)	32 (18.0)	.15	-
Chronic health issues	84 (28.7)	55 (30.9)	.61	-
History of family dysfunction	52 (17.7)	55 (30.9)	<.01	2.09 (1.18-3.70)
Social isolation	51 (17.4)	21 (11.8)	.10	-
Mental health	33 (11.3)	23 (12.9)	.59	-
History of domestic violence	16 (5.5)	40 (22.5)	<.001	N/A*
Squalor and/or hoarding	36 (12.3)	20 (11.2)	.73	-
Self-neglect	23 (7.8)	10 (5.6)	.36	-
Factors affecting the response:				
Person's views/wishes	118 (39.9)	99 (55.6)	<.01	1.70 (1.01-2.85)
Parties did not realise severity	63 (21.3)	39 (21.9)	.40	-
Recent hospital/medical contact	22 (7.4)	20 (11.2)	.26	-
PSOA did not know what to do	26 (8.8)	29 (16.3)	.02	1.46 (0.69-3.12)
PSOA refused help/refused to act	37 (12.5)	73 (41.0)	<.001	3.95 (2.15-7.27)
Serious neglect	97 (32.8)	84 (47.2)	<.01	1.66 (1.00-2.74)

* N/A indicates variable was excluded from multivariable analysis

Table 23. Comparison of regional vs. metropolitan cases (CSI cases only)

	Metropolitan n (%)	Regional n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	66.3 (25.2)	64.8 (22.1)	.52	-
Person gender:			.70	-
Female	131 (62.7)	156 (60.9)		
Male	78 (37.3)	100 (39.1)		
Aboriginal	6 (2.9)	19 (7.4)	.03	.90 (.70-1.15)
Language other than English	51 (24.4)	18 (7.0)	<.001	0.22 (0.12-0.42)
Person receiving community services	109 (52.2)	143 (55.9)	.43	-
Person condition:			.94	-
Needs not met	35 (17.3)	53 (21.6)		
Signs of neglect	121 (59.9)	127 (51.8)		
Poor	30 (14.9)	45 (18.4)		
Very unwell	9 (4.5)	9 (3.7)		
Critically unwell	7 (3.5)	11 (4.5)		
Person functioning:			.10	-
No limitation	26 (13.7)	24 (10.1)		
Core activity limitation	53 (27.9)	46 (19.3)		
Mild limitation	6 (3.2)	6 (2.5)		
Moderate limitation	9 (4.7)	15 (6.3)		
Severe limitation	20 (10.5)	48 (20.2)		
Profound limitation	76 (40.0)	99 (41.6)		
Person health needs:			.87	-
No chronic/terminal condition	34 (16.3)	51 (19.9)		
1-2 chronic health conditions	126 (60.3)	150 (58.6)		
3-4 chronic health conditions	14 (6.7)	23 (9.0)		
5+ chronic health conditions	5 (2.4)	2 (0.8)		
Terminal condition	4 (1.9)	7 (2.7)		
Not known	26 (12.4)	23 (9.0)		
Person isolated	88 (42.1)	116 (45.3)	.49	-
Concerns about Person's decision-making capacity:			.16	-
No/Unknown	108 (51.7)	110 (43.0)		
Suspected	9 94.3)	11 (4.3)		
Yes	92 (44.0)	135 (52.7)		
Disability:				
None	62 (29.7)	41 (16.0)	<.001	0.58 (0.32-1.06)
Neurological	71 (34.0)	126 (49.2)	<.01	1.42 (0.86-2.34)

	Metropolitan n (%)	**Regional n (%)**	***p*-value**	**aOR (95% CI)**
Physical	47 (22.5)	64 (25.0)	.53	-
Intellectual	34 (16.3)	44 (17.2)	.79	-
Mental health	30 (14.4)	19 (7.4)	.02	0.42 (0.21-0.83)
Other cognitive	15 (7.2)	23 (9.0)	.48	-
Autism	15 (7.2)	15 (5.9)	.57	-
Sensory	11 (5.3)	11 (4.3)	.63	-
Formal services involved:				
Disability (any)	54 (25.8)	82 (32.0)	.14	-
In-home	37 (17.7)	59 (23.0)	.16	-
Other	23 (11.0)	34 (13.3)	.46	-
Aged care (any)	55 (26.3)	62 (24.2)	.60	-
In-home	50 (23.9)	48 (18.8)	.17	-
Other	8 (3.8)	18 (7.0)	.14	-
None	82 (39.2)	92 (35.9)	.47	-
Health services involved:				
GP	92 (44.0)	111 (43.4)	.89	-
Hospital	73 (34.9)	97 (37.9)	.51	-
Community	25 (12.0)	56 (21.9)	<.01	2.18 (1.21-3.92)
Other medical	19 (9.1)	25 (9.8)	.81	-
Other	20 (9.6)	25 (9.8)	.94	-
Informal supports involved:				
PSOA	183 (87.6)	195 (76.2)	<.01	0.43 (0.25-0.76)
Family	88 (42.1)	108 (42.2)	.99	-
Friends	9 (4.3)	11 (4.3)	.99	-
Neighbour	13 (6.2)	13 (5.1)	.59	-
Person lives with PSOA	164 (78.8)	188 (73.4)	.18	-
Person lives in own home	133 (73.1)	169 (76.1)	.48	-
PSOA gender:			.35	-
Female	97 (46.4)	114 (44.5)		
Male	108 (51.7)	130 (50.8)		
Other	0	2 (0.8)		
Unknown	4 (1.9)	10 (3.9)		
PSOA relationship:				
Partner/spouse	33 (15.8)	66 (25.8)	<.01	1.53 (0.82-2.84)
Relative	159 (76.1)	167 (65.2)	.01	N/A*
Child	102 (48.8)	92 (35.9)	<.01	0.91 (0.55-1.51)
Parent	37 (17.7)	50 (19.5)	.62	-
Sibling	15 (7.2)	16 (6.3)	.69	-
PSOA primary carer	148 (70.8)	179 (69.9)	.83	-

