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Adults decision making law review

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We are writing this submission on behalf of the *New Zealand Speech-Language Therapists' Association (NZSTA), which represents the speech-language therapy community in Aotearoa New Zealand.

Our submission draws on the experiences our membership of the New Zealand Speech-Language Therapists' Association have had as speech/language/communication specialist professionals working with clients of all ages in multiple settings. Our members work alongside children, young people and adults who experience a wide range of communication accessibility barriers. Some of our members have also experienced communication access barriers first-hand themselves, or through experiences their whānau have had.

Language

- *Disabled person (rather than person with a disability).*
- *Learning disability (rather than intellectual disability or cognitive impairment).*
- *Tāngata whaikaha Māori (for Māori disabled people).*
- *Person experiencing mental distress (rather than a person with mental health needs, mental illness, or mental disorder).*
- *Personal lived experience (for adults who have personal experience of having affected decision-making).*
- *Lived experience as family, whānau member, friend or carer (for people who are a family or whānau member, friend or carer of someone who has personal experience of affected decision-making).*

Question 1. Do you agree with the terms we propose to use in our review? If not, what changes should we make?

Our response:

A range of terminology tends to be favoured by different individuals and groups, and this is a topic that may evolve further, so revision may be required. It is best to ask the individual concerned about what language they prefer. However, the proposed terms are consistent with what we understand to be currently preferred terms. Guidance is best taken from the relevant people to whom the terminology is used. Our view is that the language used throughout the preliminary issues paper is strengths-based and articulates the complexity of decision-making, significantly contrasting with the existing law. In the laying out of the scope of this paper, we appreciate that small day-to-day and life-changing decisions are acknowledged.

The NZSTA, in particular, supports the term ‘decision-making supporters’ – this indicates the appropriate legal role in supported, rather than substituted decision-making.

We also support the use of ‘will and preference’; all people can communicate in some form. The term will and preference can be an appropriate way to indicate the communication of those who may not be able to clearly or formally indicate their decision but still have important views and the ability to indicate their choices. However, this may be through a range of methods that may require accommodations by those interacting with them and accommodations to the communication context.

Tikanga ō Principles

At a wānanga we held, six tikanga principles were identified that may be particularly relevant to affected decision-making in te ao Māori:

- 1. Whanaungatanga. This can be described as the reality of whakapapa-based relationships in te ao Māori. Whanaungatanga recognises that personal decisions are made in a collective context and so may involve whānau, hapū and iwi.*
- 2. Aroha. Aroha can broadly be described as love, compassion, sympathy, empathy and concern for others.*
- 3. Mana. Mana involves concepts of spiritual force and vitality and recognised authority, influence and prestige. Mana derives from the collective and so carries with it an obligation to exercise it for collective well-being.*
- 4. Tiaki. Tiaki can be defined as to care for or support. It is concerned with providing care for and preserving taonga or precious things.*
- 5. Wairua. This can be defined as the inherent spiritual essence of a person. A related concept is ‘mauri’ or the life force of a person or object.*
- 6. Rongo. In this context, we refer to rongo as a state of internal balance or peace. A person’s decision-making might be affected by their spiritual and mental balance. Rongo might be considered to emphasise the importance of restoring that balance.*

Three key concepts were also identified that might be particularly relevant to affected decision-making in te ao Māori. These are sometimes used as translations for Western concepts of the mind but have broader meanings that contain emotional and spiritual ideas:

1. *Hinengaro. This is sometimes translated as 'mind' but can be thought of more broadly as how a person communicates, thinks and feels.*
2. *Wairangi. This has been explained as describing someone who is confused or troubled such that their decision-making is affected.*
3. *Pōrangī. This can refer to someone who is permanently in a state of deep unrest and who, therefore, cannot make decisions for themselves or their whānau*

Question 2. Have we identified the tikanga principles and concepts most relevant to decision-making? If not, what changes should we make?

Our response:

NZSTA recommends that the third concept of pōrangī be expanded to:

Pōrangī. This can refer to someone who is permanently in a state of deep unrest and who, therefore, cannot easily or conventionally make decisions for themselves or their whānau

We agree with the principles, including collective decision-making and considering a person's ability to make decisions with their usual support, in contrast to an isolated and out-of-context assessment of individual capacity as frequently occurs currently.

Question 3. How is tikanga Māori relevant to you in relation to decision making, and to affected decision-making?

