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Speech Pathology Australia

Speech Pathology Australia's Submission to the Australian Law Reform Commission

Elder Abuse Issues Paper

1 September 2016

The Speech Pathology Association of Australia Limited
ABN 17 008 393 440

The Australian Law Commission
GPO Box 3708
Sydney NSW 2001

Dear Commission staff,

Speech Pathology Australia is pleased to provide feedback on the Elder Abuse Issues Paper.Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing more than 7,000 members. Speech pathologists are the university trained allied health professionals with expertise in treating communication and swallowing difficulties (dysphagia). Speech Pathology Australia does not directly advocate on behalf of individual with communication difficulties; however our members have a significant role in supporting consumers to exercise their rights by supporting their communication access.

While communication problems affect people across the lifespan, the prevalence and complexity of these disorders increases with age. The body's natural ageing process can impact on memory, processing speed, voice, hearing, language, and speech processes. Furthermore, many common aged related conditions such as stroke, dementia, and Parkinson's disease have a high prevalence of communication problems.

Communication difficulties can have a direct negative effect on a person's adaptation to the ageing process, ability to make life decisions (including acting on these decisions), and to access and utilise basic human services including medical care. Evidence indicates that individuals with lifelong and acquired communication difficulties are a vulnerable group and can experience an imbalance in the power relationship with those who provide them with support. The nature of communication disability exposes individuals to a higher potential for abuse, neglect and ill-treatment.

Communication difficulties may negatively impact on an individual's ability to voice their concerns, to self-advocate, and to disclose/report harm done to them by another. As such, Speech Pathology Australia strongly supports the need for legal reform and a national safeguarding framework that is equipped to protect older adults with communication, swallowing and mealtime related disabilities. The Framework must have adequate provisions and safeguards in place to address the barriers that people with communication difficulties face in navigating the aged care system and successfully engaging with complaints and reporting processes processes.

Our submission begins with an overview of the communication, swallowing and mealtime difficulties that may be encountered by older people and the role that speech pathologists have with this group of Australians. We then provide comments in relation to selected questions included in the Issues Paper. Where appropriate we have made explicit recommendations regarding legal frameworks and safeguards.

Please contact Dr Jade Cartwright, Aged Care Advisor at the Speech Pathology Australia National Office on 03 9642 4899 or via agedcare@speechpathologyaustralia.org.au if you require further information or assistance.

Yours faithfully,

Gaenor Dixon
National President

Speech Pathology Australia's Submission to the Australian Law Reform Commission's Elder Abuse Issues Paper

Introduction

Speech Pathology Australia welcomes the opportunity to provide comment on the Australian Law Reform Commission's Elder Abuse Issues Paper.

Speech pathologists are university trained allied health practitioners with expertise in the assessment and treatment of communication and/or swallowing difficulties (dysphagia). Speech Pathology Australia is the peak professional body representing speech pathologists in Australia. At present, Speech Pathology Australia provides professional support services to over 7000 speech pathologists in Australia. Provision of services for older Australians living with communication and /or swallowing difficulties is a core area of professional practice for speech pathologists. Speech Pathology Australia employs a National Aged Care Advisor to provide support for our members working with older Australians. We also convene an Aged Care Advisory Group consisting of members who are recognised leaders in our profession within aged care. The expertise of these members has been drawn on in preparing this submission.

Elder abuse is recognised internationally as a pervasive and growing public health and human rights problem that requires the attention of all health professionals who provide services to older people.[iv] The issue of elder abuse has received little national attention and concern to date. Ageism contributes to the lack of federal policy and public debate, with negative attitudes and stigma resulting in unacceptable levels of apathy towards the mistreatment of older people[i].

Speech Pathology Australia welcomes any legal and policy reform that upholds communication as a basic human right, and seeks to safeguard and protect older persons from mistreatment or abuse by formal and informal carers, supporters, representatives and others. Speech Pathology Australia is particularly interested in Commonwealth laws and frameworks that safeguard and protect older persons with communication, swallowing and/or mealtime difficulties.

About older people with communication and swallowing difficulties

Communication problems encompass difficulties with speech (producing spoken language), understanding or using language, voice, fluency (stuttering), and pragmatics (the social use of language), or a combination of areas. Swallowing problems (dysphagia) affect the ability to safely swallow food or liquids and can lead to medical complications including malnutrition, chest infections/pneumonia and death. Difficulties in communication and swallowing can occur in isolation or a person may have difficulties in more than one area. For example, following a stroke a person may have speech, expressive and/or receptive language, and swallowing difficulties.

Communication and swallowing difficulties can arise from a range of conditions and may be present from birth (e.g., cleft palate, Down Syndrome or Autism Spectrum Disorder), emerge during early childhood (e.g., stuttering, severe speech sound disorder), or during adult years (e.g., traumatic brain injury, stroke and head/neck cancers, dementia, Alzheimer's disease, Parkinson's disease, other neurodegenerative diseases).

While communication difficulties affect people across the lifespan, the prevalence and complexity of these disorders increase with age. Both communication and swallowing functions are vulnerable to the natural ageing process. Changes in anatomy, physiology, sensory and motor functioning can lead to reduced function and increased risk in relation to eating and drinking safely. Similarly, the body's natural ageing process can impact on memory, processing speed, voice, hearing, and speech processes which can have an effect on how effectively the older person can communicate. Even subtle age-related changes in communication skills such as voice have been demonstrated to have a significant impact on a person's everyday life and social participation.

