

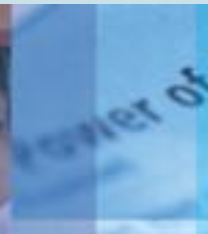
# Among the Outliers:

## A Socio-legal Perspective on the Transition to Adulthood for People with Severe Cognitive Disability

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Before we start:  
On Lived Experience and Oral History  
in Research



# Socio-Legal Research



- Core idea that sociology (and other types of social research) has something to say about Law (I know, right!)
- Seeks to study law more broadly than the self-referential way it is normally studied
- Understanding the operation of law in the social world
- In this context: how law is constructed and then constructs social meaning
- Law as a site for examining shared social meanings
- Health law

# Personhood and Citizenship



- Personhood: a core human-ness
  - being a human as distinct from an animal or other object
  - Defining (legally speaking) the beginning and end of life
  - Usually passive and fundamental – either absent or present
- Citizenship: in between the beginning and end of life
  - What a person can DO as a human being, within their system
  - Sex and relationships, work, Finances (money, ownership, contract), healthcare
  - Agency and Capacity are central
  - Some flexibility and change – can be impacted by the individual and their action or inaction

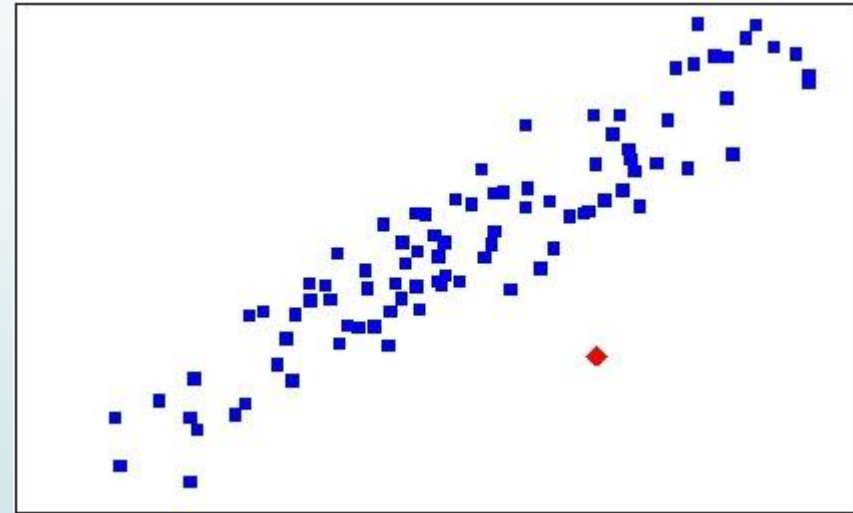
# “Adulthood”

- It’s hard to define but we know it when we see it...  
or do we??
- The “end game” of a transition phase from  
“childhood” to full citizenship
- Generally: increasing rights, roles and  
responsibilities achieved or bestowed
- Focus on how reflected in and shaped by law



