

# **SUPPORTED DECISION-MAKING FOR PEOPLE WITH DEMENTIA**

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**COGNITIVE DECLINE PARTNERSHIP CENTRE ACTIVITY  
24: SUPPORTED DECISION-MAKING AND DEMENTIA**

# *Our partners*



Australian Government

National Health and Medical Research Council



dementia  
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Helping Hand



Brightwater

# ACKNOWLEDGEMENTS

**Consumer representatives:** Kathy Williams, Ann Pietsch, Theresa Flavin, Mike Barry, Vicki Barry, Ron Sinclair, Cate McCullough, Karine Shellshear, Darcelle Wu

**Partner organisations:** Helping Hand Aged Care, Brightwater, HammondCare, Dementia Australia

**Advisory group members:** NSW Office of the Public Guardian, SA Office of the Public Advocate, SA Department of Communities and Social Inclusion, Dementia Australia (NSW, SA), Alzheimers WA, Carers Australia (NSW, SA), LASA NSW, Australian Aged Care Quality Agency, COTA SA, NSW Elder Abuse Helpline & Resource Unit, Seniors Rights Services NSW, Advocare, Partners in Culturally Appropriate Care NSW, Multicultural Aged Care SA

**RESEARCH PARTICIPANTS:** 37 people with dementia, 45 family caregivers, 31 health/legal professionals, 9 aged care staff with policy development roles

# SUPPORTED DECISION-MAKING

“ ...the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters ”

(United Nations, 2006)

