

SEE ME
HEAR ME
RESPECT ME

IMPROVING HEALTHCARE
FOR PEOPLE WITH DISABILITY

Determining decision-making abilities of people with intellectual disability consenting to participate in qualitative research – moving from substitutes to supporters

Presenter: Rhonda Beggs

HREC presentation 29/11/2024

Metro South
Health



GRIFFITH
UNIVERSITY

INCLUSIVE FUTURES:
REIMAGINING DISABILITY



Queensland
Government

Before we start



Intellectual disability

Substitute Decision Maker (SDM)

Supported decision maker/decision making supports

Context

Hearing the voice of people not substitutes

Special protections

Emphasis on decision making ability



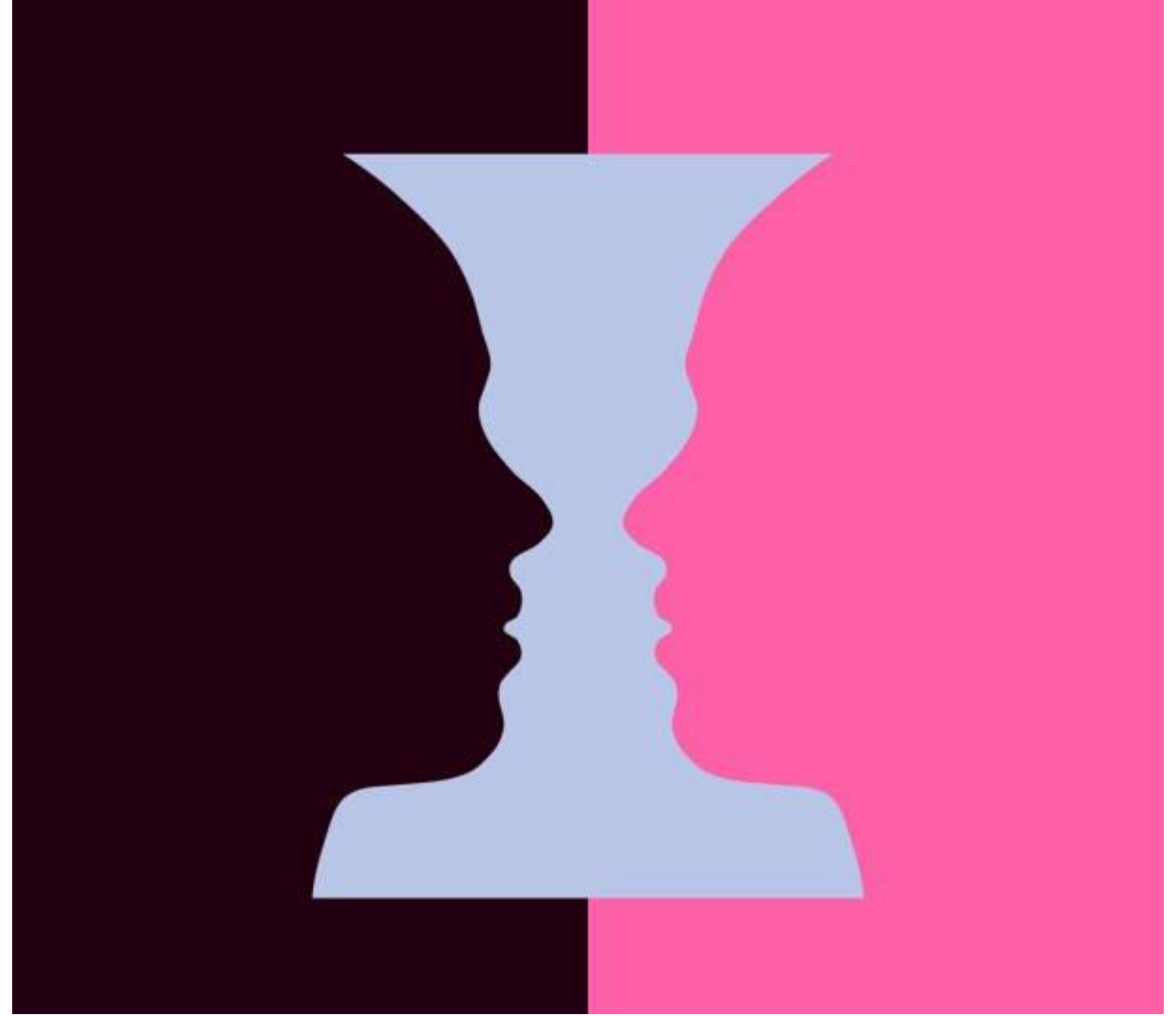
Image accessed from
<https://disability.royalcommission.gov.au/>

Challenges to inclusive research practices

1. Not a homogenous group
2. Assumption bias
3. Gate keepers
4. Fear, knowledge and understanding
5. Time poor, money poor!
6. Clarity of terminology

Park all 
bias outside
the door.

**So, what's
the issue
with status
quo?**



“SEE ME. HEAR ME. RESPECT ME.”

IMPROVING THE HEALTH
OF PEOPLE WITH DISABILITY 

Supported decision making principles

- 10 Principles suggested by DRC for reform



Image accessed from
<https://disability.royalcommission.gov.au/>

Considerations for practice



Support assent principles



Consent practices



Assessment tools



Co-design



Recognition of personhood



Ethics advisor

“SEE ME. HEAR ME. RESPECT ME.”

Considerations for HRECs

Be bold – have a decision-making *ability* stance– ask:

- 1.Has the communication strategy been adapted?**
- 2.Has the community been involved in developing the protocol?**
- 3.Is the use of proxy necessary and for what purpose?**
- 4.Is there a clear understanding of the difference between legal capacity and consent *ability*?**
- 5.Are the safeguards proportionate to the level of risk?**

The research team

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Advisory services provided by
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“SEE ME. HEAR ME. RESPECT ME.”

Literature

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