	Metropolitan **n (%)**	**Regional** **n (%)**	***p*-value**	**aOR (95% CI)**
Type of neglect:				
Failure to meet support needs	150 (71.8)	187 (73.0)	.76	-
Medical care	67 (32.1)	86 (33.6)	.73	-
Clothing/food	32 (15.3)	46 (18.0)	.45	-
Failure to provide necessities of life	15 (7.2)	20 (7.8)	.80	-
Factors contributing to issues/allegations:				
PSOA preventing access to services	96 (45.9)	142 (55.5)	.04	1.40 (0.93-2.12)
Carer stress	86 (41.1)	102 (39.8)	.78	-
Current/historical abuse	73 (34.9)	100 (39.1)	.36	-
Health literacy	24 (11.5)	38 (14.8)	.29	-
Delay in service access	19 (9.1)	22 (8.6)	.85	-
Risk factors:				
Dementia	44 (21.2)	57 (22.4)	.74	-
Chronic health issues	45 (21.6)	92 (36.2)	<.01	1.86 (1.16-2.98)
History of family dysfunction	37 (17.8)	68 (26.8)	.02	1.35 (0.81-2.25)
Social isolation	31 (14.9)	39 (15.4)	.89	-
Mental health	25 (12.0)	31 (12.2)	.95	-
History of domestic violence	16 (7.7)	39 (15.4)	.01	1.54 (0.76-3.10)
Squalor and/or hoarding	21 (10.1)	34 (13.4)	.28	-
Self-neglect	11 (5.3)	22 (8.7)	.16	-
Factors affecting the response:				
Person's views/wishes	96 (45.9)	118 (46.1)	.04	0.98 (0.63-1.50)
Parties did not realise severity	42 (20.1)	57 (22.3)	.25	-
Recent hospital/medical contact	19 (9.1)	22 (8.6)	.58	-
PSOA did not know what to do	22 (10.5)	33 (12.9)	.69	-
PSOA refused help/refused to act	51 (24.4)	57 (22.3)	.22	-
Serious neglect	79 (37.8)	98 (38.3)	.92	-

* N/A indicates variable was excluded from multivariable analysis

Table 24. Comparison of cases involving older person with dementia vs. older person without dementia (CSI cases only)

	No dementia n (%)	Dementia n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	79.6 (9.9)	82 (8.4)	.02	1.04 (1.00-1.08)
Person gender:			.25	-
Female	137 (66.2)	72 (72.7)		
Male	70 (33.8)	27 (27.3)		
Area of residence:			.56	-
Metropolitan	97 (48.0)	44 (44.4)		
Regional	105 (52.0)	55 (55.6)		
Aboriginal	12 (5.8)	7 (7.1)	.67	-
Language other than English	37 (17.9)	18 (18.2)	.95	-
Person receiving community services	95 (45.9)	38 (38.4)	.22	-
Person condition:			.65	-
Needs not met	33 (16.4)	17 (18.3)		
Signs of neglect	115 (57.2)	52 (55.9)		
Poor	31 (15.4)	18 (19.4)		
Very unwell	12 (6.0)	3 (3.2)		
Critically unwell	10 (5.0)	3 (3.2)		
Person functioning:			.65	-
No limitation	22 (11.5)	8 (8.9)		
Core activity limitation	49 (25.7)	25 (27.8)		
Mild limitation	6 (3.1)	1 (1.1)		
Moderate limitation	9 (4.7)	4 (4.4)		
Severe limitation	31 (16.2)	15 (16.7)		
Profound limitation	74 (38.7)	37 (41.1)		
Person health needs:			.12	-
No chronic/terminal condition	36 (17.4)	10 (10.1)		
1-2 chronic health conditions	113 (54.6)	81 (81.8)		
3-4 chronic health conditions	20 (9.7)	5 (5.1)		
5+ chronic health conditions	3 (1.4)	0		
Terminal condition	6 (2.9)	0		
Not known	29 (14.0)	3 (3.0)		
Person isolated	103 (49.8)	40 (40.4)	.13	-
Concerns about Person's decision-making capacity:			<.001	
No/Unknown	128 (61.8)	18 (18.2)		Ref.
Suspected	14 (6.8)	5 (5.1)		0.53 (0.06-4.74)