Our response:

NZSTA believes it is essential that this proposed law will more clearly define each article in Te Tiriti o Waitangi and how they will be enacted in relation to decision-making and the various contexts that may be relevant.

Question 4. In situations when someone's decision-making has been affected, have you and your whānau/hapū/iwi been able to act in accordance with tikanga Māori in the way you would want? If not, how could this be improved?

Our response:

We encourage feedback to be gathered from those with lived experience of these particular situations. We do not have any direct comments to offer ourselves.

Guiding principles

We have developed seven guiding principles for this review. We think the law relating to adult decision-making should:

1. *Respect and uphold the human rights of people with affected decision-making.*
2. *Uphold the Crown's obligations under te Tiriti o Waitangi.*
3. *Recognise and provide for tikanga Māori.*
4. *Empower people with affected decision-making to live flourishing lives.*
5. *Recognise and facilitate relationships built on trust.*

6. *Keep people safe from abuse and neglect, and promote accountability.*
7. *Be accessible and strike an appropriate balance between flexibility and certainty.*

Question 5. Do you agree with the seven guiding principles we have developed? If not, what changes should we make?

Our response:

We support the seven principles outlined; however, we recommend:

- Principle 3 - more clearly define each Te Tiriti o Waitangi article and how each will be enacted.
- Principle 4 - adding 'the importance of '. NZSTA recognises that institutional barriers (attitudinal, political, social and access to those with the skills, knowledge and resources to provide effective supports) significantly impact the provision of tikanga Māori.
- Including the principle: "Recognise decision-making capacity is dynamic and changes depending on the situation, the decision, and the supports around the person".

Including this last principle is important in changing the focus away from an 'all or nothing' view of capacity as exists in our current laws. This is included throughout the preliminary paper, and we would support further emphasis. Acknowledging that decision-making is variable and situation-dependent will, in turn, promote the responsibility of all parties and places where decision-making occurs to provide the right support, e.g. health and medical practices, financial organisations, justice settings, support providers, employers and education settings. The support they provide could include providing accessible information and effective communication and decision-making support. To promote accountability of decision-making supporters, a process to check the supports for the person could be integrated into the setting where decisions occur.

NZSTA believes improving the effectiveness of decision-making supports, awareness of the complexity of decision-making, and accessible information will lead to significant improvements and increased self-determination for those with affected decision-making, as well as the wider population – especially those with English as a second language and limited literacy skills. This has implications for the knowledge, training and skills of those stakeholders who might be involved in decision-making processes. Access to support must be equitable and highly effective.

The NZSTA is in full support of the new laws being accessible. However, we are concerned that the current accessibility bill does not provide sufficient guidance on what 'accessible' information looks like. There is very limited accountability to ensure this happens, and if it happens, to ensure it has occurred effectively.

Decision Making Arrangements

When a person's decision-making is affected, other people might be involved in their decisions. Sometimes people are involved in another person's decision without the law needing to step in. Other arrangements are set out in law.

People's experiences of affected decision-making can vary widely. We think the law will need to provide for a range of decision-making arrangements. We describe some possible ways below.

Decision-making supporters

Many people with affected decision-making are already supported informally to make decisions by friends and family. For example, someone might help their sibling to understand information about a decision or to communicate a decision.

There will always be an important role for this kind of informal decision-making support. However, we have heard that sometimes it can be difficult for informal supporters to help because they have no legal powers or status. For example, they might not be given access to personal information about the person they are supporting. We are thinking about how the law could make it easier for people to provide decision-making support.

Advance directives

This is when a person records in advance what they want to be done if something happens to them in the future, for example if they become unwell. Advance directives are sometimes used in Aotearoa New Zealand for healthcare decisions, but their legal status is unclear.

Enduring powers of attorney

This is where a person appoints another person to make decisions for them if they are assessed not to have decision-making capacity in the future, for example due to developing dementia. These already exist in the current law but some people think they could work better.

Making decisions for someone else under a court order

A court can make decisions for people whose decision-making is affected, such as where they must live or what medical treatment they must have. A court can also appoint someone else to make decisions on behalf of a person (for example a welfare guardian or property manager).

These kinds of court orders can only be made if the person is assessed not to have 'decision-making capacity'. They can be made without the person's consent.

Collective decision-making processes and decisions

Some people think the law should provide more ways for other people, like family and whānau, to participate in decision-making arrangements, or to jointly make decisions with a person whose decision-making is affected.