There is of course the added possibility of disease or disorder in older Australians, and many common age related conditions including stroke, dementia and Parkinson's disease have a high prevalence of communication, swallowing and mealtime difficulties associated with them. The communication, swallowing and mealtime difficulties associated with ageing vary significantly in type and severity.

The prevalence of communication and swallowing difficulties in older people in Australia is unknown due to the absence of a national mechanism for data collection and monitoring. Health Workforce Australia in its recent report on the speech pathology workforce noted that despite the number of potential data sources that exist, each has substantial limitations in providing a complete picture of demand for speech pathology services in Australia[ii].

Incidence and prevalence figures for both communication and swallowing problems in older people are commonly related to specific disorders/diseases. For example, the vast majority of people living with dementia will experience some form of communication difficulty ranging from trouble retrieving words, to problems keeping track in a conversation, and to the complete loss of communication in the later stages of the condition.

Older people with communication difficulties are vulnerable to all types of abuse, including financial, psychological, physical, sexual, and chemical abuse. Individuals living with communication difficulties face many barriers in society that are discriminatory including negative attitudes and stigma, and limited access to information within supported and accessible communication environments. This may result in difficulties participating in discussions or processes where elder abuse may be identified and acted on. Protections are required to remove such barriers in order to support and empower older people with communication difficulties to describe their experiences, express their preferences and values, and to make official complaints. Policies and laws should be designed with the involvement of people living with communication difficulties with a focus on enabling participation in all aspects of society.

In some cases, the abuse or mistreatment of older people with communication difficulties may be unintentional, due to the general lack of understanding and awareness of communication disorders and support needs. OIder people with communication difficulties are at heightened risk of social isolation and neglect, with implications for an individual's health and wellbeing.

Older people with communication difficulties must be afforded the opportunity and tailored communication supports to participate in medical, lifestyle and financial decisions, including specific supports that may be required by an individual to make a complaint. Negative stereotypes and misconceptions persist in the community that communication impairment is synonymous with loss or competence and autonomy, with such stigma resulting in violations of human rights.

Swallowing disorders affect the ability to safely swallow food or liquids and can lead to medical complications including chest infections/pneumonia. Swallowing difficulties impact on a person's health and well-being and often lead to poor nutrition, health complications and social isolation. Swallowing is a critical bodily function and swallowing complications (dysphagia) can lead to malnutrition, respiratory problems and in some circumstances, death. People with swallowing difficulties may require mealtime support (where they are assisted to swallow safely). Neglecting to provide such support is in the view of Speech Pathology Australia, a form of neglect and places the person at significant risk of increased morbidity (through inadequate nutrition, acute aspiration of fluid or food into the lungs leading to medical complications and potentially death through choking).

Speech pathology and aged care

Speech pathologists, as experts in the assessment, diagnosis, and treatment of communication and mealtime support needs (for those with swallowing problems) are essential members of the multi-disciplinary healthcare team providing services to older people.

Speech pathologists can provide identification of disease/disorder, assessment, intervention, counselling/support of families and caregivers, education of other professionals, case management, consultation, and advocacy. Speech pathologists have an important role to play in promoting healthy ageing and minimizing the social, emotional and economic costs associated with communication disability and swallowing disorders. Speech pathologists also provide valuable contributions to the assessment of decision making capacity and the facilitation of supported decision making for older people with communication support needs. This includes developing communication accessible health information and decision making procedures and protocols.

Speech pathologists provide services in the acute care (hospitals), sub-acute care, rehabilitation and primary care sector (including community health and general practice) as well as within other sectors such as disability, residential and community based aged care, education, juvenile justice, and community settings. We work across public and privately funded services.

A small, but significant proportion of speech pathologists in Australia work in the aged care sector: 1,790 Speech Pathology Australia members identify as working with adults aged 65 years or older. This is approximately 24.8% of the current Speech Pathology Australia membership.

To date speech pathology is not an included profession in the National Registration and Accreditation Scheme (NRAS). Subsequently, Speech Pathology Australia maintains robust self-regulation of its members mirroring that required by NRAS in relation to monitoring and systematic self-regulation mechanisms for quality and safety in the delivery of health care by practitioners. This includes responsibilities for developing and maintaining the clinical, educational and ethical standards that promote high quality and safe speech pathology care.

There are no formally recognised/credentialed areas of specialty within the speech pathology profession in Australia. New graduate speech pathologists enter the workforce with a minimum level of skills that equip them to commence working with the full range of ages and speech pathology client groups. It is recognised within the profession, however, that there are a number of client groups (e.g. older people) and a number of speech pathology services (e.g. palliative care) that benefit from further skills and competencies. Practitioners tend to work within areas of special interest. Consequently, our Association has a range of special interest groups in relation to specific areas of practice or clinical interests. There is an active Ageing and Aged Care online network as well as a number of state based special interest groups, whereby members share information regarding topics relevant to speech pathology in aged care.

Response to Issues Paper Questions

Question 1: To what extent should the following elements, or any others, be taken into account in describing or defining elder abuse?