	No dementia n (%)	Dementia n (%)	*p*-value	aOR (95% CI)
Yes	65 (31.4)	76 (76.8)		10.51 (4.89-22.64)
Disability:				
None	89 (43.0)	17 (17.2)	<.001	N/A*
Neurological	66 (31.9)	72 (72.7)	<.001	N/A*
Physical	41 (19.8)	13 (13.1)	.15	-
Intellectual	5 (2.4)	2 (2.0)	.83	-
Mental health	19 (9.2)	3 (3.0)	.05	N/A*
Other cognitive	11 (5.3)	8 (8.1)	.35	-
Autism	0	0	-	-
Sensory	13 (6.3)	1 (1.0)	.04	N/A*
Formal services involved:				
Disability (any)	19 (9.2)	9 (9.1)	.98	-
In-home	17 (8.2)	6 (6.1)	.50	-
Other	3 (1.4)	3 (3.0)	.35	-
Aged care (any)	74 (35.7)	40 (40.4)	.43	-
In-home	65 (31.4)	33 (33.3)	.74	-
Other	14 (6.8)	8 (8.1)	.68	-
None	97 (46.9)	42 (42.4)	.47	-
Health services involved:				
GP	91 (44.0)	51 (51.5)	.22	-
Hospital	90 (43.5)	37 (37.4)	.31	-
Community	40 (19.2)	17 (17.2)	.65	-
Other medical	17 (8.2)	9 (9.1)	.80	-
Other	13 (6.3)	11 (11.1)	.14	-
Informal supports involved:				
PSOA	174 (84.1)	83 (83.8)	.96	-
Family	87 (42.0)	49 (49.5)	.22	-
Friends	10 (4.8)	5 (5.1)	.93	-
Neighbour	13 (6.3)	13 (13.1)	.04	1.94 (0.64-5.83)
Person lives with PSOA	157 (75.8)	71 (72.4)	.52	-
Person lives in own home	127 (71.3)	73 (83.0)	.04	2.34 (1.03-5.34)
PSOA gender:			.41	-
Female	85 (41.1)	38 (38.4)		
Male	113 (54.6)	60 (60.6)		
Other	1 (0.5)	0		
Unknown	8 (3.9)	1 (1.0)		
PSOA relationship:				
Partner/spouse	49 (23.7)	18 (18.2)	.28	-
Relative	134 (64.7)	74 (74.7)	.08	N/A*
Child	120 (58.0)	68 (68.7)	.07	1.27 (0.63-2.54)

	No dementia n (%)	Dementia n (%)	*p*-value	aOR (95% CI)
Parent	1 (0.5)	0	.49	-
Sibling	8 (3.9)	3 (3.0)	.71	-
PSOA primary carer	138 (66.7)	77 (77.8)	.05	1.26 (0.60-2.65)
Type of neglect:				
Failure to meet support needs	155 (74.9)	77 (77.8)	.58	-
Medical care	63 (30.4)	32 (32.3)	.74	-
Clothing/food	35 (16.9)	17 (17.2)	.95	-
Failure to provide necessities of life	20 (9.7)	7 (7.1)	.46	-
Factors contributing to issues/allegations:				
PSOA preventing access to services	98 (47.3)	57 (57.6)	.09	1.26 (0.65-2.45)
Carer stress	73 (35.3)	39 (39.4)	.48	-
Current/historical abuse	80 (38.6)	30 (30.3)	.16	-
Health literacy	21 (10.1)	17 (17.2)	.08	0.88 (0.33-2.31)
Delay in service access	14 (6.8)	14 (14.1)	.04	4.96 (1.57-15.65)
Risk factors:				
Chronic health issues	60 (29.0)	20 (20.2)	.10	-
History of family dysfunction	42 (20.3)	19 (19.2)	.82	-
Social isolation	30 (14.5)	13 (13.1)	.75	-
Mental health	22 (10.6)	7 (7.1)	.32	-
History of domestic violence	22 (10.6)	6 (6.1)	.20	-
Squalor and/or hoarding	22 (10.6)	10 (10.1)	.89	-
Self-neglect	9 (4.3)	10 (10.1)	.05	6.68 (1.89-23.60)
Factors affecting the response:				
Person’s views/wishes	114 (55.1)	34 (34.3)	<.01	0.62 (0.10-9.41)
Parties did not realise severity	38 (18.4)	21 (21.2)	.48	-
Recent hospital/medical contact	22 (10.6)	7 (7.1)	.54	-
PSOA did not know what to do	28 (13.5)	8 (8.1)	.38	-
PSOA refused help/refused to act	42 (20.3)	24 (24.2)	.72	-
Serious neglect	90 (43.5)	34 (34.3)	.13	-

* N/A indicates variable was excluded from multivariable analysis

Table 25. Comparison of cases where PSOA was blocking service access vs. PSOA not blocking service access (CSI cases only)

	PSOA not blocking services n (%)	PSOA blocking services n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	65.3 (24.5)	65.6 (22.7)	.90	-
Person gender:			.30	-
Female	137 (58.8)	153 (63.5)		
Male	96 (41.2)	88 (36.5)		
Area of residence:			.04	
Metropolitan	113 (49.8)	96 (40.3)		Ref.
Regional	114 (50.2)	142 (59.7)		1.62 (1.04-2.53)
Aboriginal	13 (5.6)	12 (5.0)	.77	-
Language other than English	34 (14.6)	36 (14.9)	.92	-
Person receiving community services	130 (55.8)	130 (53.9)	.69	-
Person condition:			.67	-
Needs not met	40 (18.0)	50 (21.4)		
Signs of neglect	126 (56.8)	126 (53.8)		
Poor	42 (18.9)	35 (15.0)		
Very unwell	5 (2.3)	14 (6.0)		
Critically unwell	9 (4.1)	9 (3.8)		
Person functioning:			<.001	1.04 (0.94-1.15)
No limitation	30 (14.2)	21 (9.3)		
Core activity limitation	64 (30.3)	37 (16.4)		
Mild limitation	5 (2.4)	7 (3.1)		
Moderate limitation	11 (5.2)	13 (5.8)		
Severe limitation	27 (12.8)	46 (20.4)		
Profound limitation	74 (35.1)	102 (45.1)		
Person health needs:			.20	-
No chronic/terminal condition	51 (21.9)	35 (14.5)		
1-2 chronic health conditions	135 (57.9)	147 (61.0)		
3-4 chronic health conditions	15 (6.4)	23 (9.5)		
5+ chronic health conditions	4 (1.7)	3 (1.2)		
Terminal condition	6 (2.6)	5 (2.1)		
Not known	22 (9.4)	28 (11.6)		
Person isolated	71 (30.5)	138 (57.3)	<.001	2.17 (1.35-3.48)
Concerns about Person's decision-making capacity:			.04	
No/Unknown	123 (52.8)	99 (41.1)		Ref.
Suspected				

