Advance Care Planning Australia

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Thank you for the opportunity to respond to the draft *Improving outcomes for people with disability under the National Disability Strategy and the National Disability Insurance Scheme* ('Outcomes Framework'). Advance Care Planning Australia (ACPA) is a national program funded by the Australian Government. Our program is focused on improving advance care planning policy and systems, community awareness, understanding and uptake, workforce capability, quality monitoring and evidence. We promote a national collaborative approach to achieving excellence in advance care planning. ACPA delivers national advance care planning leadership, advocacy, communications, advisory services, and education and information resources for consumers, the health and aged care workforce, and/or service providers.

In response to the different elements contained in the draft structure of the Outcomes Framework the table below offers a number of recommendations along with justification for those changes. Any changes to the current framing of the Outcomes Framework has been written in red.

Table 1– Recommended changes to the Draft Outcomes Framework

Title	Page Number	Recommended Change(s)	Justification
Domain: Health and Wellbeing Sub-outcomes (person-centred)	8	**Please insert the following sub-outcomes:** I can: Participate in advance care planning and have the opportunity to document my preferences in an advance care directive and appoint a substitute decision-maker who will provide consent on my behalf in the event I lose decision-making capacity.	Participation in advance care planning is a voluntary process but should be encouraged where appropriate. When a person has decision-making capacity, they can provide consent themselves. When the person loses decision-making capacity values and preferences documented in an advance care directive or preferences expressed by a substitute decision-maker become important. This is particularly important with people who have a disability given they often have an uncertain disease trajectory that may see them lose capacity at various times.

Domain: Health and Wellbeing Sub-outcomes (person-centred)	8	**Please insert the following sub-outcomes:** I can: Access medical treatment that aligns with my values and preferences.	This outcome extends from the previous one and recognizes that a person with a disability should not only have access to medical treatment but also have access to medical treatment that aligns with their values and preferences, including those documented in an advance care directive or given by a substitute decision-maker on their behalf. People with a disability have a right to not be subjected to medical treatment without their consent.
Domain: Health and Wellbeing Example indicators	8	**Please insert the following indicator:** Existence of an advance care directive and documents appointing a substitute decision-maker.	In order to measure the sub-outcome identified above it is important that the existence of advance care directives and substitute decision-maker appointment is noted, given their existence increases the likelihood that the person will receive medical treatment that aligns with their values and preferences.
Domain: Health and Wellbeing Example indicators	8	**Please insert the following indicator:** Health professional compliance with their professional responsibilities set out in legislation and professional codes of conduct.	It is important to recognize the effectiveness of a health system is contingent upon health professional compliance with professional responsibilities. For instance, there are obligations of health professionals to implement a person's values and preferences when delivering health care, unless it would be unreasonable not to do so.
Domain: Rights, protection justice and legislation Sub-outcomes (person-centred)	9	**Please make the following amendment:** I have equal treatment in the legal, health and justice systems to people without disability.	The amendment reflects the fact that a person should have equal treatment in the health system. This recognizes that individuals with disabilities have the right to enjoy the highest attainable standard of health without discrimination.
Domain: Rights, protection justice and legislation Sub-outcomes (person-centred)	9	**Please insert the following sub-outcome:** A person with a disability has a right to exercise their autonomy and make self-determined decisions.	It is important to recognize that despite any impairment that results from their disability, a person with a disability's autonomy should be respected and upheld.

			A person can still be supported in their decision-making and have their autonomy upheld, but they should not be subject to coercion.
Domain: Rights, protection justice and legislation Example indicators	9	**Please insert the following indicator:** Ability to make self-determined decisions.	This provides an appropriate measure for the suggested sub-outcome.
Sub-outcomes (person-centred) Sub-outcomes (person-centred)	11	**Please make the following amendment:** I have the ability to actively participate in decisions that affect my life, and I have access to the information and support I need to make choices related to my support and care.	The proposed amendment acknowledges that whilst it is important that people with a disability have access to information relevant to their choices that they also provided with the opportunity to actively participate in decisions. This word has been adapted from the principles underpinning the *Disability Act 2006* (Cth) s 5(2).

ACPA would like to see the progress against the outcomes for people with disability in the National Disability Strategy and the National Disability Insurance Scheme reported annually and have the results made publicly available and notify relevant stakeholders, including ACPA, when they do become available. In areas where the progress against the outcomes is deemed unsatisfactory for a particular period, policy consistent with the strategy should be created in order to try and improve progress.

The Department of Social Services should consider the importance of formally incorporating advance care planning in the current strategy.
The rights of people living with disability to be involved in deciding their future health care is often left out of conversations about improving equity, access and empowerment of the disabled community. However, there is evidence that these individuals will often experience discrimination in healthcare settings because of a presumed lack of ability to understand or engage in these conversations.(1-5) Despite this, all Australians have the right to actively engage in decisions about their health care.(6) These rights are protected by law, and one such right is the right to engage in advance care planning to ensure future health care aligns with a person's preferences for care. (7)

To facilitate the inclusion of advance care planning in the next strategy, we have provided a brief summary of the advance care planning process and sources of additional information that could be included:

Advance care planning is the process of planning for future health and personal care needs. It provides a way for a person to make their values and preferences for future medical care known. Advance care planning documents are then used to help guide decision-making at a future time if and/or when the person cannot make or communicate their decisions. Advance care planning is an ongoing process that should be undertaken early and revisited regularly. Engaging in advance care planning helps people to determine their healthcare priorities and align their health and care preferences with the actual care they receive.

