

Centering the Margins:

*perspectives on stigma, discrimination
and epistemic injustice*

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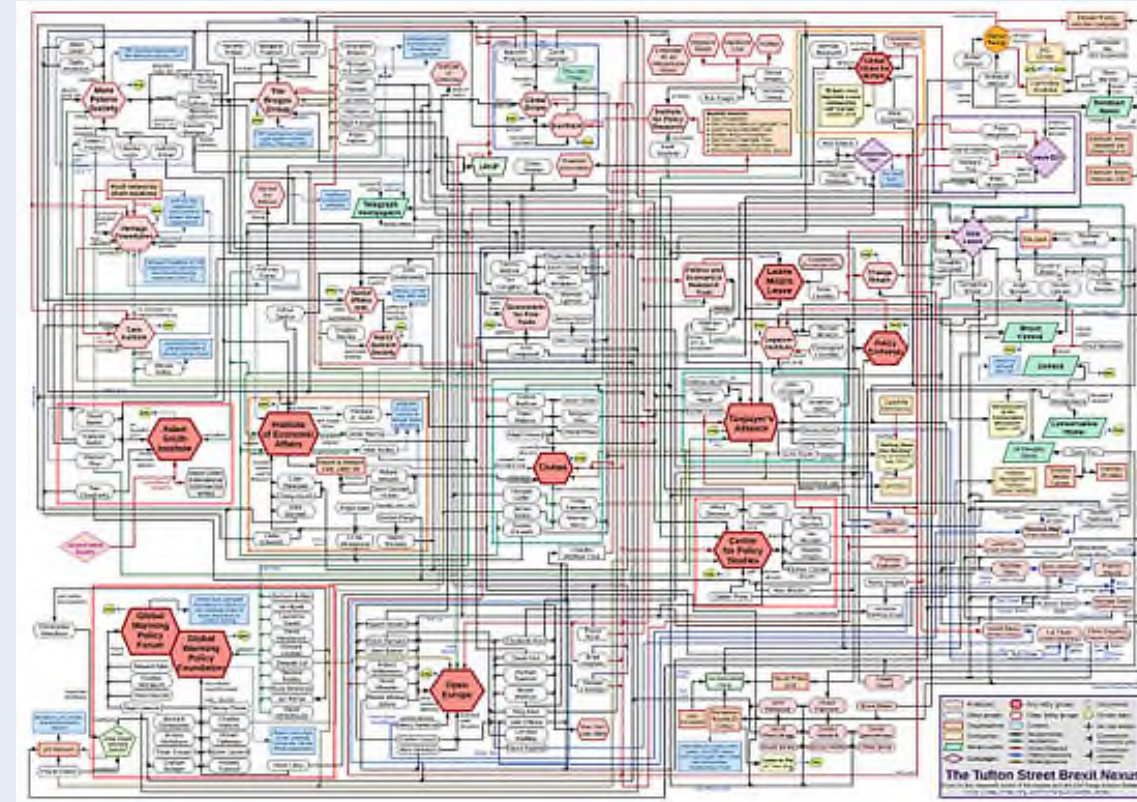


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Disability Studies

Study of *disability* as a complex societal phenomenon

“Disability is both a signifier of inequity and the promise of something new and affirmative.” (Goodley et al, 2019, p. 973)



Dis/ability

Both sides of the ‘/’:

- Ambivalence
- Critical reflection on normality

-> disability: not only another side of the coin, but also an alternative

-> identify norms (pragmatic and political), but also question these norms:

queering the norm

‘For disabled people, independence cannot exist without interdependence.’