	PSOA not blocking services n (%)	PSOA blocking services n (%)	*p*-value	aOR (95% CI)
Yes	8 (3.4)	12 (5.0)		2.35 (0.75-7.31)
	102 (43.8)	130 (53.9)		1.67 (1.04-2.68)
Disability:				
None	56 (24.0)	50 (20.7)	.39	-
Neurological	96 (41.2)	102 (42.3)	.80	-
Physical	46 (19.7)	67 (27.8)	.04	1.35 (0.79-2.30)
Intellectual	48 (20.6)	33 (13.7)	.05	0.62 (0.34-1.14)
Mental health	25 (10.7)	24 (10.0)	.78	-
Other cognitive	15 (6.4)	24 (10.0)	.16	-
Autism	19 (8.2)	11 (4.6)	.11	-
Sensory	16 (6.9)	6 (2.5)	.02	0.36 (0.11-1.13)
Formal services involved:				
Disability (any)	64 (27.5)	75 (31.1)	.38	-
In-home	40 (17.2)	57 (23.7)	.08	1.10 (0.62-1.95)
Other	27 (11.6)	32 (13.3)	.58	-
Aged care (any)	64 (27.5)	56 (23.2)	.29	-
In-home	54 (23.2)	47 (19.5)	.33	-
Other	14 (6.0)	12 (5.0)	.62	-
None	79 (33.9)	97 (40.2)	.15	-
Health services involved:				
GP	92 (39.5)	114 (47.3)	.09	1.46 (0.93-2.30)
Hospital	76 (32.6)	99 (41.1)	.06	1.35 (0.85-2.16)
Community	40 (17.2)	44 (18.3)	.76	-
Other medical	23 (9.9)	21 (8.7)	.66	-
Other	23 (9.9)	23 (9.5)	.90	-
Informal supports involved:				
PSOA	184 (79.0)	202 (83.8)	.18	-
Family	103 (44.2)	94 (39.0)	.25	-
Friends	9 (3.9)	11 (4.6)	.70	-
Neighbour	13 (5.6)	13 (5.4)	.93	-
Person lives with PSOA	163 (70.0)	196 (81.7)	<.01	1.71 (0.99-2.96)
Person lives in own home	147 (75.8)	158 (73.5)	.60	-
PSOA gender:			.16	-
Female	114 (48.9)	102 (42.3)		
Male	109 (46.8)	133 (55.2)		
Other	2 (0.9)	0		
Unknown	8 (3.4)	6 (2.5)		
PSOA relationship:				
Partner/spouse	41 (17.6)	60 (24.9)	.05	0.94 (0.54-1.66)

	PSOA not blocking services n (%)	PSOA blocking services n (%)	*p*-value	aOR (95% CI)
Relative	165 (70.8)	167 (69.3)	.72	-
Child	92 (39.5)	104 (43.2)	.42	-
Parent	43 (18.5)	45 (18.7)	.95	-
Sibling	19 (8.2)	13 (5.4)	.23	-
PSOA primary carer	143 (61.4)	192 (79.7)	<.001	2.15 (1.29-3.58)
Type of neglect:				
Failure to meet support needs	167 (71.7)	177 (73.4)	.67	-
Medical care	66 (28.3)	89 (36.9)	.05	1.42 (0.89-2.27)
Clothing/food	36 (15.5)	43 (17.8)	.49	-
Failure to provide necessities of life	20 (8.6)	16 (6.6)	.42	-
Factors contributing to issues/allegations:				
Carer stress	70 (30.0)	123 (51.0)	<.001	1.68 (1.05-2.68)
Current/historical abuse	68 (29.2)	110 (45.6)	<.001	1.83 (1.23-2.99)
Health literacy	17 (7.3)	45 (18.7)	<.001	1.78 (0.87-3.64)
Delay in service access	15 (6.4)	28 (11.6)	.05	1.39 (0.65-2.96)
Risk factors:				
Dementia	42 (18.3)	59 (24.5)	.10	-
Chronic health issues	58 (25.2)	81 (33.6)	.05	0.99 (0.59-1.68)
History of family dysfunction	46 (20.0)	61 (25.3)	.17	-
Social isolation	30 (13.0)	42 (17.4)	.19	-
Mental health	25 (10.9)	31 (12.9)	.50	-
History of domestic violence	22 (9.6)	34 (14.1)	.13	-
Squalor and/or hoarding	28 (12.2)	28 (11.6)	.85	-
Self-neglect	20 (8.7)	13 (5.4)	.16	-
Factors affecting the response:				
Person's views/wishes	109 (46.8)	108 (44.8)	.86	-
Parties did not realise severity	41 (17.6)	61 (25.3)	.09	1.01 (0.57-1.80)
Recent hospital/medical contact	15 (6.4)	27 (11.2)	.14	-
PSOA did not know what to do	25 (10.7)	30 (12.4)	.82	-
PSOA refused help/refused to act	19 (8.2)	91 (37.8)	<.001	N/A*
Serious neglect	91 (39.1)	90 (37.3)	.70	-