Making decision-making arrangements work better

We are also thinking about whether there are other things that could make decision-making arrangements easier or more effective for people with affected decision-making and those around them. These could be practical things like providing template documents, or offering training to supporters who are helping people to make decisions.

Question 6. Has someone supported you to make a decision, or have you been a decision-making supporter to someone with affected decision-making? If so, how well do you think that process worked? What could be improved?

Worked very well/Worked somewhat well/**Didn't work well**/I don't know/have no opinion

Our response::

NZSTA members who have contributed to this submission have a range of professional and personal backgrounds and experiences. In our professional roles, we have frequently been in positions to support people with various day-to-day decisions and serious decisions that have had high-stakes consequences for the individual.

The role of speech-language therapists (SLTs) varies but can be, first, to assess in a functional way what information the person can understand and how they express themselves and what might impact effective communication with the person. Communication occurs between people, so it is not only the communication of the individual that must be considered but also the context in which interactions occur, the modes of communication involved, and how the communication partners participate in the interaction. We have often noticed that many stakeholders only focus on the individual, but communication is more dynamic and complex, with many aspects to consider.

SLTs have the skills to ascertain the style of communication that enables effective participation for an individual, recognise potential barriers, and identify effective communication strategies and solutions. This allows SLTs to give information clearly and simply without reducing or limiting the content or quality of the information provided. We also specialise in providing information and asking questions in ways designed to be unbiased and non-leading so the person assisting does not influence decisions. We have a wide range of potential tools to use to enable people to express their views to others when conventional communication methods (e.g. speaking or writing) may not be available to them. There is a range of evidence-based tools we use to do this, to support people's engagement, language processing, cognitive skills and thinking. In some situations, communication support helps the person understand their options and make their decision. In other instances, communication support may not get the person to indicate exactly what they choose. Still, it can increase understanding and insight into their will and preference and indicate which aspects of a decision the person can understand. This can lead to more appropriate additional support or substituted decision-making when necessary.

We would like to highlight the significant concern that, at present, there is limited access to speech-language therapy and effective communication supports for adults with affected decision-making.

- Adults with an acquired neurological condition, such as stroke, traumatic brain injury, or progressive conditions, such as Parkinson’s or dementia, may be able to access some SLT services through public health or ACC. This is typically limited, often focused on swallowing, and may only be in place for a short time. This support is not targeted around decisions.
- Adults with affected capacity involved in some legal processes can access communication assistants (CAs) who are neutral and impartial communication specialists trained to deliver these services. This support is specifically for engagement in the legal system. Access to these services is growing, and as well as services in courts, there is sometimes engagement of CAs in other justice processes such as Parole Board hearings, Family Group Conferences, and Police interviews. More information can be viewed on the Ministry of Justice’s website - please see the [Communication Assistant Quality Framework](#).
- [Communication assistance | New Zealand Ministry of Justice](#)
- Some adults may access private SLT services, but there are very few private practitioners offering this kind of support, and cost can be a major barrier.
- Some small services offer specialised support in a particular area of communication; however, these are not widely available in the context of adult decision-making.
- Adults with learning disabilities do not have access to SLT support. Te Whatu Ora community health services are not able to provide services to those with a developmental disability. While disability support providers are contractually required to support a person’s communication and decision-making, there is no funding allocated to enable staff to access communication training or any SLT support.
- Access to SLT services is not currently equitable – geographic, socioeconomic, and cultural barriers impact access to support.

Increased access to communication and SLT support is essential for decisions to be well supported.

Question 7. Have you experienced making, or been involved in using, an advance directive? If so, how well did you think that process worked? What could be improved?

Worked very well/Worked somewhat well/Didn’t work well/I don’t know/have no opinion

Our response:

SLTs can be key in determining a person’s mental capacity (ability to make decisions) and supported decision-making.

SLTs protect and promote the interests of people with communication needs by supporting them to demonstrate whether or not they have decision-making capacity. The SLT would test various methods that enable more effective participation in decision-making processes to recommend how a person is best supported. They promote inclusion, dignity, choice, and equality of access to services and reduce the potential risk of people with communication needs being wrongly deemed as lacking capacity.

Question 8. Have you made, or been involved in using, an enduring power of attorney? If so, how well did you think that process worked? What could be improved?

Our response:

No comment

Question 9. Have you been involved in a process of making decisions for someone else under a court order, or having decisions made for you under a court order? If so, how well did you think that process worked? What could be improved?