Elder abuse is associated with distress and increased mortality in older people and caregiver morbidity[iii]. A large longitudinal study of older people found that those who were mistreated were 3.1 times more likely to die during a 3-year period than older people who do not experience abuse[iv]. Elder abuse is also associated with other adverse consequences ranging from depression through to premature transition into residential aged care. Elder abuse is recognised as a growing problem given the ageing population and rising prevalence of conditions like dementia. As a result, there will be increasing obligations for governments and the judicial system to respond to detection and assessment of elder abuse.

Describing elder abuse is inherently challenging, with widely varying and sometimes poorly constructed definitions of elder abuse used in the literature[iv]. The World Health Organization (WHO) defines elder abuse as “a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person”[v]. It is important to recognise that elder abuse can take various forms (i.e. physical, psychological, emotional, sexual and financial abuse) and can be the result of intentional or unintentional neglect[v].

Speech Pathology Australia supports a broad description of elder abuse, taking into account mistreatment and neglect. The description should cover the full spectrum of elder abuse and not just the most severe cases. The description should acknowledge the complex, multi-factorial nature of elder abuse and consider the different risk-factors associated with elder abuse. The WHO has further emphasised the need for definitions of elder abuse to be placed within a cultural context[v].

Withholding access to health services (including speech pathology) should be included in definitions of elder abuse as a form of mistreatment and neglect.

While prevalence data is limited, the description of elder abuse should emphasise the significant and growing scale of the problem. This should acknowledge that elder abuse can no longer be ignored or underestimated, rather elevated to a public health priority, particularly given the expected rise in incidence and prevalence as a result of Australia’s ageing population.

A number of different risk-factors for abuse in community-dwelling older adults have been identified[vi]. Risk factors relate to the older person (e.g. cognitive impairment, behavioural problems, psychological problems, functional dependency, frailty, low income), perpetrator (e.g. caregiver burden or stress, psychiatric illness or psychological problems), relationship (e.g. family disharmony), and environment (e.g. low social support, living with others). Culturally specific risk factors also need to be considered and understood. Importantly, the risk factors that have been identified are also recognised as potential barriers to the detection of abuse[vii]. While the aetiology of elder abuse is typically multi-factorial, not all patients who experience abuse readily demonstrate or express risk factors and many patients with risk factors are not mistreated[vii]. This complexity contributes to poor detection of elder abuse[vii].

The description of elder abuse should consider certain sub-populations suggested to have higher risk of abuse, such as people with dementia, where cognitive and communication difficulties often co-occur with behaviours of concern that limit a person's participation, undermine their rights, and pose a risk to the health and safety of the individual and their carers[viii]. The type of abuse is thought to vary depending on the stage of dementia, with greater risk of financial exploitation in the early stages of dementia and greater risk of physical abuse and/or neglect in the more advanced stages as the individual becomes increasingly dependent on others[ix].

Speech Pathology Australia advocates for recognition of communication difficulties as a critical risk factor when considering the vulnerability for abuse and/or human rights violations. Older people with communication difficulties are inherently vulnerable to all types of abuse due to the mere fact that they are often unable to raise concerns or seek assistance. All people with communication difficulties should be considered as vulnerable witnesses as their ability to provide testimony, make statements, comprehend instructions, and understand the processes and language of the justice system are compromised.

It is known that people with communication disability are at increased risk of experiencing adverse and undesirable events in hospital settings. Such events are distressing to individuals and family members. It has been recommended that hospital policies acknowledge the important role that spouses and family members have with patients with communication difficulties and the need for communication friendly environments in order to prevent and manage adverse events in this cohort of patients[xi].

The presence of communication difficulties increases the likelihood of behaviours of concern, as a means of communicating emotional status and basic wants and needs. Such behaviours can cause stress and distress for carers, increasing the risk of physical or chemical restraints being used to assist with care. Furthermore, communication difficulties are associated with social isolation and poor social function, which are also recognised risk factors for elder abuse. Social isolation may further exacerbate family and carer stress. Relationship and environmental factors are associated with the highest odds ratios, highlighting the importance of socio-cultural aspects of elder abuse[ix]. This should be considered in definitions of elder abuse, emphasising the importance of helping individuals to develop or maintain strong bonds with community to provide emotional, social and practical supports to help protect against abuse.

When describing types of abuse, mistreatment or neglect of older persons, Speech Pathology Australia recommends specific consideration of swallowing and/or mealtime support needs. Elder abuse includes failure of a carer to satisfy an older person's basic needs or to protect them from harm. This applies to older adults with swallowing and/or mealtime difficulties, in particular those who are dependent on feeding assistance to eat and drink, to prepare appropriate texture modified meals, and to maintain nutrition and hydration needs. Dehydration, malnutrition, and medically unexplained weight loss are recognised as signs and symptoms of possible elder abuse or neglect[vii]. It should be noted however that clinical indicators like weight loss are commonly associated with chronic disease in older people making it difficult to determine whether this is due to illness or the intentional withholding of food, medicine, or care[iv].

Speech Pathology Australia highlights that choking is a leading cause of premature death[x] in residential aged care settings demonstrating that older people with significant swallowing difficulties and/or feeding dependency should be recognised as a vulnerable clinical population where specific protections and safeguards are required.

