INQUIRY INTO SUBSTITUTE DECISION-MAKING FOR PEOPLE LACKING CAPACITY

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Standing Committee on Social Issues Legislative Council Parliament House Macquarie Street SYDNEY NSW 2000

To Whom It May Concern

We are pleased to submit this response to the Inquiry into substitute decision making for people lacking capacity to the NSW Legislative Council's Standing Committee on Social Issues.

The Diversity Health Institute (DHI) is comprised of key public health services and programs that work together to improve the health and wellbeing of Australia's culturally and linguistically diverse (CALD) community. The DHI is auspiced by the Sydney West Area Health Service (SWAHS), and comprises of units with a state-wide, national and international focus and is funded from a variety of sources including NSW Health and the Commonwealth Department of Health and Ageing.

The DHI services and programs include: Co-Exist NSW: Diversity Health Comorbidity Service, DHI Clearinghouse, DHI Research Laboratory, Multicultural Mental Health Australia, Multicultural Problem Gambling Service, NSW Program on Female Genital Mutilation, Transcultural Mental Health Centre, Women's Health at Work

The DHI works with diverse communities to develop and deliver effective health services and programs and delivering savings to the health budget by improving the health of the community, facilitating more accurate diagnosis and more appropriate delivery and treatment reducing hospital stays.

The issues that the DHI would like to put forward to the Standing Committee relate to the specific needs of people from culturally and linguistically diverse backgrounds when encountering issues of supported or substitute decision- making.

The DHI would particularly like to raise the following concerns on behalf of CALD communities, many of which are aging in the community, living with a mental illness or dementia and being confronted with issues related to their security and quality of life. In addition to cognitive impairment or disability, individuals from CALD backgrounds may have difficulties with language and understanding different systems and processes.

1. ISSUES

In relation to an understanding of the concepts of supported and substitute decision-making, it is our view that communities from culturally and linguistically diverse backgrounds, as a whole are well behind in their understanding both issues and in their awareness of the current legislation in NSW.

- 1.1 As a result, decisions regarding the capacity of an individual often have to be made in a time of crisis without any background knowledge. Decisions of this nature take time. If individuals are pressured by service providers, family and friends, the choices made are not always the most appropriate or in the best interest of the individual. This often leads to increased vulnerability of individuals from CALD backgrounds leaving them at risk of abuse, neglect and exploitation.
- 1.2 Access to culturally sensitive and appropriate information regarding supported or substitute decision-making is limited, as is timely access to appropriate linguistic support including interpreting services
- 1.3 Individuals from CALD backgrounds with cognitive and other impairments and disabilities experience discrimination in relation to accessing to justice services, complaints processes, processes for reassessing guardianship. They may be unable to initiate action to protect themselves, or their interests or access someone to act on their behalf. The initiation of such actions is often a lengthy process leaving individuals exposed to abusive or exploitative situations. In many CALD communities people with disabilities are often hidden and isolated and may therefore be more vulnerable to abuse or exploitation.
- 1.4 For example, when a vulnerable individual from a CALD background is isolated from all external support and have had been prevented from accessing support services by a guardian, this should be sufficient grounds for review.
- 1.5 Individuals from CALD backgrounds with cognitive and other impairments often experience widespread abuse, neglect and exploitation due to the limited options available to them in managing their affairs and making decisions and where those providing support will not benefit from the situation. Doctors, solicitors, community and religious leaders within CALD communities may be more readily trusted by but once guardianship has been granted individuals are often isolated from any other community support, often inappropriately cared for or even abandoned. There is often a belief that people from within the same cultural group are to be trusted and therefore consumers do not challenge their advice or ask for clarification.

2. RECOMMENDATIONS

- 2.1 The law in NSW that relates to legal capacity and decision making should be able to be applied equally to all members of society who are experiencing difficulties in managing their affairs and making important decisions.
- 2.2 The law should apply to all situations where individuals with cognitive impairment are being assisted in decision-making ranging from informal family of community-based support to institutional support.

- 2.3 The law should protect all individuals irrespective of their cultural or linguistic backgrounds from exploitation, neglect or abuse.
- 2.4 The law should ensure that an appropriate independent body that upholds and protects the rights of that individual should undertake any assessment of the legal capacity of an individual with a disability.
- 2.5 The law should ensure that any restriction regarding decision-making should be reviewed regularly and by an independent body.
- 2.6 There should be clear criteria developed regarding the quality of guardianship so that a single breach would immediately lead to a review of the arrangements for substitute decision-making. Specific criminal offences related to the exploitation, neglect or abuse of individuals with cognitive impairment or disability where supported or substitute decision making arrangements are in place. The process of revoking substitute decision-making should be simplified.
- 2.7 More work should be done directly with CALD communities in a culturally appropriate way, to increase the overall knowledge skills and understanding of the rights of the individuals with cognitive impairment and disability. The use of ethnic media would be particularly effective in raising this issue and ensuring it is widely discussed in CALD communities.
- 2.8 Bilingual/ bicultural liaison personnel should be engaged by key agencies to develop, implement and monitor decision-making options that are appropriate and applicable across culturally diverse communities.
- 2.9 The use of interpreters should be utilised in accordance with NSW.
- 2.10 All relevant documents should be in plain language.

If you require any further information, please do not hesitate to contact Ms Monika Latanik on Ph: (02) 8838 2175 or Monika Latanik@wsahs.nsw.gov.au.

Regards

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