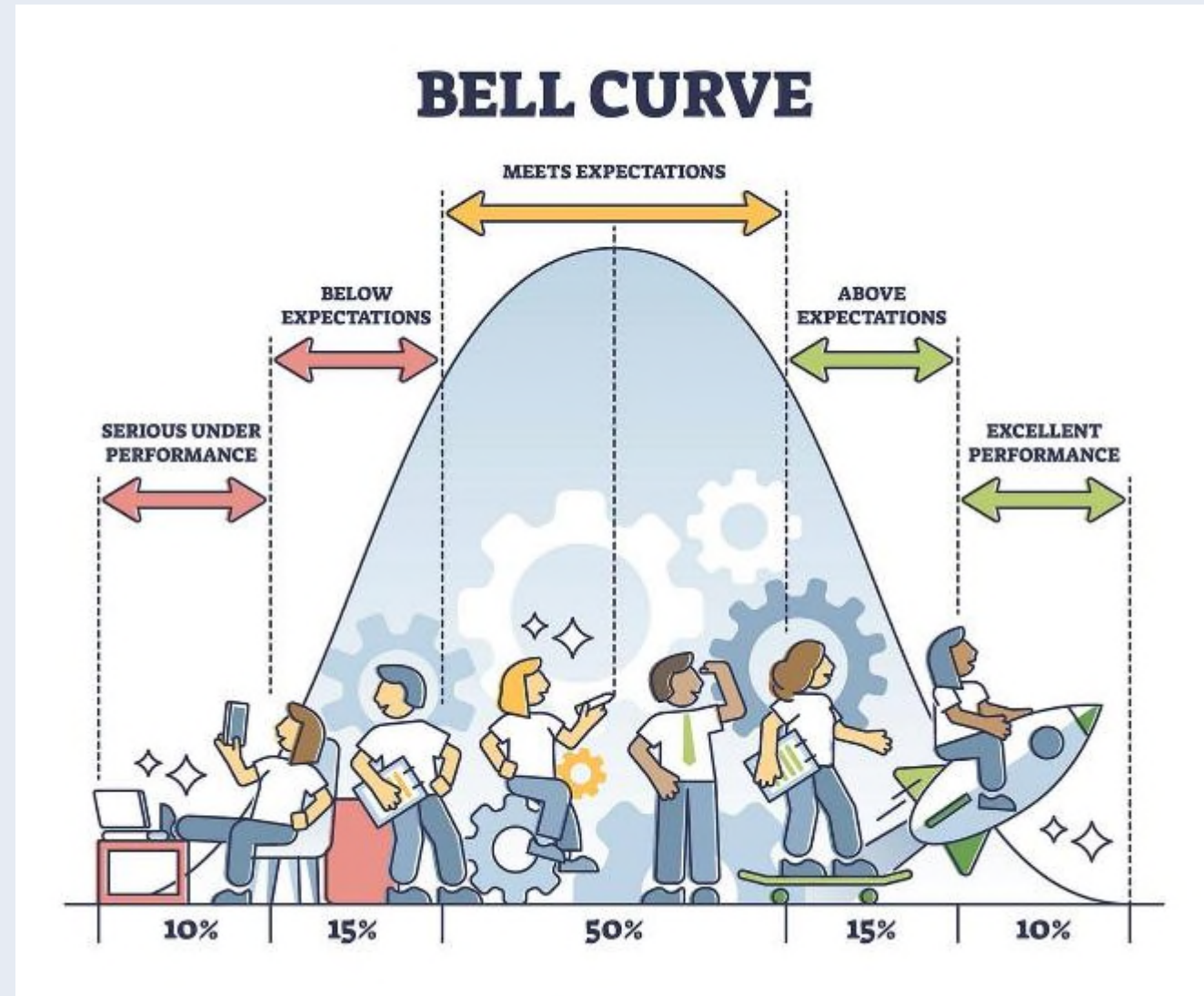
‘Meaningful access means redesigning societal systems, not “fixing” disability.’

‘For many, disability is an identity—not something that needs to be overcome.’

Normalcy

- Social tyranny of *normalcy*: there is a 'normal' that tells you how to behave and how to judge (Davis, 2017)
- Confronted by norms, imposed on them, but not being able to live a 'normal' life (Boelsma et al, 2018)

-> *marginalisation*



'The Reference Man'