Failure to seek appropriate clinical advice from a speech pathologist for an older person with a swallowing difficulty should be considered a form of neglect.

Question 2: What are the key elements of best practice legal responses to elder abuse?

The best practice approach to addressing elder abuse must be multi-faceted and focus on protecting the rights of all older persons. Specific safeguards should be considered for older people with communication difficulties to minimise the risk of mistreatment and neglect. This should recognise communication as a basic human right and address the inherent barriers that communication difficulties present to legal processes. Legislation requires a principle of "appropriate communications", mandating use of necessary and appropriate modifications and adjustments to ensure that older people with communication difficulties have equal access to information and legal processes.

It has been recommended in the literature that cognitive (and communication) impairment should be screened for before investigating for abuse in older people and determining the most appropriate course of action[vii]. Comprehensive cognitive and communication assessment may be required to determine decision making capacity. Where individuals have capacity to make decisions independently or with tailored support their right to decline intervention or action in response to identified abuse should be respected- however consideration should also be given to the vulnerability of older people relying on family and carers and the effect of this relationship on their ability to report abuse, unrelated to their legal capacity to do so. It should be noted, that the Aged Care Act has compulsory reporting provisions requiring services to report suspicions or allegations of assaults to local police and the Department. This legal requirement ensures that those affected receive timely help and that organisational and operational strategies are put in place that prevent recurrence. Reportable assaults include unreasonable use of force and unlawful sexual contact. Individuals can make reports direct to the police and the Act has protections for those who make the report.

Speech Pathology Australia highlights that current complaints processes are communication rich/heavy, relying on commitment by and capacity of the person to raise concerns, often at a crisis point. For this reason, individuals with communication difficulties face profound challenges raising concerns and engaging with complaints processes.

Speech Pathology Australia calls for greater consideration of 'soft-entry' points into the elder abuse investigation and legal processes. This must include accessible and appropriately supported feedback and complaints mechanisms and greater consumer engagement in the design and evaluation of care services.

Individualised strategies are required to help older people and their family to reduce the risk of harm, through mechanisms such as advocates, guardians, and decision making support persons. Robust internal complaints processes are critical for ensuring that protections are in place within aged care organisations, as well as quality frameworks, mechanisms for staff supervision, and professional development and mentoring.

There has been a call for comprehensive, systematic, coordinated, multi-level advocacy and policy efforts to address elder abuse in legislation[xi]. Routine collection of robust national level data is required covering the abuse, neglect and mistreatment of vulnerable older people. This would provide an opportunity to learn lessons to prevent abuse and to enhance the rights of vulnerable groups, such as older people with dementia. It has also been recommended in the literature that complaints systems and advocacy groups have important roles to play in collecting meaningful evidence from witnesses or survivors. Crime related data may also be used to indicate which older people are at risk but also what might constitute effective protective factors[viii].

Question 3: The ALRC is interested in hearing examples of elder abuse to provide illustrative case studies, including those concerning: people with a disability

Speech Pathology Australia would like to share the details of a case study received from a practicing member of the Association to highlight the human rights violations that can be experienced by older people with communication difficulties.

The case concerns a 77 year-old-lady with a diagnosis of primary progressive aphasia, a type of frontotemporal dementia that directly targets the language areas of the brain. The client was referred by her Neurologist to a private speech pathologist for assessment and ongoing treatment. The client presented with marked expressive (spoken) language difficulties however her ability to understand information was largely preserved. Assessment indicated that she had retained the ability to make decisions and express her preferences when appropriate assistance was provided to enable verbal expression (e.g. written choices, multiple choice options, picture supports, and additional time to formulate and produce a spoken message).

The client's daughter, however, had assumed that her mother's diagnosis of 'dementia' meant that she was no longer capable of making medical, financial or lifestyle decisions. She was actively progressing Guardianship and Power of Attorney applications against the client's wishes – to appoint herself as the client's substitute decision maker. The client reported a complex family history and a strained relationship with her daughter - which was long standing. The client was able to clearly communicate that she did not wish her daughter to make decisions on her behalf and was incredibly angry and distressed about the attempts to undermine her autonomy and control.

The daughter was also pushing for an ACAT assessment to transition her mother into residential aged care or to commence home care support, which the client did not want. This was despite the client clearly coping well at home at that point in time. On each visit the client was immaculately dressed, the house was spotlessly clean, and she was keeping track of appointments via text messaging and use of a calendar.

The client was in a highly vulnerable situation and given her expressive language difficulties was unable to advocate for herself. This was resulting in significant anger outbursts towards her daughter as a means of expression, placing additional strain on their relationship. The client required extensive advocacy support around her retained competence, communication abilities, and rights. She was extremely isolated, living alone, with a complex mental health history. She had another daughter who lived overseas, with limited capacity to provide assistance.

The client presented with a number of risk factors for abuse, mistreatment and neglect, showing how vulnerable individuals with communication difficulties can be - particularly in the community, where access to speech pathology services can be limited and stereotypes relating to dementia, communication and capacity remain.

Speech Pathology Australia would welcome the opportunity to provide the ALRC with further de-identified information about this case and/or other similar scenarios encountered by our members and their clients.