Worked very well/Worked somewhat well/Didn't work well/I don't know/have no opinion

Our response:

As the review states, decisions on capacity are often the opinion of a doctor, which has several limiting factors:

- General practitioners and most doctors are not required to have specific communication training, nor can they easily access professional support from SLTs.
- Assessments tend to be conducted in a clinical setting outside the person's usual environment and supports.
- Assessments are often highly dependent on the information given by the person who is likely to become the welfare guardian (e.g. a parent supports their adult child to go to the doctor, who determines the adult child is not capable, and then the parent is appointed welfare guardian).

The enactment of the current PPPR act is highly variable in which people are considered 'capable' and which individuals are deemed 'appropriate' guardians. Guardians (both welfare and property) do not consistently understand their role. Sometimes, a welfare guardian will support the person in making decisions and ensure they get appropriate information, support and care. In other instances, a welfare guardian may make substituted decisions on behalf of the person without their active inclusion or consideration of their will and preference. As the person has already been deemed 'not capable' under the law, it is challenging for a person with affected decision-making to change a legal order over them.

Many adults, especially those with learning disabilities who have lived in socially isolating settings such as institutions or some residential care, have very limited natural networks. This means there is not an appropriate person/persons outside paid staff to take on guardianship. We have supported many people who have been denied access to some form of services or healthcare when the provider was not confident the person could consent because there was no guardian in place. We have also supported people with no guardians in place; however, those around the person – such as family members or paid support staff, have been treated as though they have substituted decision-making authority for the person.

We feel strongly this is discrimination based on communication and disability, which is a breach of people's rights. The new law should consider how to support the decision-making

of those who cannot clearly communicate a choice but do not have a guardian or natural support network to be decision-making supporters.

Other NZSTA members have been involved as court-appointed Communication Assistants to enable lawyers or other stakeholders to gather the views of individuals involved in court orders. We could provide additional information about these roles if this is requested.

Question 10. Do you think there should be more ways for other people to be involved, in a more collective way, in decision-making arrangements when a person's decision-making is affected? If so, how?

Our response:

We are in support of collective decision-making arrangements and decision-making supporters. We feel this aligns much better with Māori and joint decision-making practices, which are more appropriate in various social and cultural environments.

Assessment needs to be functional and holistic, taking into account the way the person gets information and the support within their natural networks and environment. Assessment that includes the network of support people, who will then be part of formal decision-making arrangements, is likely a more appropriate assessment process.

Decisions are incredibly diverse, as is the type of support, and the person's best place to provide support, e.g. deciding on getting a tattoo, financial decisions, and health care decisions may all be best supported by different people. A collective decision-making arrangement that enabled the person to select who they want to assist them with a particular decision would be more appropriate than one guardian.

Collective decision-making would need to have safeguarding and conflict resolution frameworks easily accessible to help identify the person's will and preference where a network of decision supporters could not agree.

Question 11. Do you think there are any other decision-making arrangements we should explore? If so, what are they?

Our response::

We would support creating services that enable ongoing access to professional decision-making (and communication) support. We would also support broadening accountability to provide support to all.

Speech-language therapists are qualified health practitioners who support people with communication and swallowing needs. They are uniquely trained and qualified to:

- Undertake an in-depth assessment of an individual's current, and likely future, ability to communicate, including their ability to understand, express themselves, retain and recall information, and reason (weigh up different options)

- Contribute to multidisciplinary capacity assessments of people with communication needs
- Support people with communication needs to demonstrate their decision-making capacity.
- Support people to express their preferences and wishes concerning any decision made on their behalf, regardless of whether they are deemed to have capacity.
- Advise and train people on the best means by which someone with a communication disability might overcome their disability to make and communicate informed decisions about their treatment and care.
- Support people to understand how to communicate with individuals who have been found to lack decision-making capacity.
- In New Zealand, speech-language therapists can be appointed as communication assistants in the court. This ensures that communication adjustments are made to enable people to participate fairly in the court process. See the Court Appointed Communication Assistant Quality Framework referenced above for more on this role.

Question 12. What things might make decision-making arrangements easier or more effective?

Our response:

Communication is complex and dynamic. It is crucial to consider how people understand information and express themselves. A simple framework to identify what a person understands and how they express themselves would be highly valuable in understanding capacity and ensuring they have appropriate support.

We would also encourage a decision-making arrangement to include *who* should be involved in a decision and *how* decisions can be supported. This could make it simpler to check the person has been appropriately supported and provide accountability measures for legally appointed decision-makers. It would also provide a framework for people/professionals who need to become more familiar with the person but are involved in a decision to provide and/or access the right support, e.g. doctors, lawyers, and employers.

