Central Australian
Aboriginal Congress
ABORIGINAL CORPORATION | ICN 7823

Submission regarding proposed Northern Territory Health Care Decision Makers legislation

February 2020

Background

1. Central Australian Aboriginal Congress (Congress) is the largest Aboriginal community-controlled health service (ACCHS) in the Northern Territory, providing a comprehensive, holistic and culturally-appropriate primary health care service to more than 16,000 Aboriginal people living in Alice Springs each year as well as the remote communities of Ltyentye Apurte (Santa Teresa), Ntaria (Hermannsburg) and Wallace Rockhole, Utju (Areyonga), Mutitjulu and Amoonguna.

2. Since our establishment in the 1970s, we have developed a comprehensive model of primary health care that includes: multidisciplinary clinical care; health promotion and disease prevention programs; and action on the social, cultural, economic and political determinants of health and wellbeing. Alongside clinical treatment and prevention programs, we also provide services on issues such as alcohol, tobacco and other drugs; early childhood development and family support; aged and disability; and mental health and social and emotional well-being.

Response to the Discussion Paper

3. Overall, Congress supports the approach to the legislation outlined in the *Northern Territory Health Care Decision Makers Discussion Paper*. In particular, we support the aim of the new laws to ensure that that wherever possible, health care decisions are made for an adult who is unable to decide for themselves by a person who is familiar with their views and wishes. We believe that the proposed legislative approach would promote the rights and wellbeing of Aboriginal adults who are unable to consent to health care and their families, and would also provide clarity for health care service providers such as Congress.

4. Congress is not able to provide comments on all aspects of the proposed legislation. However, the following are some of the key points that we believe should be taken into account in drafting the new laws.

Aboriginal culture, kinship and family

5. We acknowledge the attempt to take account of customary law and tradition in determining who an Aboriginal adult's health care decision maker should be. As we understand it, Section 10 of the *Discussion Paper* suggests that where an adult is not able to make health care decisions for themselves, a 'health care decision makers hierarchy' be used to determine who may make such decisions on their behalf using the following order:

   a. someone already appointed in the adult's 'advance personal plan'
   b. a guardian already appointed under the *Guardianship of Adult's Act 2016*
   c. a relative who is considered the appropriate health care decision maker in accordance with customary law or tradition (including Aboriginal customary law or tradition)
   d. a spouse or domestic partner
   e. the primary carer (excluding a paid carer)
   f. an adult child
   g. a parent
   h. an adult sibling

6. We also understand that this hierarchy would be embedded in legislation and be automatic when a person does not have capacity to make health care decisions for themselves.

7. Overall, we agree with the hierarchy as described in the *Discussion Paper*: unless someone has already been legally determined to be the health care decision-maker under Western law (though an advanced care plan, or through being appointed as a guardian), the first people that a health care provider must approach are those relatives who are appropriate under Aboriginal law.

8. However, determining just <u>who</u> that right person might be under Aboriginal law in a timely manner could be very difficult for many health care providers, because:

   - there is a great diversity of Aboriginal cultures and families across the Northern Territory – for example, in Central Australia, it is grandparents who are generally considered the key decision-makers in such situations, but this may not be true for other parts of the Territory or even for all families;

   - there is a lack of specific cultural and community knowledge especially amongst non-Aboriginal health care providers; and

   - the mobility of Aboriginal people and families may result in large distances between where the health provider is located and the community (and its cultural context) where the health care decision maker may be.

9. These difficulties highlight the fact that the legislated hierarchy will not be enough by itself. There is a need for effective guidelines under the legislation to provide guidance to health professionals about what might be culturally appropriate in different parts of the Northern Territory, emphasising the diversity of Aboriginal families and culture; how Aboriginal families might be consulted about this critical decision; and what other sources of information might be available to help guide them (for example, through Aboriginal community controlled health services or other Aboriginal organisations in a person's home community).

10. Providing such guidance would take account of the diversity of Aboriginal families and culture across the Northern Territory, protect health care providers, and most importantly empower Aboriginal people themselves to make health care decisions for their kin.

Health care decision making – scope of authority

11. Congress supports ensuring that the scope of authority is the same for all health care decision makers regardless of whether they are appointed under the *Advance Personal Planning Act 2013* or the *Guardianship of Adults Act 2016.*

12. Congress supports the inclusion of the medical treatment definition that is contained in the *Victorian Medical Treatment Planning and Decisions Act 2016*. However, we would like to ensure that legislation also ensures clarity around the following points:

    - health care decision makers may not approve decisions in relation to 'restricted health matters' [1] without Northern Territory Civil and Administrative Tribunal (NTCAT) approval;
    - health care decision makers may not approve non-therapeutic procedures (e.g. cosmetic surgery, body-piercing, botox) without NTCAT approval;
    - health care decision makers may not refuse palliative care to reduce a person's suffering at end-of-life without NTCAT approval;
    - health care decision maker may approve participation in clinical research as long as it has been approved by the Chief Health Officer of the Department of Health, upon recommendation of the Ethics Committee

[1] Defined in the Discussion Paper as including 'sterilisation, termination of pregnancy, removal of non-generative tissue (eg a kidney), special medical research or experimental health care, new health care of a kind that is not yet accepted as evidenced-based, best practice health care, electroconvulsive therapy and any treatment that involves the use of an aversive stimulus'

How will a health care decision-maker exercise their authority?

13. The guiding principles for decision-making should be the same for all health care decision makers regardless of whether they are appointed under the *Advance Personal Planning Act 2013* or the *Guardianship of Adults Act 2016*.

Health care without advance consent / health care decision maker

14. Congress supports introduction of introduction of definitions of 'routine health care' and 'significant health care' as outlined in the Discussion Paper, noting that 'significant health care' will require health care provider to obtain consent from either the Public Guardian or NTCAT.

15. Health care providers should be authorised to provide 'routine health care' without consent as long as is in line with evidence-based treatment guidelines (e.g. the Central Australian Rural Practitioners Association (CARPA) Manual).

Time requirements for health care decision makers

16. Once a child who may have an impaired capacity to make their own decisions reaches adulthood at 18 years old, a formal assessment should made of their capacity to make health care decisions. If they are found to be not able at that point, a health care decision maker should be appointed indefinitely unless / until a health care decision maker or medical practitioner seeks a review.

Safeguards

17. In relation to safeguards to protect the rights of the person with impaired capacity, we suggest that following the *Discussion Paper*:

- as per other jurisdictions, the health care decision maker cannot compel care unless:
    - the health care decision maker is a guardian and has approval from NTCAT to override the person's objection
    - the adult has minimal or no understanding about what the treatment entails and the treatment will cause no distress or the distress is likely to be reasonably tolerable and only transitory
- should a health care decision maker refuse care, the health care provider may notify the Public Guardian / NTCAT for review
- where there is a conflict between possible health care decision makers, the NTCAT may determine a person's health care decision maker
- where a person is likely to regain decision-making capacity, the health care decision maker may not make non-immediate but permanent and irreversible health care decisions without the approval of the NTCAT.