Question 13: What changes should be made to aged care laws and legal frameworks to improve safeguards against elder abuse arising from decisions made on behalf of a care recipient?

Speech Pathology Australia supports the move towards supported decision making as distinct from substitute decision making within legal and policy frameworks. This emphasises that individuals with communication difficulties often retain the capacity to make and communicate decisions about their own life and medical care when provided with appropriate and tailored supports. It is however acknowledged that provision of such supports is often dependent upon comprehensive assessment of an individual's communication support needs. This is essential for promoting, protecting, and ensuring that the rights and freedoms of older people with communication related disability are upheld. Where support people are adequately trained and skilled, individuals with communication difficulties can be empowered to exercise greater choice and control. Reform should focus on identifying strategies to develop the decision making ability of those who may require support so that they become more effective, empowered, and independent decision-makers, despite the presence of cognitive and/or communication difficulties.

There is evidence from the speech pathology literature that there can be problems and risks around ensuring the 'autonomy' of the message for a person with communication difficulties. Familiar communication partners (such as partners, carers or adult children) can deliberately or unwittingly contribute their own messages, based on an assumption that they 'know' what the person is expressing, or that they know what the person wants and/or needs. There is also evidence that people with communication difficulties are vulnerable to being actively and intentionally directed and exploited by

family members and others who are in a 'caring' role. While this occurs in the minority of instances, it is a possibility which needs to be acknowledged, and addressed in systems based strategies and responses to identifying, reporting and investigating elder abuse.

Question 14: What concerns arise in relation to the risk of elder abuse with consumer directed care models? How should safeguards against elder abuse be improved?

Older people with cognitive and communication difficulties are inherently vulnerable to violation of rights under a consumer directed care model. Older people perceive abuse to include deprivation of choices and decisions.

Communication difficulties are one of the greatest barriers to the execution of choice and active participation in decision making and care planning, including development of a support or care plan under a consumer directed care model. Communication difficulties can impact a person's capacity to make decisions, understand the range of choices available to them, and their ability to express their wishes and preferences to their family and the interdisciplinary health care team.

Speech Pathology Australia highlights the important role that communication processes play in determining an individual's decision making capacity. The determination of capacity requires a comprehensive and multi-disciplinary approach to assessment. For example, assessment by a speech pathologist is important for determining whether an individual can understand information relevant to the decision and the effect of the decision. The individual's understanding may be enhanced through provision of tailored communication supports. Without the input of a speech pathologist and tailoring of communication strategies, a person's decision making capacity may be under or overestimated, with direct implications for autonomy, choice and control. It is important to recognise that there will be instances where a person may have capacity to make decisions, however they have lost their capacity to communicate their decisions or preferences. As such, appropriate safeguards and supports for individuals with communication difficulties to make decisions about their care are needed.

It is vitally important that older people with cognitive and communication difficulties have access to tailored communication supports and tools to assist the individual and their carers, guardians or advocates to support decision making and expression of preferences, values and concerns. Older people with cognitive and communication difficulties have the right to be involved in decisions about their care. There should be the requirement for legislation to be consistent with National Decision-Making Principles as in the disability sector. This should ensure that all decisions are made in line with the preferences and values of the older person, adopting a person-centred approach and taking the relevant human rights issues into account.

Regular, independent and impartial monitoring of the enactment of consumer directed care is required, with particular consideration of whether or not older people with cognitive and communication difficulties are being adequately and appropriately supported. Support plans developed under a consumer directed care model should undergo independent auditing or review by a panel of health professionals including speech pathologists.

Speech pathology services play an important role in ensuring provision of tailored communication. The speech pathologist role includes:

- Comprehensive assessment to determine an individual's communication abilities
- Provision of information to other team members about communication support needs
- Identification of appropriate interventions and supports to assist a person to understand their choices and express their preferences for medical treatment and care
- Provision of health care information that is clear, appropriately targeted, and accessible in order for a person and their family to understand the choices available to them and to make informed decisions relating to medical treatment and care.

Older people with communication difficulties retain the right to be included in information and decisions about care, to have access to information presented in easy-to-understand formats, and to have a support person present during consultations (e.g. ward rounds)[xii]. Reform should focus on developing the ability of people with communication difficulties to make decisions and express preferences.

Similar to the frameworks currently used in the NDIS, the aged care legislation should place emphasis on the role of family, carers and others in providing informal support to older people to assist decision making under a consumer directed care model. Specific training and information should be required for those providing informal and formal decision making support to older people with cognitive and/or communication difficulties. An older person should be able to appoint a support person to assist the development of a support plan or to determine care preferences and choices.

Question 15: What changes to the requirements concerning quality of care in aged care should be made to improve safeguards against elder abuse?

In terms of speech pathologists working with older people, there are two important but distinct issues;

1) Protection of older people from sub-standards or unsafe clinical care provided by a speech pathologist
2) The role and support offered by speech pathology expertise in assessing and supporting an older person with communication impairment to report a concern about abuse or neglect.

System level safeguards to protect quality of care include strategies to ensure practitioner registration or credentialing. The legal reform should consider the responsibilities and legal requirements for sub-contractors delivering services to older people to ensure the highest standard and quality of care.