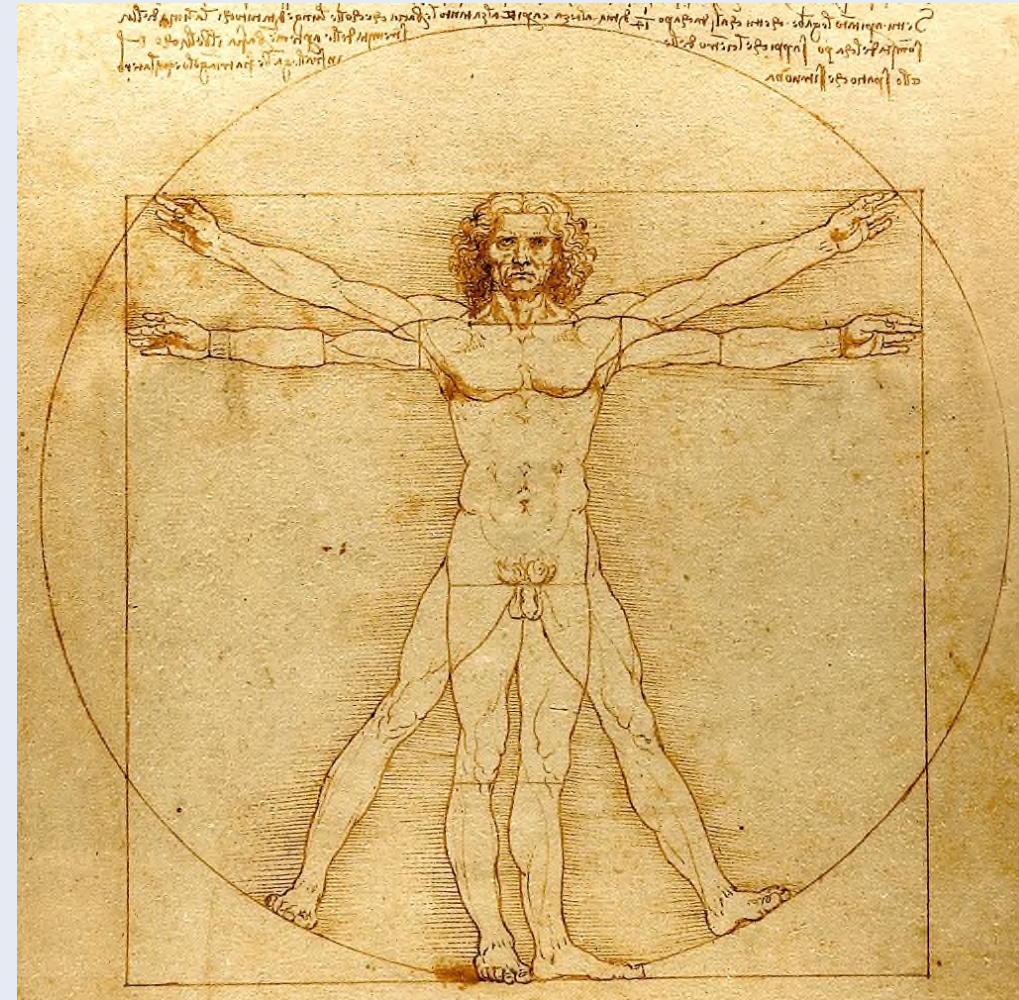
Typical person: Vitruvian Man (Leonardo da Vinci)

- ✓ Male
- ✓ ± 35 yrs
- ✓ White
- ✓ Upper middle class
- ✓ Employed
- ✓ Heterosexual
- ✓ Reproductive
- ✓ **Health??**

Intersectionality:

Dis/ability interconnects with ethnicity, gender, social class and age

-> *ableism*



True Colors – Bert Janssen (2013)

Ableism: form of discrimination

- ❖ Ableism refers to hyper-recognition of ‘ableness’ and the way these norms are embedded in legal structures, social policies and cultural values;
 - ❖ Norms based on assumptions about legal and social status (‘ticket to unemployment’);
 - ❖ Differentiation between ‘normal people’ and the ‘disposables’ (e.g. old people in covid times, immigrants etc.)

“Ableism is everyone’s business, not because of some ideological imperative but because we (...) are affected by the (...) spectrum of the ‘abled’ body.

It is critical that ableism stops being thought of as just a disability issue” (Campbell, 2009).



