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Background to Health Decision Making with a Cognitive Disability

- Last few years increasing national change to document, in advance, our health preferences to take effect when we are no longer able to make our own decisions.
- Often assumed to be most useful for end of life decisions.
- Can be used for complex health conditions where capacity fluctuates, obvious example being for Mental Illness.
- Maybe useful in other circumstances?

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Capacity assessment problems

- Diagnosis is often seen as sufficient.
  - Binary approach
- Unsophisticated understanding and assessment of capacity.
  - Communication differences equate readily to impaired capacity.
  - Having an intellectual disability also seen to readily equate to impaired capacity
    - See https://www.nice.org.uk/guidance/ng108/chapter/Recommendations#assessment-of-mental-capacity

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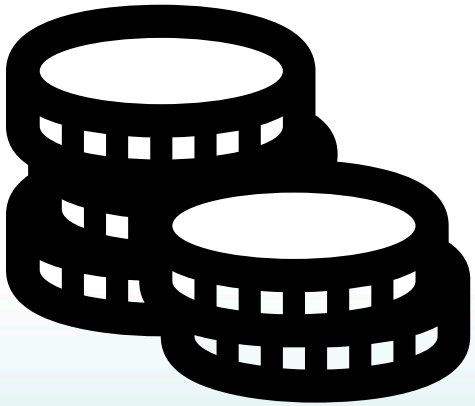
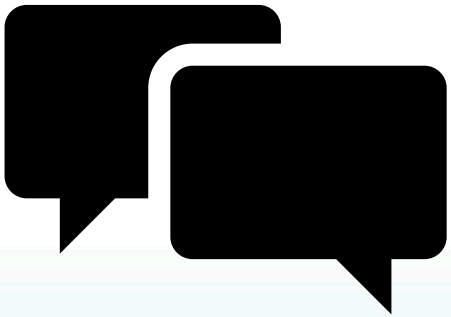
Unhelpful unpacking of Capacity



- Capacity is not global
- Capacity is domain specific
- Can have capacity for some things and not others
- **Heads I win, tails you lose approach**: you have capacity for the matters in which it is convenient for me, and the converse applies.

Mental Health Act Qld, 2016



- Purpose to improve compliance with CRPD
- Allowed for specific Mental Health Advance Health Directive
- Feedback:
  - Consumers “Looks great but will anyone read it?”
  - Clinicians “No one has taught us to work with patients views and wishes”

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Disability & Health Sectors Intersection

- Historically very poor connection
- Each side deeply & primitively suspicious of the other
- NDIS not assisting this divide

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Disability & Health Sectors cont'd

- Poor sector connection,
- Combined with inadequate understanding of capacity
- Difficult to achieve positive health outcomes for people with a cognitive impairment.

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Known Health Risks

- respiratory disease
- epilepsy
- dysphagia
- heart disease
- neoplasm/cancer
- reducing use of psychotropic medication
- chronic constipation

- An Action Plan: Meeting the Health Needs of People in Care with a Disability, The Queensland Government's 2019 implementation plan in response to the Public Advocate's Report, 'Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland, A systemic advocacy report' ,

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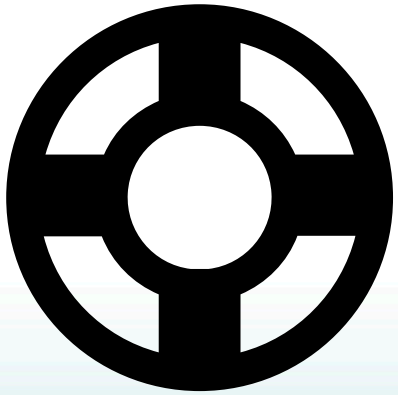
Antidotes



- Common screening tools embedded into health records.
- Doctors “friend”, descending sliding scale calculator for reducing antipsychotics for time poor doctors – app?
- Regular medical reviews involving actual review of the person and their current medications.
- Overall Directive/Plan that pulls key information, key professionals, views, wishes and preferences together

Health Planning and Advance Health Planning

- Difficulty with enforceability of ordinary “plan” with health teams:
  - Particularly when the person is unknown to health professional
    - New GP as regular GP on holidays
    - Emergency department
- Assumption of what is contained in the plans
  - Is there a lesser valuing of life???
    - This concern is often raised regarding Assisted Dying Laws, but same issue can appear in relation to assistance with living.
- Monitoring of the situation
  - Currently insufficient for Coroner to track “Deaths in Care”, without healthcare critical incidents being tracked.

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Utility

- Advance Health/Care Directives can summarise treatment preferences.
- Can be for periods other than “End of Life”
- Many people could complete a directive with support.
  - How would support be verified, would witnessing and medical sign off be sufficient safeguarding?
  - Consider Representation Agreements
- Could the person’s supporters/decision makers complete the plan?
  - Some plans are already written this way.
- Traditionally, Statutory DM’s reluctance to sign off plans in advance.

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Current Practice is not sufficient

- Need to tip the scales in favour of the person with a disability and their verified supporters.
- Health Care plans for people with a disability need to be more than aspirational.
- Should be a legal requirement for plans/directives to be identified at entry to hospital or health service.
  - Health professional has obligation to read plan and implement unless it is not relevant to presenting health situation.

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Accessible Document

- Legal status
- Useful to access preventive and emergency care that is in alignment with current treatment
- Sourced on arrival to new health professional, or health service or hospital

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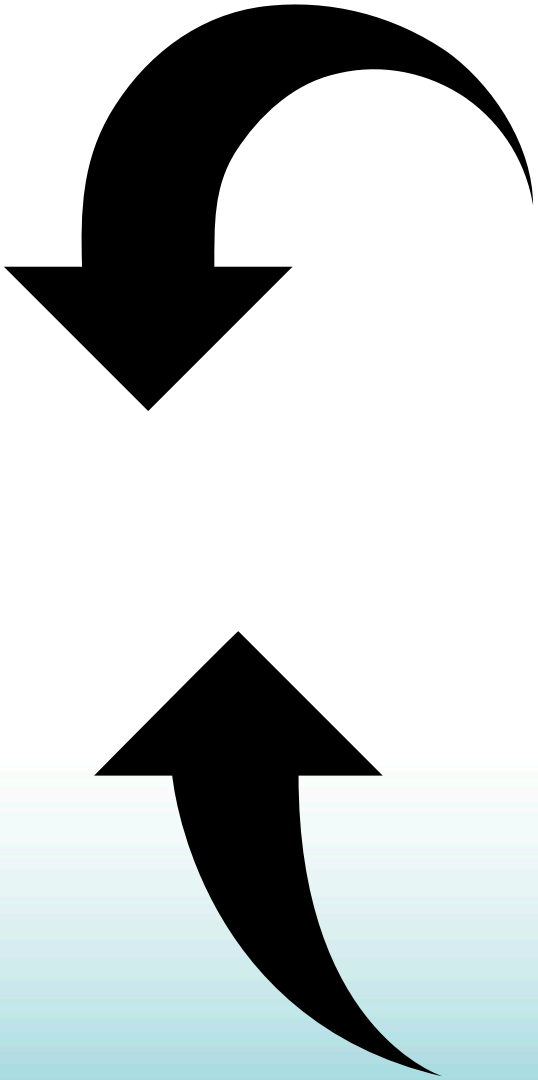

Conclusion

Decrease barriers between Health and Disability sector that prevent adequate care.

Increase structured access to regular health services

Thank you

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