* N/A indicates variable was excluded from multivariable analysis

Table 26. Comparison of cases involving Person receiving disability services vs. Person with disability not receiving disability services (CSI cases only)

	Person not receiving disability services n (%)	Person receiving disability services n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	38.0 (15.2)	38.2 (15.2)	.95	-
Person gender:			.70	-
Female	28 (50.0)	52 (46.8)		
Male	28 (50.0)	59 (53.2)		
Area of residence:			.62	-
Metropolitan	24 (44.4)	44 (40.4)		
Regional	30 (55.6)	65 (59.6)		
Aboriginal	2 (3.6)	4 (3.6)	.99	-
Language other than English	8 (14.3)	7 (6.3)	.09	0.37 (0.05-2.83)
Person receiving community services	26 (46.4)	100 (90.1)	<.001	N/A*
Person condition:			.18	-
Needs not met	15 (27.8)	24 (22.4)		
Signs of neglect	22 (40.7)	63 (58.9)		
Poor	14 (25.9)	14 (13.1)		
Very unwell	1 (1.9)	3 (2.8)		
Critically unwell	2 (3.7)	3 (2.8)		
Person functioning:			<.01	1.10 (0.90-1.34)
No limitation	11 (23.4)	10 (9.3)		
Core activity limitation	12 (25.5)	15 (13.9)		
Mild limitation	3 (6.4)	2 (1.9)		
Moderate limitation	2 (4.3)	9 (8.3)		
Severe limitation	6 (12.8)	21 (19.4)		
Profound limitation	13 (27.7)	51 (47.2)		
Person health needs:			.38	-
No chronic/terminal condition	30 (53.6)	57 (51.4)		
1-2 chronic health conditions	2 (3.6)	11 (9.9)		
3-4 chronic health conditions	2 (3.6)	2 (1.8)		
5+ chronic health conditions	1 (1.8)	4 (3.6)		
Terminal condition	15 (26.8)	25 (22.5)		
Not known	6 (10.7)	12 (10.8)		
Person isolated	23 (41.1)	43 (38.7)	.77	-
Concerns about Person's decision-making capacity:			.67	-
No/Unknown	24 (42.9)	52 (46.8)		
Suspected				

	Person not receiving disability services n (%)	Person receiving disability services n (%)	*p*-value	aOR (95% CI)
Yes	0	1 (0.9)		
	32 (57.1)	58 (52.3)		
Disability:				
Neurological	13 (23.2)	46 (41.1)	.02	3.80 (1.22-11.86)
Physical	19 (33.9)	40 (36.0)	.79	-
Intellectual	24 (42.9)	50 (45.0)	.79	-
Mental health	9 (16.1)	19 (16.2)	.98	-
Other cognitive	3 (5.4)	17 (15.3)	.06	22.08 (2.10-231.84)
Autism	15 (26.8)	15 (13.5)	.04	0.59 (0.17-2.03)
Sensory	4 (7.1)	4 (3.6)	.31	-
Formal services involved:				
Disability (any)	0	111 (100)	-	-
In-home	0	74 (66.7)	<.001	N/A*
Other	0	53 (47.7)	<.001	N/A*
Aged care (any)	3 (5.4)	2 (1.8)	.20	-
In-home	1 (1.8)	2 (1.8)	.99	-
Other	3 (5.4)	0	.01	N/A*
None	37 (66.1)	0	-	-
Health services involved:				
GP	25 (44.6)	39 (35.1)	.23	-
Hospital	19 (33.9)	29 (26.1)	.29	-
Community	6 (10.7)	21 (18.9)	.17	-
Other medical	4 (7.1)	14 (12.6)	.28	-
Other	8 (14.3)	14 (12.6)	.76	-
Informal supports involved:				
PSOA	41 (73.2)	87 (78.4)	.46	-
Family	20 (35.7)	41 (36.9)	.88	-
Friends	1 (1.8)	4 (3.6)	.52	-
Neighbour	0	0	-	-
Person lives with PSOA	40 (71.4)	91 (82.0)	.12	-
Person lives in own home	32 (72.7)	72 (73.5)	.93	-
PSOA gender:			.55	-
Female	30 (53.6)	62 (55.9)		
Male	23 (41.1)	46 (41.4)		
Other	1 (1.8)	0		
Unknown	2 (3.6)	3 (2.7)		
PSOA relationship:				
Partner/spouse	9 (16.1)	25 (22.5)	.33	-
Relative	43 (76.8)	80 (72.1)	.51	-