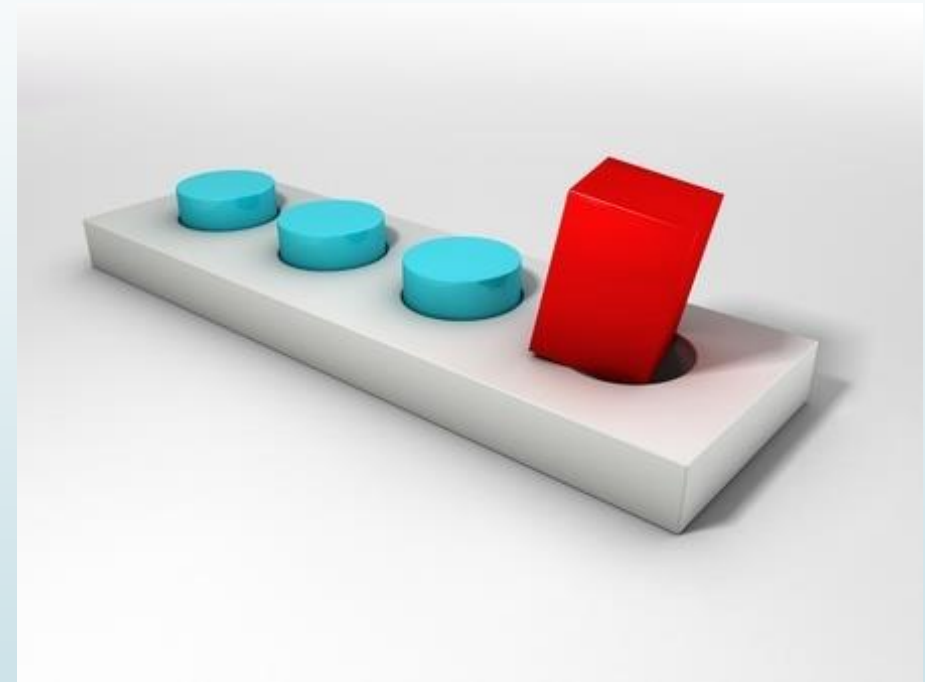
# “Outliers”

- The usefulness of what doesn't fit
- Liminal Spaces
- Outside the box helps us see what is IN the box, identifying the box itself
- Illustrating our shared assumptions



# Outliers and Adulthood: Capacity

- Despite their age, people with severe cognitive impairment have trouble fitting our legal (and social) discourse about adulthood
- Capacity is the core concept
- Removal of agency is a core “solution”
- Reversion to “childhood” state in law





# Adulthood in Law: Criminal Responsibility

- No criminal responsibility under the age of 10 years (*doli incapax*)
- A rebuttable presumption under the age of 14
- s29(2) A person under the age of 14 years is not criminally responsible for an act or omission, unless it is proved that at the time of doing the act or making the omission the person had capacity to know that the person ought not to do the act or make the omission. *Criminal Code* 1899 (Qld)



# Adulthood in Law: Health

- Consent (without a parent or guardian) to medical procedures: 14-16 years old, depending on the jurisdiction
- From age 14: Medicare won't provide information about treatment to parents or carers
- From age 15: can get an independent Medicare card
- After age 14: if a person remains on their parents/guardian's Medicare card, that parent or guardian won't see doctors visits or costs on *mygov*
- GILLICK competence: mature enough to understand the treatment, effects and risks:
  - Generally 16-18
  - Reasonably likely from 14-16
  - Less likely from 14



# Adulthood in Law

- Education: Compulsory from age 6 to 16
- Markers “bestowed” by law – a collection at 18 years of age
  - Voting
  - Capacity to Contract
  - Drinking
  - Military Service
  - Marriage (though note exceptions possible from age 16)