A mechanism for allied health professionals to register as aged care providers is important for regulating the quality of care provided. To provide an illustrative example, speech pathologists are rarely employed directly by aged care organisations in either community or residential aged care settings. Speech pathology services are typically brokered or sub-contracted from private speech pathologists often working as sole providers in small private practices. This raises concerns regarding accreditation and regulation of standards of care. Speech pathologists are not required to be registered through the National Registration and Accreditation Scheme (NRAS). In the absence of national registration, Speech Pathology Australia maintains robust self-regulation of its members. The Certified Practicing Speech Pathologist (CPSP) credential ensures speech pathologists have the credentials and recency of practice to work as a speech pathologist. This credential is accepted by organisations such as all private health funds, Medicare, Department of Veteran Affairs, and the Commonwealth Home Support Programme for aged care, who all require speech pathology providers to be CPSP members of the Association. It is important that speech pathologists are required to have the certified practicing speech pathologists (CPSP) credential to deliver aged care services, equivalent to the protections in place for registered health professions under the NRAS. Accreditation standards for aged care services (that are currently under development by the federal Department of Health) need to cover both employed and sub-contracted clinical staff.

Supervision and mentoring of staff is another important safeguard concerning quality of care, particularly in relation to sub-contracted services. A recent workforce survey of speech pathologists working with older adults indicated that a very small proportion of speech pathologists working in community and residential aged care receive regular supervision or mentoring. This is in part due to the fact that many of these clinicians work in sole positions and private practice, where they are not part of a larger speech pathology department or interprofessional team.

Older people from CALD backgrounds are known to have heightened vulnerabilities to exploitation and abuse. Safeguards are required to ensure that services are culturally appropriate and responsive. With the increasingly diverse ageing population, the need to understand the cultural nuances of elder abuse has been highlighted in the literature as a critical factor for improving the quality of care for older adults[xi].

Question 16: In what ways should the use of restrictive practices in aged care be regulated to improve safeguards against elder abuse?

Significant concerns have been expressed regarding the use of restrictive practices with people with dementia, particularly in the more advanced stages of the condition where challenging behaviours may present as a result of cognitive and communication difficulties. Use of restrictive practices, including the use physical or chemical restraints, restrict the rights or freedom of movement of the individual. The use

of restrictive practices is particularly concerning when imposed as a means of convenience. For example, using pharmacological interventions to make a person with dementia more docile and easier to care for.

Prominent communication difficulties can manifest as challenging or disruptive behaviours that have been associated with increased use of chemical and physical restraints. This has been documented most frequently in relation to people living with dementia. Provision of appropriate individualised communication supports may be one effective safeguard to minimise the risk of such restrictive practices being required. Even in the advanced stages of dementia, decision making and choice can be facilitated through use of communication aids (e.g. Talking Mats), access to trained communication partners, and communication friendly environments. Through providing tailored communication support the incidence of responsive behaviours may be reduced. This requires strategies to ensure better access to speech pathology and interprofessional services in an aged care context. Multi-disciplinary interventions should be recognised as a key strategy for minimising and preventing use of restrictive practices, requiring targeted education and training for relevant staff and volunteers.

A National Quality and Safeguards Framework is required for aged care, with specific protections to reform restrictive practices across community and residential aged care services. A national framework should include data collection and monitoring mechanisms. Specific on-site auditing is recommended in relation to the protections for older people with cognitive and communication difficulties.

Where restrictive practices are required there should be a requirement for clear documentation, monitoring and review to ensure that they are implemented for the least possible period of time and only where they are required to minimise risk to the individual or others.

Question 18: What changes to aged care complaints mechanisms should be made to improve responses to elder abuse?

Speech Pathology Australia understands that in 2013-2014[xiii], 8,288 in scope complaints were investigated by the aged care complaints scheme. While the top issue related to 'health and personal care' (2,714 complaints), the second issue related to 'consultation and communication' (1,156 complaints). This includes issues with internal complaints processes, provision of information, and family consultation. This highlights how central communication processes are to complaints processes and the need for specific safeguards. This includes improved provision of communication supports and accessible information to facilitate complaints processes.

Communication difficulties present a direct barrier to engaging with the complaints process. Older people with cognitive-communication difficulties may not have the communication abilities to provide feedback, raise concerns or make an official complaint. When identifying, investigating, and responding to instances of elder abuse the unique needs of older people with cognitive and communication difficulties must be considered. It is important to recognise that the highest proportion of complaints are made by a representative or family member (35.6%), with only 8.4% of complaints made by a care recipient themselves. This highlights the need for strategies to empower and develop the capacity of older people to engage with feedback and complaints processes. Soft-entry points into the complaints process are required in order to prevent more severe incidents and to promote a proactive approach.

The complaints process should be independent from providers of support. A mechanism should exist so that complaints can be referred onto the relevant professional body if a complaint relates to profession specific standards of practice.

Question 23: Are the safeguards and protections provided under the NDIS a useful model to protect against elder abuse?

The National Disability Insurance Agency (NDIA) is yet to publicly release the national Quality and Safeguarding Framework that will be enacted to build systemic safeguards into the National Disability Insurance Scheme (NDIS). The NDIA has forecast possible options for quality and safeguards in 2015 with a public consultation process and until a national framework is in place, quality and safeguarding arrangements are in place through bilateral agreements between the jurisdictions and commonwealth government. As such, it is difficult to say with any certainty whether the NDIS safeguards and protections

could act as a useful model to consider in terms of the aged care sector and protection of older people from abuse and neglect.