In- and Exclusion

Difference, 'being special' :

- Classified
- Pathologised
- Stigmatised
- Discriminated

Placing people outside the norm, into the margins : '**Normalising Exclusion**'

(Titchkovsky, 2012)



Stigmatising

- Negative stereotypes -> prejudice and discrimination
- Public meaning -> internalised
- Vicious circle of stigma

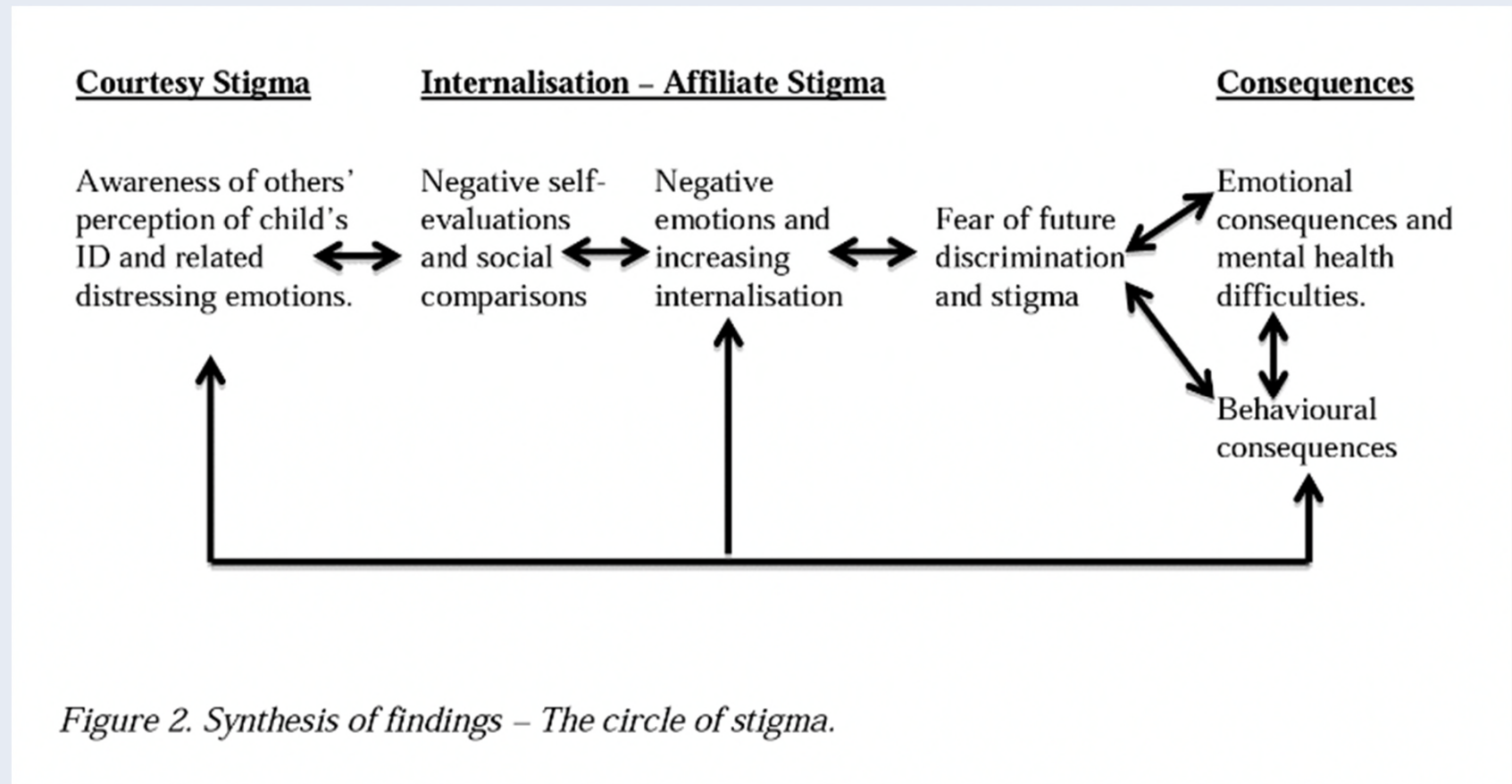


Figure 2. Synthesis of findings – The circle of stigma.