There is no national advance care directive legislation in Australia. Each jurisdiction determines legislation or policy about Advance Care Directives for documenting preferences of care and/or appointing substitute decision-makers. The law exists to allow people autonomy and choice in their future medical treatment decisions, including consent, withdrawal, refusal, or substitute decision-making.

All Australians have the right to self-determination and can choose to consent or not consent to health treatments. However, there may be times where a person's capacity to make informed decisions about their care is diminished. When this happens, Advance Care Directives are an important tool for a person to pre-emptively provide important information about their healthcare priorities and preferences. An Advance Care Directive is a voluntary, person-led document completed and signed by a competent person describing the person's values and preferences for future medical treatment decisions, including their preferred outcomes and care. An Advance Care Directive may include binding instructions regarding consent, refusal, or withdrawal of medical treatment, and may also be used to appoint a substitute decision-maker who can make decisions about health or personal care on the person's behalf.

If a person has diminished or no capacity, they are still able to have someone (preferably the substitute decision-maker) document their preferences in an Advance Care Plan. Although Advance Care Plans do not have the same legal standing as an Advance Care Directive, it can still be used to inform care by providing the substitute decision-maker or treating health professionals with important information about what the person does and/or does not want in terms of the care they receive. Advance Care Directives only come into effect when the person loses decision-making capacity. If the loss of capacity is only temporary (e.g. delirium related to illness or treatment), the Advance Care Directive will only be in effect until the person regains decision-making capacity.

For your convenience, we have provided the nationally proposed advance care planning terminology in appendix 1. More information about advance care planning, including access to forms, can be found on the Advance Care Planning Australia website and legal resources hub. Alternatively, a national advance care planning advisory service 1300 208 582 is also available for consumers, the health and disability care workforce, and service providers.

References:

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2. Voss H, Vogel A, Wagemans AM, Francke AL, Metsemakers JF, Courtens AM, de Veer AJ. Advance care planning in palliative care for people with intellectual disabilities: a systematic review. Journal of Pain and Symptom Management. 2017 Dec 1;54(6):938-60.

3. Cardona M, Lewis E, Shanmugam S, Nicholson M, Williamson M, Hanly L, Hillman K. Dissonance on perceptions of end-of-life needs between health-care providers and members of the public: Quantitative cross-sectional surveys. Australasian journal on ageing. 2019 Sep;38(3):e75-84.
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6. Haining C, Nolte L, Detering KM. 2019. Australian advance care planning laws: Can we improve consistency? Austin Health, Melbourne: Advance Care Planning Australia.
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Appendix 1: National terminology related to advance care planning and advance care planning documents

Significant variability exists in the terminology used to describe advance care planning and its related documents across jurisdictions, legislation and policy. However, a recent shift to ensure consistent terminology use at a national level has occurred.

Table 2 includes a list of common terms and their origins currently in use. While not all of these terms may be relevant to the Outcomes Framework, we believe that it is important to acknowledge these terms to more clearly understand how advance care planning documents may relate to the Outcome Framework.

Table 2 – Recommended advance care planning terminology, definitions and sources

Term	Definition
Advance Care Directive [a]	Advance Care Directive is a catch-all term to refer to the instruments which are recognised in each jurisdiction under advance care planning legislation or common law. In Australia, Advance Care Directives are recognised either by specific legislation (statutory Advance Care Directive) or by common law (non-statutory Advance Care Directive). Advance Care Directives can record the person's preferences for future care, and/or record the appointment of a substitute decision-maker to make decisions about the person's health care. An Advance Care Directive is a voluntary, person-led document completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care. They come into effect when an individual loses decision-making capacity.
Statutory Advance Care Directive [a]	A structured document that focuses on an individual's values and preferences for future health and medical treatment decisions, completed and signed by a competent person, using a statutory form and/or meets formalities within relevant legislation.
Advance care plan [a]	Documents that capture an individual's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date).
Advance care planning (ACP) [a]	Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known.
Advance care planning documents (ACP Documents) [a]	A catch all term to include documents that results from advance care planning. This includes Advance Care Directives and advance care plans.
Advance care planning legislation [a]	A catch all term to refer to jurisdictional legislation that promotes advance care planning and Advance Care Directives. Legislation, including, but not limited to Advance Care Directives, advance

Term	Definition
	personal planning, guardianship and administration, and medical treatment decisions.
Capacity [a]	The ability to make a decision for oneself. Decision-making capacity can be assessed by trained professionals, and its assessment depends on the type and complexity of the decision to be made. Capacity assessment does not assess whether the decision is considered “good” or “bad” by others such as clinicians or family, but rather considers the person’s ability to make a decision and comprehend its implications. Generally, when a person has capacity to make a particular decision they can do all of the following: ▪ understand and believe the facts involved in making the decision ▪ understand the main choices ▪ weigh up the consequences of the choices ▪ understand how the consequences affect them ▪ make their decision freely and voluntarily ▪ communicate their decision By default, people are assumed to have capacity, unless there is evidence to the contrary.
Substitute decision-maker [a]	Substitute decision-maker is a person appointed or identified by law to make substitute healthcare decision(s) on behalf of a person whose decision-making is impaired. A substitute decision-maker may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker within legislation. Substitute decision-makers listed in Advance Care Directives are statutory appointments. Substitute decision-makers listed in advance care plans are not legally binding.

Definition source:

a. National Framework for Advance Care Planning Documents (drafted, awaiting National Federation Reform Council approval).