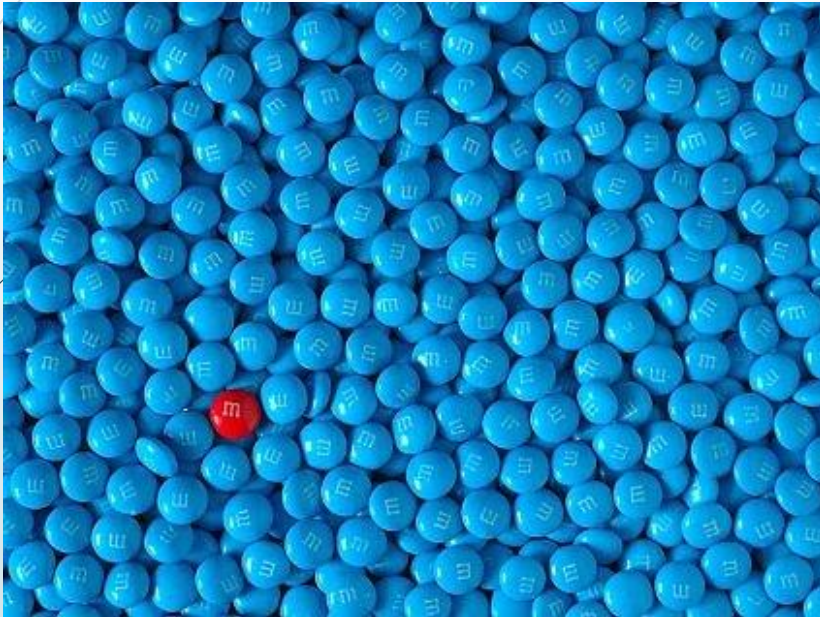


# Transition Points: Outliers

- Money and Banking
- Education
- Centrelink
- Medicare
- Consent to Medical treatment
- Contract for services
- Funding agreements
- Housing
- Voting
- NDIS?

- **Common elements:**
- **Lack of Capacity is key**
- **Medicalised**
- **Permission-based**
- **Silos (not universal)**
- **Bureaucratic**
- **Guardianship is the endpoint**
- **Systems and law built around substituted decisions and deficit model of disability**
- **Challenges core citizenship**

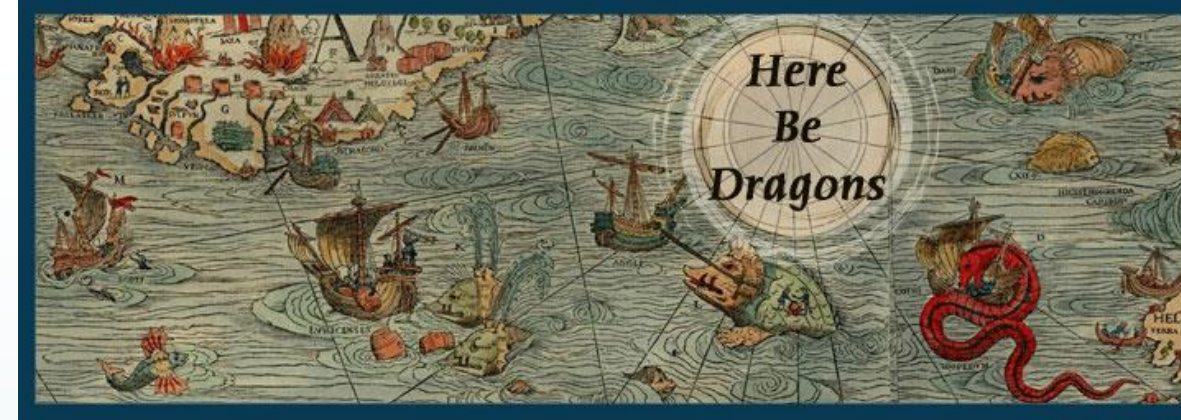
# Among the Outliers: What happens?



- If a person cannot “perform” adulthood according to our current law, what happens?
- UNCRPD and the shift to supported decision-making
- Principles underlie the NDIS and its regulation
- BUT – our current legal systems is based on substituted decision making
- AND even if we shift, legally speaking, to Supported Decision making, what about the OUTLIERS?



# Future Directions



- My empirical work – based around lived experience and oral histories of transition to adulthood, including my own experience
- Inclusive Research? How do we do inclusive research with people who have severe cognitive impairments?
- How do we preserve the voices of parents and carers without speaking FOR the person they care for?
- Future Directions and the NDIS – how will a supported model sit within a substituted system?
- We must do a better job of seeing our outliers: who they are, what they tell us, and how well our programs and "solutions" fit
- If it doesn't work for our Outliers, does it really work?



## Questions?

- Contact me at [m30.king@hdr.qut.edu.au](mailto:m30.king@hdr.qut.edu.au)
- If you're interested in my work, or know a parent or carer of a person with severe cognitive impairments, aged between 18 and 22!

