University of
South Australia

“People Should Respect My Wishes”: Enablers and Barriers to Advance Care Planning for Adults with Intellectual Disability

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Context

- People with intellectual disabilities often experience barriers to exercising self-determination, including at end of life. There is a range of literature supporting this.

- Advance Care Planning (ACP) enables individuals to document preferences for future care as well as managing their body after death.

- This study as a Social Work honors project explored perspectives of six adults with intellectual disability in South Australia.

Research Aims

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- 1. Identify enablers and barriers to ACP participation.
- 2. Examine processes and tools used in ACP.
- 3. Inform social work practice to enhance autonomy and inclusion for people with intellectual disability.

Theoretical Framework

- Grounded in the Social Model of Disability and Social Constructionism.
- Recognises disability as arising from social and attitudinal barriers rather than impairment.
- Focuses on relational autonomy and supported decision-making.
- Emphasises co-construction of meaning and participant voice.

Methodology Overview

- Qualitative, interpretivist design.
- Six adults with mild to moderate intellectual disability participated.
- Semi-structured interviews – verbal, AAC, or email communication.
- Reflexive journaling used as secondary data.
- Ethics approval from UniSA Human Research Ethics Committee.

Accessibility and Data Collection

- Easy-read information and adapted consent forms ensured informed participation.
- My Life Decisions (SA Developed Document by Dr Margaret Brown) document used to scaffold understanding of ACP as part of an SA Health consideration of implementing legislation.
- Researcher built trust and rapport to support comprehension.
- Interviews transcribed and analysed using Braun & Clarke's Six-Step Thematic Analysis.

Findings Overview

Two major themes:

- 1. Barriers to Advance Care Planning
- 2. Enablers to Advance Care Planning
- Sub-themes highlight knowledge gaps, risk aversion, and relational supports.

Barriers to Engagement in ACP

Theme 1: Lack of Exposure to Advance Care Planning

- None of the participants had an advance care plan; most had never heard of ACP.
- Participants misunderstood ACP, confusing it with disability or guardianship processes.
- ACP was not seen as relevant — “it just doesn’t come up.”
- Indicates both a **lack of awareness** and **limited opportunity** to engage in ACP.
- Highlights a need for **promotion and education** about ACP for people with intellectual disabilities and their supporters.

Barriers to Engagement in ACP

Theme 2: Denying Us the Dignity of Risk

- Participants described being **excluded from important conversations** and decisions.
- Many reported others speaking for them or disregarding their input — “it goes in one ear and out the other.”
- Overprotection limited autonomy and reinforced assumptions of incapacity.
- Participants expressed frustration at being treated differently from other adults.
- Denying the “dignity of risk” restricts growth, confidence, and the right to self-determination.

Barriers to Engagement in ACP

Theme 3: Embedded Decision-Making Expectations

- Participants expected **others (family or professionals)** to make healthcare decisions for them.
- None viewed themselves as the **primary decision-maker**.
- Some accepted substitute decision-makers, while others felt **their preferences were overlooked**.
- Revealed tensions between **relational dependence** and **desire for autonomy**.
- Suggests limited opportunities to document or influence end-of-life decisions meaningfully.

Enablers to Engagement in ACP

Theme 4: Belief in Our Capacity to Make Decisions for Ourselves

- Participants expressed strong **self-belief** in their ability to make decisions.
- “It’s for me to choose, not everybody else.”
- Trusted supporters who respected autonomy were key facilitators.
- Demonstrated understanding of ACP in medical contexts and openness to discussion.
- Indicates the importance of **trusted relationships** and **affirmation of capacity**.

Enablers to Engagement in ACP

Theme 5: Giving Us Time to Consider What is Important to Us

- Participants wanted **information presented slowly and step-by-step**.
- Time and repetition help build understanding and confidence.
- Researcher adaptation (rapport, shared interests, flexible communication) improved engagement.
- ACP conceptualised as a **process over time**, not a single event.
- Highlights need for **time, trust, and tailored communication** in ACP facilitation.

Enablers to Engagement in ACP

Theme 6: Supportive Environments and Appropriate Resources

- Participants needed **extra support** and simpler, more accessible information.
- Preferred **relaxed, informal environments** (e.g., family or partner discussions).
- Written forms (like *My Life Decisions*) were often overwhelming or unappealing.
- Suggested alternatives like **videos** or **interactive tools** to express wishes.
- Calls for **adapted, creative, and person-centred resources** to enhance inclusion in ACP.

Discussion and Key Insights

- **Human rights foundation:** The UNCRPD underpins the right of people with intellectual disabilities to make decisions about their own healthcare, including at life's end — a right still inconsistently realised.

- **Persistent barriers:** Limited awareness of ACP and risk-averse attitudes continue to deny people the **dignity of risk** and opportunities for self-determination in end-of-life planning.

- **Challenging assumptions:** The study shows adults with intellectual disabilities are **capable and willing** to engage in discussions about future care, countering stereotypes of incapacity.

Discussion and Key Insights

- **Supported decision-making:** Empowering, trusting relationships and everyday decision-making opportunities strengthen autonomy and prepare individuals for complex choices about care.

- **Practice implications for social workers:** Social workers are well placed to lead ACP facilitation — requiring training, accessible resources, and commitment to **human rights-based practice**.

- **Systemic and resource needs:** Development of **adapted, creative, and easy-read ACP tools**, along with sufficient time and supportive environments, is essential to ensure equitable access and participation.

Future

- People with intellectual disabilities can and want to engage in ACP.
- Barriers are primarily systemic and attitudinal, not cognitive.
- ACP is an evolving process requiring relational trust and adapted communication.
- In line with a number of other projects such as My Life My Wishes and studies by Office of Pubilc Advocate in some states, a broader studies are needed.

Conclusion

- ACP is a critical pathway to uphold dignity and autonomy.
- People with intellectual disabilities must be supported to express and document their wishes.
- Another challenge is each state in Australia does something different.
- Consideration of a national approach and exploring value of ACP's even if not legally binding – surely recorded and regularly discussed wishes are important!

Conclusion

- **“People should respect my wishes.” – Participant**

Fab Resource from across the ditch

- Katie and the supervisors have ongoing conversations about ACP and the government/policy folk who seem to think if it is not legally binding then is it worth doing –
- We need to take a look at New Zealand as an EOL Doula I use this tool.
- https://www.understandable.org.nz/advance-care-planning

Katie's Supervision Team

- Associate Professor Caroline Ellison
- Dr Nilan Yu
- Dr Margaret Brown

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