	Person not receiving disability services n (%)	**Person receiving disability services n (%)**	***p*-value**	**aOR (95% CI)**
Child	6 (10.7)	1 (0.9)	<.01	N/A*
Parent	25 (44.6)	62 (55.9)	.17	-
Sibling	9 (16.1)	12 (10.8)	.33	-
PSOA primary carer	33 (58.9)	86 (77.5)	.01	2.10 (0.78-5.65)
Type of neglect:				
Failure to meet support needs	35 (62.5)	76 (68.5)	.44	-
Medical care	21 (37.5)	39 (35.1)	.76	-
Clothing/food	11 (19.6)	16 (14.4)	.39	-
Failure to provide necessities of life	5 (8.9)	4 (3.6)	.15	-
Factors contributing to issues/allegations:				
PSOA preventing access to services	26 (46.4)	50 (54.1)	.35	-
Carer stress	15 (26.8)	65 (58.6)	<.001	4.61 (1.55-13.68)
Current/historical abuse	16 (28.6)	52 (46.8)	.02	3.68 (1.19-11.40)
Health literacy	6 (10.7)	18 (16.2)	.34	-
Delay in service access	5 (8.9)	10 (9.0)	.99	-
Risk factors:				
Dementia	0	2 (1.8)	.31	-
Chronic health issues	17 (30.9)	42 (38.2)	.36	-
History of family dysfunction	14 (25.5)	32 (29.1)	.62	-
Social isolation	20 (36.4)	9 (8.2)	<.001	0.04 (0.01-0.18)
Mental health	13 (23.6)	14 (12.7)	.07	0.76 (0.18-3.13)
History of domestic violence	14 (25.5)	14 (12.7)	.04	0.10 (0.02-0.42)
Squalor and/or hoarding	12 (21.8)	12 (10.9)	.06	1.24 (0.27-5.64)
Self-neglect	8 (14.5)	6 (5.5)	.05	0.50 (0.09-2.92)
Factors affecting the response:				
Person's views/wishes	24 (42.9)	44 (39.6)	.80	-
Parties did not realise severity	12 (21.4)	31 (27.9)	.66	-
Recent hospital/medical contact	3 (5.4)	10 (9.0)	.10	-
PSOA did not know what to do	3 (5.4)	16 (14.4)	.21	-
PSOA refused help/refused to act	10 (17.9)	34 (30.6)	.13	-
Serious neglect	28 (50.0)	29 (26.1)	<.01	0.76 (0.28-2.03)

* N/A indicates variable was excluded from multivariable analysis

Table 27. Comparison of cases involving Person receiving aged care services vs. older Person not receiving aged care services (CSI cases only)

	Person not receiving aged care services n (%)	Person receiving aged care services n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	79.2 (9.8)	82.9 (8.6)	<.01	1.05 (1.01-1.08)
Person gender:			.40	-
Female	128 (66.7)	82 (71.3)		
Male	64 (33.3)	33 (28.7)		
Area of residence:			.52	-
Metropolitan	86 (45.3)	55 (49.1)		
Regional	104 (54.7)	57 (50.9)		
Aboriginal	12 (6.3)	7 (6.1)	.95	-
Language other than English	34 (17.7)	21 (18.3)	.90	-
Person receiving community services	54 (28.1)	80 (69.6)	<.001	5.45 (3.01-9.88)
Person condition:			<.01	0.69 (0.46-1.02)
Needs not met	27 (14.7)	24 (21.6)		
Signs of neglect	98 (53.3)	69 (62.2)		
Poor	35 (19.0)	14 (12.6)		
Very unwell	14 (7.6)	1 (0.9)		
Critically unwell	10 (5.4)	3 (2.7)		
Person functioning:			.64	-
No limitation	20 (11.5)	10 (9.3)		
Core activity limitation	43 (24.7)	31 (28.7)		
Mild limitation	5 (2.9)	2 (1.9)		
Moderate limitation	8 (4.6)	5 (4.6)		
Severe limitation	25 (14.4)	21 (19.4)		
Profound limitation	73 (42.0)	39 (36.1)		
Person health needs:			.60	-
No chronic/terminal condition	27 (14.1)	19 (16.5)		
1-2 chronic health conditions	121 (63.0)	74 (64.3)		
3-4 chronic health conditions	15 (7.8)	10 (8.7)		
5+ chronic health conditions	3 (1.6)	0		
Terminal condition	5 (2.6)	1 (0.9)		
Not known	21 (10.9)	11 (9.6)		
Person isolated	96 (50.0)	47 (40.9)	.12	-
Concerns about Person's decision-making capacity:			.79	-
No/Unknown	94 (49.0)	52 (45.2)		
Suspected				

	Person not receiving aged care services n (%)	Person receiving aged care services n (%)	*p*-value	aOR (95% CI)
Yes	11 (5.7)	8 (7.0)		
	87 (45.3)	55 (47.8)		
Disability:				
None	67 (34.9)	39 (33.9)	.86	-
Neurological	86 (44.8)	53 (46.1)	.83	-
Physical	35 (18.2)	19 (16.5)	.70	-
Intellectual	4 (2.1)	3 (2.6)	.77	-
Mental health	15 (7.8)	7 (6.1)	.57	-
Other cognitive	11 (5.7)	8 (7.0)	.67	-
Autism	0	0	-	-
Sensory	6 (3.1)	8 (7.0)	.12	-
Formal services involved:				
Disability (any)	25 (13.0)	3 (2.6)	<.01	N/A*
In-home	20 (10.4)	3 (2.6)	.01	N/A*
Other	6 (3.1)	0	.06	N/A*
Aged care (any)	0	115 (100)	-	N/A*
In-home	0	98 (85.2)	<.001	N/A*
Other	0	23 (20.0)	<.001	N/A*
None	139 (72.4)	0	<.001	N/A*
Health services involved:				
GP	88 (45.8)	54 (47.0)	.85	-
Hospital	83 (43.2)	44 (38.3)	.39	-
Community	34 (17.7)	23 (20.0)	.62	-
Other medical	15 (7.8)	11 (9.6)	.59	-
Other	14 (7.3)	10 (8.7)	.66	-
Informal supports involved:				
PSOA	157 (81.8)	101 (87.8)	.16	-
Family	89 (46.4)	47 (40.9)	.35	-
Friends	10 (5.2)	5 (4.3)	.74	-
Neighbour	18 (9.4)	8 (7.0)	.46	-
Person lives with PSOA	143 (74.9)	85 (73.9)	.85	-
Person lives in own home	129 (75.0)	72 (75.8)	.89	-
PSOA gender:			.29	-
Female	74 (38.5)	50 (43.5)		
Male	109 (56.8)	64 (55.7)		
Other	1 (0.5)	0		
Unknown	8 (4.2)	1 (0.9)		
PSOA relationship:				
Partner/spouse	44 (22.9)	23 (20.0)	.55	-