**Supported decision-making**  
VS  
**support *for* decision-making**

**A voluntary process**

**Person's own decision**

**Assisting person to understand**

**Assisting person to weigh options**

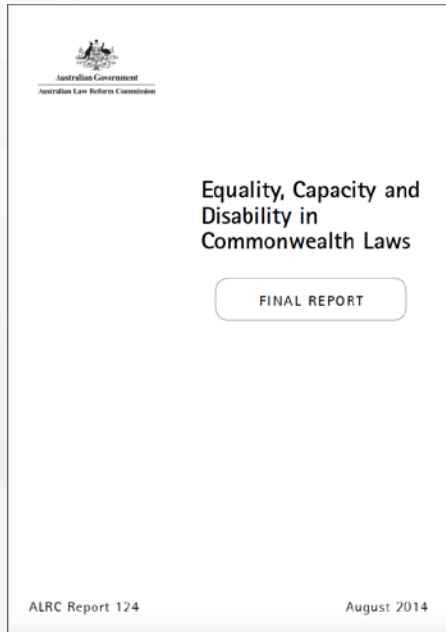
**Assisting person to communicate**

**Developing person's decision-making ability**

**Creating enabling contexts**

# AUSTRALIA'S RESPONSE

## Australian Law Reform Commission Report 2014



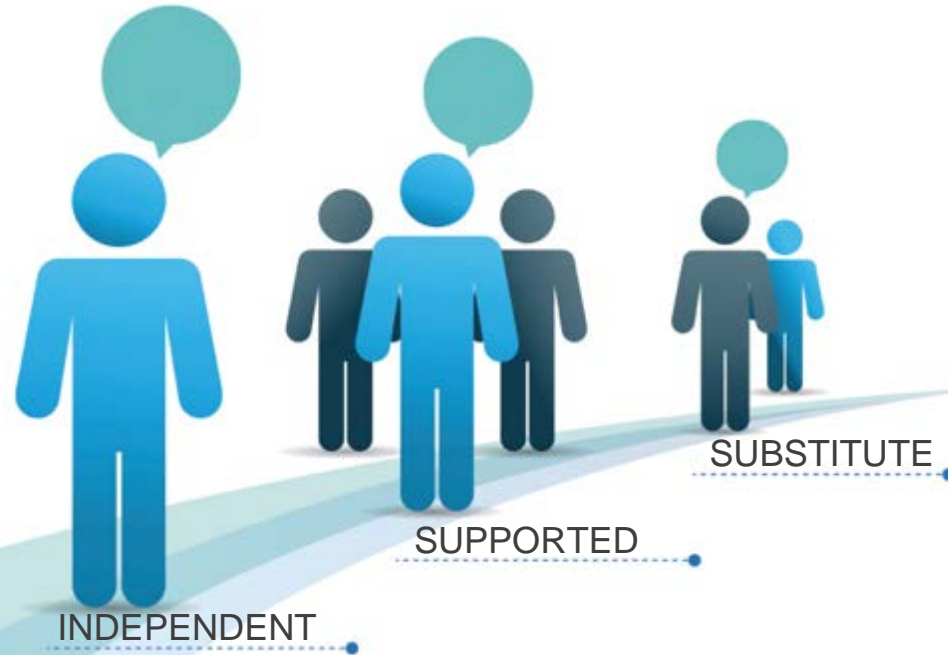
01  
The right to  
make decisions

02  
Support to  
make  
decisions

03  
Will,  
preferences  
and rights

04  
Safeguards to  
prevent undue  
influence and  
abuse

# DECISION-MAKING CONTINUUM



# 'SUPPORT TO MAKE ONE'S OWN DECISIONS' VERSUS PROGRESSIVE COGNITIVE IMPAIRMENT

## 'Involvement dependent on stage of dementia'

"I think that will depend on the stage to be honest. That would be totally impossible now because there's just not the cognition ... I think definitely earlier on *and after the doctors have deemed [husband] not competent*, I still think there was probably another 12 months where we could have done that" (59 year old woman, spouse and caregiver, interviewed with spouse)

"It's my life. I don't mind if the decision doesn't go my way, none of that matters. *It's to be acknowledged and recognised that you're still a person* and you've still got the ability to reflect what it is that I want, that I would like, and I'm quite happy to listen if there is to be another judgment..." (71 year old woman, living with dementia, interviewed with spouse)

# INDIVIDUALIST VERSUS RELATIONAL PERSPECTIVES

## 'It's OUR problem'

"..what we are faced with here is a problem that *you and I have and you and I have to deal with it*. So, it's not the individual. It's at least the individual and their carer. To take it further, it's the family, the friends, the associates ...who have gone through the same process, all those people are somehow affected."

(67 year old man, living with dementia, interviewed alone)

## 'Maintaining and redefining couplehood'

"..when he's doing his banking on the computer he loses some finances from whichever account ..but we work through – you know 'let me sit down and I'll see where you're going and what you're doing' ...instead of taking the whole lot off him at this moment *because he likes to be the husband and the protector*"

(65 year old woman, spouse caregiver, interviewed with spouse)



# RECOMMENDATIONS

- Supported decision-making is **already happening** informally. Community attitudes generally support the idea of **maintaining involvement in decision-making for as long as possible**
- A relational approach. **Focus on 'we' rather than 'me'** – support for the 'relational decision-making unit' where possible
- A **formal supported decision-making framework** which clarifies roles and includes a 'spectrum approach'
- Independent supported decision-making facilitators who operate in a capacity building role
- Advocacy, education and community development to address social and contextual barriers. Addressing constraints in service options and service provision

# RESOURCES & IMPLEMENTATION

<http://sydney.edu.au/medicine/cdpc/resources/supported-decision-making.php>



# PILOT TRAINING PACKAGE

- 6 x pilot workshops (81 participants, 3–5 hours duration)
- 2 x 'train the trainer' sessions (31 participants, 4 hrs duration)
- Aim to deliver sessions more broadly and evaluate more fully
- Long term aim to embed supported decision-making learning materials in dementia and aged care training pathways

# POLICY GUIDELINES

## 1.3 Each consumer is supported to exercise choice and independence, including to:

- a. make decisions about their own care and the way that care and services are delivered
- b. make decisions about when family, friends, carers or others should be involved in their care
- c. communicate their decisions
- d. make connections with others and maintain relationships of choice, including intimate relationships



# SUPPORTED DECISION-MAKING FORUM

- National Plan on Elder Abuse (Council of Attorney General's Working Group on Protecting the Rights of Older Australians)
- Initiative 4.5.1: "Building skills in supported decision-making"
- 38 participants – consumers, policy, research, practitioners
  - Bring together key stakeholders
  - Prioritise initiatives
  - Agree on a set of recommendations
  - Develop agreements on ongoing collaborative work

A woman with long, white hair styled in a braid, wearing a white sleeveless top and a gold chain necklace. She is sitting in a white chair outdoors, surrounded by lush green plants. The background shows a wooden building with windows.

# Theresa Flavin

Dementia Advocate

# REFERENCES & FURTHER RESOURCES

- Australian Law Reform Commission (2014). 'Equality, Capacity and Disability in Commonwealth Laws'. Sydney: Australian Law Reform Commission. <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>
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- Sinclair, C., Gersbach, K., Hogan, M., Bucks, R. S., Auret, K. A., Clayton, J. M., Agar, M., Kurrle, S. (2018). How couples with dementia experience healthcare, lifestyle, and everyday decision-making. *International Psychogeriatrics*, 1-9. doi:10.1017/S1041610218000741

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*Thank you*