There are a number of 'principles' however espoused in the NDIS Quality and Safeguarding consultation process that are useful to consider in the elder abuse context including Provider Registration and complaints processes

Speech Pathology Australia supports the development of an Aged Care Provider Register, for all individual and organisational providers of supports funded through the Commonwealth Aged Care Funding. In the absence of registration through the NRAS for health professions, Speech Pathology Australia strongly recommends that to be a registered provider of speech pathology interventions under Commonwealth aged care funding, individuals must demonstrate that they have met the standards required by our Association, currently Certified Practising Speech Pathologist.

It is essential that the aged care sector has a robust complaints system that is independent from providers of services. In order to assure procedural fairness and transparency for all parties, Speech Pathology Australia supports the option to have a Commonwealth managed process for responding to complaints regarding services provided under Commonwealth aged care funding.

Question 35: How can the role that health professionals play in identifying and responding to elder abuse be improved?

According to the World Health Organisation, both primary health care and social service sectors need to build the capacity of health professionals to identify and deal with elder abuse as a key strategy for improving detection and response. This calls for widespread evidence-based education on elder abuse. It has been suggested that the best policy at this time seems to be education to raise awareness of elder abuse in clinicians rather than strategies that encourage over-reliance on a specific screening strategy or clinical algorithm. Awareness raising strategies should alert health professionals to the fact that elder abuse is common enough to be encountered readily in daily clinical practice. It has been documented that a busy clinician seeing between 20 and 40 older people per day could encounter at least one clinical or sub-clinical victim of elder abuse daily[iv].

To support identification of elder abuse, it is important that health professionals understand the risk factors associated with elder abuse, while acknowledging that abuse can take place without any of these factors being apparent and that many families with extensive risk factors do not manifest abuse[iv]. Knowledge of risk factors should be understood to enable health professionals to construct a profile of individuals who may be more vulnerable to abuse, mistreatment or neglect and where safeguards and legal frameworks may apply. The need for a multi-disciplinary approach to the identification and assessment of elder abuse is recognised[iv]. All health professionals should be committed to detecting high-risk situations and should be supported by clear legal frameworks to guide selection of the most appropriate response.

One of the challenges facing health professionals in the identification of elder abuse concerns the lack of valid or reliable measures of abuse and/or neglect. Linguistically and culturally specific approaches and vocabulary are required[xiv], challenging the development of a globally/nationally applicable instrument for detecting elder abuse. It has been suggested that health professionals should be provided with a set of questions to serve as a starting point in raising awareness about elder abuse[iv]. Studies have suggested that vulnerable older people and their family carers should be routinely asked about abuse to support detection[xv]. Other studies have cautioned that routine screening for elder abuse may worsen matters in contentious family violence situations. The current evidence has been deemed insufficient to determine the balance of harms and benefits of screening all older or vulnerable adults for abuse and neglect[vii]; however routine inquiry is recommended.

Research suggests that asking people about abuse may be more effective than using observer measures[iii]. Given that this approach is highly dependent upon communication abilities, speech pathologists may play an important role in supporting vulnerable older clients with cognitive and/or communication difficulties to talk about abuse, working closely with other members of the interprofessional health care team. Observer measures are noted to play an important role in detecting serious abuse in non-verbal individuals or in those who are too afraid or unwilling to report it[iii].

Question 36: How should professional codes be improved to clarify the role of health professionals in identifying and responding to elder abuse?

The Speech Pathology Australia Code of Ethics (2010) supports speech pathologists to demonstrate the highest standards of professional integrity and ethical practice[xvi]. The Code of Ethics describes the values of professionalism and respect and care, amongst others, which mandate an obligation for speech pathologists to act in a professional and objective manner at all times within their professional role. This obligation extends to provision of intervention that is in the best interests of the client while respecting the rights and dignity of clients and the context in which they live. The Safety and Welfare Standard of Practice obliges Speech Pathology Australia members to ensure client safety and comply with all relevant legislation.

While the Code of Ethics does not specifically reference identification of and response to elder abuse, the values, principles and standards described within the document bind members of Speech Pathology Australia to providing services as identified and needed by clients, including the identification of and appropriate response to instances of elder abuse. The Speech Pathology Australia Code of Ethics supports robust self-regulation within speech pathology, in that failure to abide by the Code of Ethics can result in ineligibility of membership and sanctions on practice.

A National Code of Conduct for Health Care Workers ('the National Code') was agreed to in 2014 by the Australian Health Minister's Advisory Council, which is to be enacted by states and territories. The National Code provides consistency for definitions of terms and scope of application nationally, as well as containing elements that pertain to prevention of elder abuse, ie. prohibition of financial exploitation or sexual abuse. Speech Pathology Australia considers the National Code to describe a baseline of standards applicable to all health service providers that is well below the standards expected by the speech pathology profession (as described in the Speech Pathology Australia Code of Ethics). To date, full national roll out of the National Code has not been achieved, however Speech Pathology Australia would consider it appropriate for the National Code to include specific reference to the role of health professionals, including allied health specifically, in identification and response to elder abuse.