	Person not receiving aged care services **n (%)**	**Person receiving aged care services** **n (%)**	***p*-value**	**aOR (95% CI)**
Relative	128 (66.7)	81 (70.4)	.49	-
Child	117 (60.9)	72 (62.6)	.77	-
Parent	1 (0.5)	0	.44	-
Sibling	5 (2.6)	6 (5.2)	.23	-
PSOA primary carer	132 (68.8)	84 (73.0)	.43	-
Type of neglect:				
Failure to meet support needs	145 (75.5)	88 (76.5)	.84	-
Medical care	62 (32.3)	33 (28.7)	.51	-
Clothing/food	36 (18.8)	16 (13.9)	.27	-
Failure to provide necessities of life	21 (10.9)	6 (5.2)	.09	0.46 (0.11-1.92)
Factors contributing to issues/allegations:				
PSOA preventing access to services	101 (52.6)	54 (47.0)	.34	-
Carer stress	62 (32.3)	51 (44.3)	.03	1.46 (0.80-2.67)
Current/historical abuse	73 (38.0)	37 (32.2)	.30	-
Health literacy	20 (10.4)	18 (15.7)	.18	-
Delay in service access	18 (9.4)	10 (8.7)	.84	-
Risk factors:				
Dementia	59 (30.7)	40 (35.1)	.43	-
Chronic health issues	47 (24.5)	33 (28.9)	.39	-
History of family dysfunction	43 (22.4)	18 (15.8)	.16	-
Social isolation	35 (18.2)	8 (7.0)	<.01	0.33 (0.12-0.88)
Mental health	20 (10.4)	9 (7.9)	.47	-
History of domestic violence	17 (8.9)	11 (9.6)	.82	-
Squalor and/or hoarding	25 (13.0)	7 (6.1)	.06	0.62 (0.19-2.02)
Self-neglect	16 (8.3)	3 (2.6)	.05	0.58 (0.11-3.24)
Factors affecting the response:				
Person's views/wishes	105 (54.7)	44 (38.3)	.02	0.48 (0.27-0.88)
Parties did not realise severity	38 (19.8)	21 (18.3)	.66	-
Recent hospital/medical contact	10 (9.9)	10 (8.7)	.01	0.87 (0.31-2.41)
PSOA did not know what to do	23 (12.0)	13 (11.3)	.70	-
PSOA refused help/refused to act	38 (19.8)	28 (24.3)	.44	-
Serious neglect	87 (45.3)	37 (32.2)	.02	1.04 (0.54-2.01)

* N/A indicates variable was excluded from multivariable analysis

Table 28. Comparison of cases where health services considered neglect vs. where health services did not consider neglect

	Health services did not consider neglect n (%)	Health services did consider neglect n (%)	*p*-value	aOR (95% CI)
Age: Mean (SD)	65.4 (23.1)	76.2 (15.4)	<.001	0.99 (0.96-1.03)
Person gender:			.21	-
Female	78 (58.6)	48 (67.6)		
Male	55 (41.4)	23 (32.4)		
Area of residence:			.99	-
Metropolitan	56 (43.8)	31 (43.7)		
Regional	72 (56.3)	40 (56.3)		
Aboriginal	8 (6.0)	2 (2.8)	.31	-
Language other than English	17 (12.8)	18 (25.4)	.02	2.23 (0.90-5.53)
Person receiving community services	72 (54.1)	33 (46.5)	.30	-
Person condition:			<.01	1.21 (0.82-1.78)
Needs not met	31 (24.2)	7 (10.1)		
Signs of neglect	54 (42.2)	29 (42.0)		
Poor	27 (21.1)	12 (17.4)		
Very unwell	9 (7.0)	10 (14.5)		
Critically unwell	7 (5.5)	11 (15.9)		
Person functioning:			.02	1.22 (1.01-1.46)
No limitation	17 (13.5)	4 (5.9)		
Core activity limitation	14 (11.1)	9 (13.2)		
Mild limitation	4 (3.2)	1 (1.5)		
Moderate limitation	10 (7.9)	1 (1.50		
Severe limitation	33 (26.2)	16 (23.5)		
Profound limitation	48 (38.1)	37 (54.4)		
Person health needs:			.34	-
No chronic/terminal condition	23 (17.3)	11 (15.5)		
1-2 chronic health conditions	72 (54.1)	39 (54.9)		
3-4 chronic health conditions	15 (11.3)	7 (9.9)		
5+ chronic health conditions	1 (0.8)	2 (2.8)		
Terminal condition	5 (3.8)	5 (7.0)		
Not known	17 (12.8)	7 (9.9)		
Person isolated	66 (49.6)	42 (59.2)	.19	-
Concerns about Person's decision-making capacity:			.23	-
No/Unknown	58 (43.6)	29 (40.8)		
Suspected				

