



**Barwon  
Health**

## **“HEAR MY VOICE”**

**Advance Care Planning (ASK, CHAT, PLAN)**

**with and for**

**People with Disability**

**Jacqui Pierce, Elica Petroska and Jill Mann**

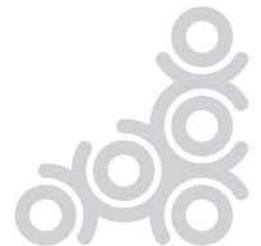


## Disenfranchised Death

**“Disenfranchised death is a death that is not openly acknowledged with the dying person, where the dying person is socially excluded from the process of dying and deliberately excluded from the decision making processes...”**

Reed 2006.

**How dare we assume people do not understand?**



## Disability and health outcomes

- Based on the limited data available, we know that the overall health of people with disabilities is much worse than that of the general population. By definition, people with disabilities must have a health condition or impairment, so a degree of difference in health status is inevitable.
- The difference observed, however, extends to areas of health that have no biological connection to the health condition or impairment that is associated with a person's disability.

*Citation: 2012, Disability and health inequalities in Australia, VicHealth*

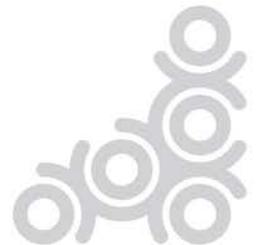


# Disability and health outcomes

## Self-reported health outcomes (among those aged 15–64 years)

- 35% of people with disabilities report poor or fair health (Kavanagh & Krnjacki 2012) compared with 5 per cent of people without disabilities (AIHW 2010).
- Self-reported health is worse for people with profound or severe disabilities, with 45 per cent reporting fair or poor health (AIHW 2010).

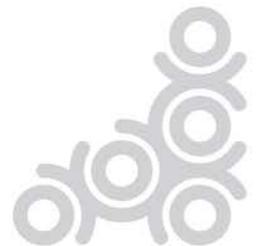
*Citation: 2012, Disability and health inequalities in Australia, VicHealth*



# The BDPAAC Partnership and Project

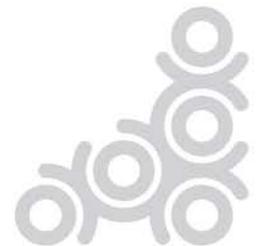
Barwon  
Disability  
Palliative  
Approach  
Advisory  
Committee

Established 2013



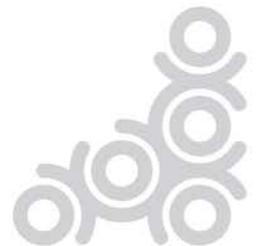
# The BDP AAC Partnership Committee

- Chairperson - Intensive Care Specialist - Barwon Health
- Project Consultants
- Karingal – Accommodation Support
- Karingal – Individual Support
- Karingal - Mental Health Support
- Barwon Health – Advance Care Planning Co-ordinator
- Barwon South Western Region Palliative Care - Palliative Aged Care Support Nurse
- Anam Cara House Geelong (Our Community Hospice) representative
- Person Living with a Disability
- Family Members
- Office of the Public Advocate
- Barwon Medicare Local (Primary Health Net work Western Victoria)



## BDPAAC – work to date

- Awareness raising and marketing tools with the messages of ASK, CHAT, PLAN and LIVING WELL Dying Well have been developed for use in the disability sector.
- Presentations at a number of disability related forums and conferences have occurred.
- A project brief for a Disability Quality Improvement Project has been developed to undertake with an established ACP program.



# The BDPAAC Project

## PURPOSE:

To assess the efficacy of an established ACP program model, when involving people with a disability and their significant others.

## METHODS:

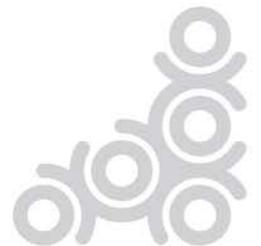
Recruit 30 people with a disability and their significant others to take part in the project.

The participants will ideally consist of:

- 10 people deemed competent
- 10 people deemed non-competent
- 10 people who require supported decision making.

Develop and administer a post ACP survey for:

- Participants and/or their “person responsible”
- ACP program staff.



# The BDPAAC Project

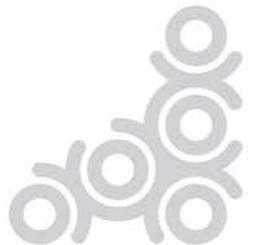
## EARLY RESULTS:

People with a disability may require:

- More time, more explanation and consultation during the ACP process.
- Improved plain language, easy read information with pictorial inclusions.

ACP staff may require:

- Additional resources, information and education in working with this cohort of people regarding their ACP.

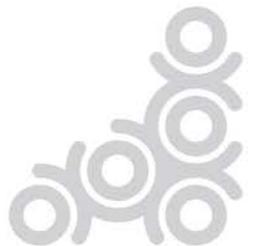


# The BDPAAC Project

## CONCLUSION:

We hope to demonstrate:

- Enablers and barriers regarding the current ACP model.
- Recommendations and best practice evidence for future ACP implementation for people with disability.
- Findings to improve participation in ACP for people with a disability across Australia.



# THANK YOU and QUESTIONS

Thank you for attending our session today and we hope you have inspired you to undertake some similar work in your area of Australia 😊



Questions  
are  
guaranteed in  
life;  
Answers  
aren't.