One method to do this could be the implementation of communication profiles/passports that outline the person's communication skills and support needs. This could include tools and strategies for professionals and others supporting a particular decision. These can be developed by the person concerned with appropriate support, so their own views about what supports they need or want are clearly identified and recorded.

What safeguards and accountability mechanisms might be needed?

Question 13. Do you think there needs to be safeguards or accountability mechanisms when a person with affected decision-making has an informal decision-making supporter? If so, what should they be?

Our response:

The new law should include how a person is supported.

Safeguards could require people to demonstrate how communication is supported, their involvement, and their will and preference were indicated.

Question 14. Do you think there needs to be safeguards or accountability mechanisms when a person uses an enduring power of attorney? If so, what should they be?

Our response:

The conditions when the person put EPOA in place are directly relevant to the situation of affected capacity.

Question 15. Do you think there needs to be safeguards or accountability mechanisms when a person moves to a rest home or care facility? If so, what should they be?

Our response:

All support providers should collect/be provided with information about how the person makes decisions and indicates their will and preference. If there are decision supporters, they should be involved in the transition process.

The person receiving care or support should have choice and control in guiding the type of care received. There should also be feedback and complaints procedures in place in an accessible format for those with affected communication. Audits of providers are an important way to ensure people are supported safely and appropriately. Auditing tools should also be reviewed to reflect the nuances of communication and decision-making, aligning with the principles outlined in this review and moving away from an all-or-nothing assumption on consent and capacity.

Question 16. Do you think there needs to be safeguards or accountability mechanisms if a person has a welfare guardian? If so, what should they be?

Our response:

Yes, we would support increasing safeguards for welfare guardians but also more explicit expectations and supports to ensure people understand their role and can access the support to do it. There are processes to ensure that the role is carried out effectively.

The current safeguards of a welfare guardian appointed by the Family Court are not rigorous enough. They don't occur in a person's environment, and many court professionals and lawyers don't have enough specialist knowledge of disability and the communication issues involved in effective decision-making. We believe a system where one individual is given power and authority over another will always have significant risks.

Question 17. Do you think there needs to be safeguards or accountability mechanisms to help supporters? If so, what should they be?

Our response:

Yes, there should be safeguards for supporters, which could include:

- Access to resources, tools and professional support.
- Frameworks to help them provide appropriate support and demonstrate how they are supporting the person.
- Clear information about their role and responsibilities.
- A service or group where concerns can be raised by any party – with the power to investigate, review and change decision-making arrangements that are found to be unsafe or unsuitable.
- A review period for all legal decision-making orders. People with affected decision-making may change their preferences and skills over time. Appointed supporters' personal circumstances may change, e.g. moving geographic location, their own health and cognition, or changing relationship/dynamics with the supported person.

[Is there anything else you would like to tell us?](#)

Our response:

With increased resourcing for existing services, and the creation of additional roles to integrate the speech-language therapists' skillset across all areas where decision-making occurs, speech-language therapists could improve communication of people with impacted decision-making and provide support, training and resources for decision-making supporters.

The NZSTA would welcome opportunities to discuss further and contribute to this review.

Bibliography

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***Who are we?**

The New Zealand Speech-language Therapists' Association (NZSTA), established in 1946, represents speech-language therapists (SLTs). NZSTA supports over 1,100 registered speech-language therapists nationally. Well over 90 per cent of the workforce are registered members.

The Association operates a self-regulatory process that provides for –

- annual practising certificates
- a clear scope of practice
- code of ethics
- complaints process
- programme accreditation of tertiary speech and language courses, and the approval of international speech-language therapy qualifications to ensure equivalency with New Zealand standards.
- a structured supervisory framework for new graduates or return-to-practice therapists
- continued quality assurance of its registered professionals.

Speech-language therapists study, diagnose and treat communication disorders, including difficulties with speaking, listening, understanding language, reading, writing, social skills, stuttering and using voice.

They work with people of all ages who have difficulty communicating because of developmental delays, stroke, brain injuries, learning disability, intellectual disability, cerebral palsy, dementia and hearing loss, and other problems that affect speech and language.

A speech-language therapist can also help people who experience difficulties swallowing food and drinking safely.

Speech-language therapists work in various settings, including schools, hospitals, courts, prisons, childcare centres, or a client's home.

Speech-language therapists complete a four-year bachelor's degree or a master's in speech-language therapy.

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