Question 47: How should victims' services and court processes be improved to support victims of elder abuse?

The justice systems across Australia need to be reformed to make them more accessible, equitable and responsive to the needs of people with disability – in particular, to the needs of older people whose communication difficulties render them less able to participate in the highly verbally mediated legal processes.

Often people with communication difficulties lack the skills to render a consistent or concise account of the events they witnessed or experienced. This means that their stories can be disregarded and viewed as less credible when considered in terms of evidence.

People with communication difficulties will likely pose challenges for police and court officials to interview. The questioning style routinely used in these settings can result in incomplete or inaccurate information.

It is critical that older people with communication impairments who wish to seek legal redress for abuse or neglect are given every opportunity to understand the investigative process and are supported to provide accurate information to the best of their ability.

The recommended way in which older people with communication problems can be supported is through the use of an independent Communication Intermediary.

Communication Intermediary schemes (sometimes called Communication Assistant or Communication Partner schemes) operate in a number of other countries including New Zealand, Canada, South Africa, Israel, England, Wales and Norway.

Whilst schemes differ depending on the legal systems, the best practice examples offer a Communication Intermediary who is an independent, trained person who assists the person to achieve complete, coherent and accurate communication during interaction with the justice system. They do this by

assessing the person's communication capabilities and advising on (among other things) appropriate styles of questioning to be used that are congruent with the person's comprehension and communication capacity.

In Australia, there is growing recognition of the need for Australian judicial systems to support communication impaired people to interact with the justice systems. For example, New South Wales is in the midst of trialling a Communication Intermediary/Children Champion scheme, South Australia is currently defining the parameters of their scheme and the Tasmanian Law Reform Commission is currently investigating a communication assistant/intermediary scheme.

The impetus for these reforms is a growing recognition that people with communication needs have been excluded from obtaining access to justice. This contention has been supported by the work of the Royal Commission into Institutional Responses to Child Sexual Abuse and the recent Senate Inquiry into the sexual abuse and exploitation of people with disabilities in Australia. Also, Australian courts have an obligation within the International Human Rights frameworks set out in Article 12 of the UN *Convention on the Rights of the Child* and article 13 of the UN *Convention on the Rights of Persons with Disabilities* to optimise the circumstances for people with disabilities and children to give their accounts of events and participate in criminal justice processes.

Trained, independent Communication Intermediaries can assist to ameliorate the difficulties older people with communication problems who are the victims of elder abuse will experience when providing accurate and reliable evidence during legal processes.

Significant improvements in helping people with communication difficulties to access the justice systems could also be achieved by:

- The development of communication accessible information about their rights and how to seek justice. This should be written in Easy English – a style which includes simple words, a clear visual layout and key concepts presented in pictorial form.
- Accessible information should include:
    - What to do if a person experiences abuse, harm or mistreatment
    - Who to report such issues to
    - How to report it
    - What happens if a person reports a crime to the police (e.g. Interview by police, making a statement, going to court)
    - The general criminal justice system process
- Pictorial resources to aid comprehension and expression should be available in all police stations

Recommendations

Speech Pathology Australia recommends that the Australian Law Reform Commission consider the following:

1) That legal and policy frameworks for elder abuse recognise that communication and cognitive impairments are an underlying risk factor/vulnerability for abuse and neglect.

2) That legal and policy frameworks for elder abuse recognise that communication and cognitive impairment are *additional* barriers to reporting abuse and neglect through existing complaints systems than those experience by older people without communication problems.

3) That legal and policy frameworks define and encourage 'supported decision making' as distinct from 'substitute decision making' for people with communication difficulties.

4) That mechanisms are establish to support people with communication and cognitive impairment to report abuse and neglect. Legislation requires a principle of "appropriate communications", mandating use of necessary and appropriate modifications and adjustments to ensure that older people with communication difficulties have equal access to information and legal processes.

5) That legal and policy frameworks for elder abuse recognise the withholding of health services as a form of neglect.

6) That legal responses and processes for elder abuse and neglect characterise all older people who are communication impaired as 'vulnerable witnesses' and have appropriate supports in place to enable their effective participation in judicial processes.

7) That 'soft-entry' points into the elder abuse investigation and legal processes are considered, including accessible and appropriately supported feedback and complaints mechanisms and greater consumer engagement in the design and evaluation of care services.

8) That cognitive and communication impairment should be screened for before investigating for abuse in older people.

9) That specific communication competency training and information is mandated for those providing informal and formal decision making support to older people with cognitive and/or communication difficulties.

10) That a National Quality and Safeguards Framework is developed for aged care.

11) That an awareness raising campaign for medical and allied health professionals is developed to support identification of elder abuse.

12) That independent Communication Intermediary Schemes are put in place to support older people who are victims of elder abuse to participate in legal processes.

13) That communication accessible information be developed and provided to older Australians regarding their rights and how to seek justice.

If Speech Pathology Australia can assist in any other way or provide additional information please contact National Office on 03 9642 4899, or contact Jade Cartwright on 03 9642 4899 or by emailing agedcare@speechpathologyaustralia.org.au

Appendix A: Evidence cited in the development of this submission

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