	Health services did not consider neglect n (%)	Health services did consider neglect n (%)	*p*-value	aOR (95% CI)
Yes	4 (3.0)	6 (8.5)		
	71 (53.4)	36 (50.7)		
Disability:				
None	28 (21.1)	22 (31.0)	.12	-
Neurological	57 (42.9)	31 (43.7)	.91	-
Physical	35 (26.3)	15 (21.1)	.41	-
Intellectual	23 (17.3)	4 (5.6)	.02	0.81 (0.15-4.36)
Mental health	19 (14.3)	2 (2.8)	.01	0.14 (0.01-1.44)
Other cognitive	11 (8.3)	5 (7.0)	.76	-
Autism	7 (5.3)	0	.05	N/A*
Sensory	6 (4.5)	4 (5.6)	.72	-
Formal services involved:				
Disability (any)	45 (33.8)	8 (11.3)	<.001	0.22 (0.06-0.89)
In-home	30 (22.6)	7 (9.9)	.03	N/A*
Other	21 (15.8)	2 (2.8)	<.01	N/A*
Aged care (any)	31 (23.3)	21 (29.6)	.33	-
In-home	26 (19.5)	17 (23.9)	.46	-
Other	8 (6.0)	5 (7.0)	.78	-
None	46 (34.6)	39 (54.9)	<.01	0.57 (0.23-1.41)
Health services involved:				
GP	69 (51.9)	34 (47.9)	.59	-
Hospital	62 (46.6)	34 (47.9)	.86	-
Community	26 (19.5)	16 (22.5)	.62	-
Other medical	20 (15.0)	4 (5.6)	.05	0.25 (0.05-1.16)
Other	16 (12.0)	4 (5.6)	.14	-
Informal supports involved:				
PSOA	111 (83.5)	59 (83.1)	.95	-
Family	49 (36.8)	28 (39.4)	.72	-
Friends	3 (2.3)	1 (1.4)	.68	-
Neighbour	7 (5.3)	4 (5.6)	.91	-
Person lives with PSOA	106 (79.7)	54 (76.1)	.55	-
Person lives in own home	88 (76.5)	42 (71.2)	.44	-
PSOA gender:			.68	-
Female	55 (41.4)	29 (40.8)		
Male	72 (54.1)	41 (57.7)		
Other	1 (0.8)	0		
Unknown	5 (3.8)	1 (1.4)		
PSOA relationship:				
Partner/spouse	30 (22.6)	26 (36.6)	.03	4.29 (1.03-17.88)

	Health services did not consider neglect n (%)	**Health services did consider neglect n (%)**	***p*-value**	**aOR (95% CI)**
Relative	93 (69.9)	43 (60.6)	.18	-
Child	56 (42.1)	39 (54.9)	.08	2.55 (0.65-10.03)
Parent	25 (18.8)	2 (2.8)	<.01	0.41 (0.04-3.93)
Sibling	6 (4.5)	1 (1.4)	.25	-
PSOA primary carer	98 (73.7)	54 (76.1)	.71	-
Type of neglect:				
Failure to meet support needs	98 (73.7)	48 (67.6)	.36	-
Medical care	52 (39.1)	30 (42.3)	.66	-
Clothing/food	25 (18.8)	10 (14.1)	.40	-
Failure to provide necessities of life	8 (6.0)	11 (15.5)	.03	
Factors contributing to issues/allegations:				
PSOA preventing access to services	81 (60.9)	39 (54.9)	.41	-
Carer stress	62 (46.6)	24 (33.8)	.08	0.66 (0.30-1.45)
Current/historical abuse	48 (36.1)	27 (38.0)	.79	-
Health literacy	24 (18.0)	12 (16.9)	.84	-
Delay in service access	15 (11.3)	10 (14.1)	.56	-
Risk factors:				
Dementia	25 (18.9)	17 (23.9)	.40	-
Chronic health issues	49 (37.1)	22 (31.0)	.38	-
History of family dysfunction	27 (20.5)	11 (15.5)	.39	-
Social isolation	19 (14.4)	14 (19.7)	.33	-
Mental health	18 (13.6)	3 (4.2)	.04	0.42 (0.04-4.66)
History of domestic violence	17 (12.9)	7 (9.9)	.53	-
Squalor and/or hoarding	19 (14.4)	10 (14.1)	.95	-
Self-neglect	8 (6.1)	3 (4.2)	.58	-
Factors affecting the response:				
Person’s views/wishes	63 (47.4)	33 (46.5)	.28	-
Parties did not realise severity	41 (30.8)	24 (33.8)	.78	-
Recent hospital/medical contact	21 (15.8)	13 (18.3)	.87	-
PSOA did not know what to do	21 (15.8)	16 (22.5)	.19	-
PSOA refused help/refused to act	36 (27.1)	26 (36.6)	.15	-
Serious neglect	53 (39.8)	43 (60.6)	<.01	2.14 (0.85-5.36)

* N/A indicates variable was excluded from multivariable analysis