Systemic exclusion and marginalisation

Manifest in institutional and other socio-structural systems and in interpersonal interactions (Thomas, 2012)

Subdivided by Reeve (2012)

- *Structural*: physical barriers, inaccessible information
- *Psycho-emotional*: micro-aggressions, stigmatising
- Often internalised: *self-stigma*



#everydayableism

Disability as metaphor: 'don't behave autistic'

– for everyday problems of non-disabled persons without elevating marginalisation of disabled people

- What are the dangers of disability being used as a metaphor for explaining other potentially disconnected processes?
- How does our language and discourse shape the way people are categorized, and how do these categories shape the infrastructure around which people's lives are organized?
- To what extent are our theoretical and professional resources in tune with *normalcy* and *ableism*?

Specific form of social (in)justice:

➔ epistemic (in)justice

**"Why are your
needs "human"
and our needs
"special?"**

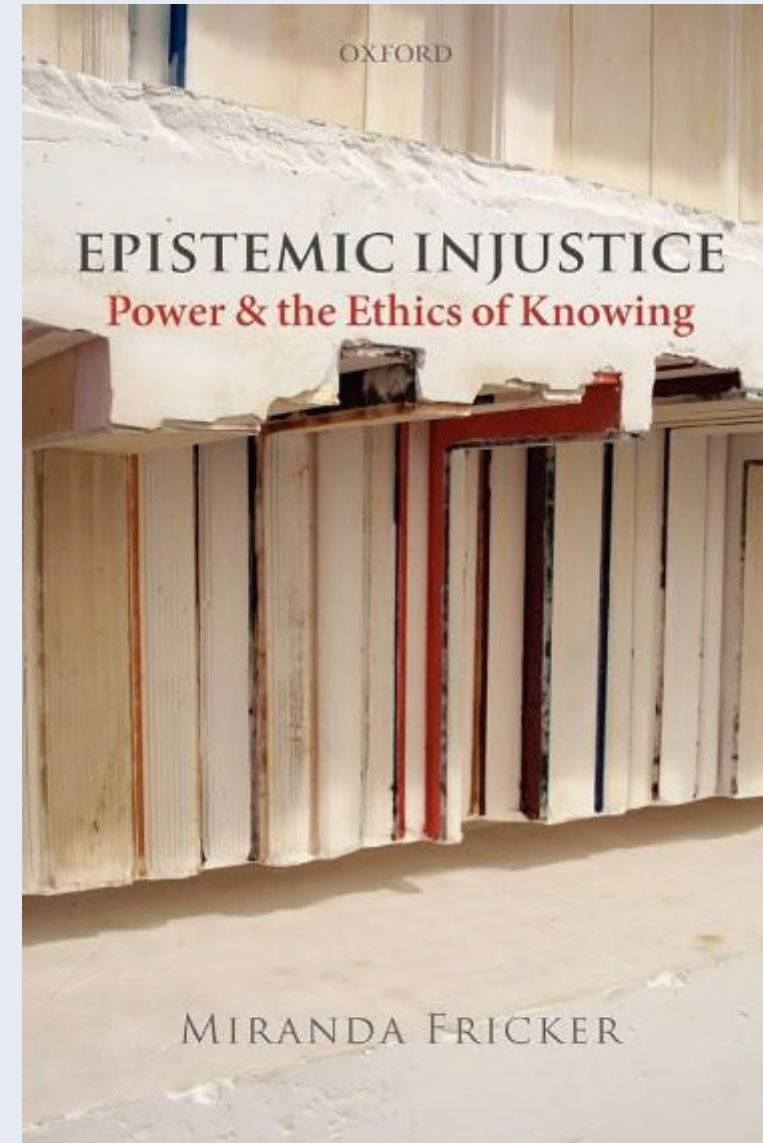
**Ableism." -
Gregory Mansfield**

Epistemic injustice

Fricker (2007): injustice related to *knowledge*

- *hermeneutic injustice*
Ignoring, excluding and/or misinterpreting knowledge provided by knowers
- *testimonial injustice*
Undervaluing of persons in communicative practices and makes unfair distinctions in authority

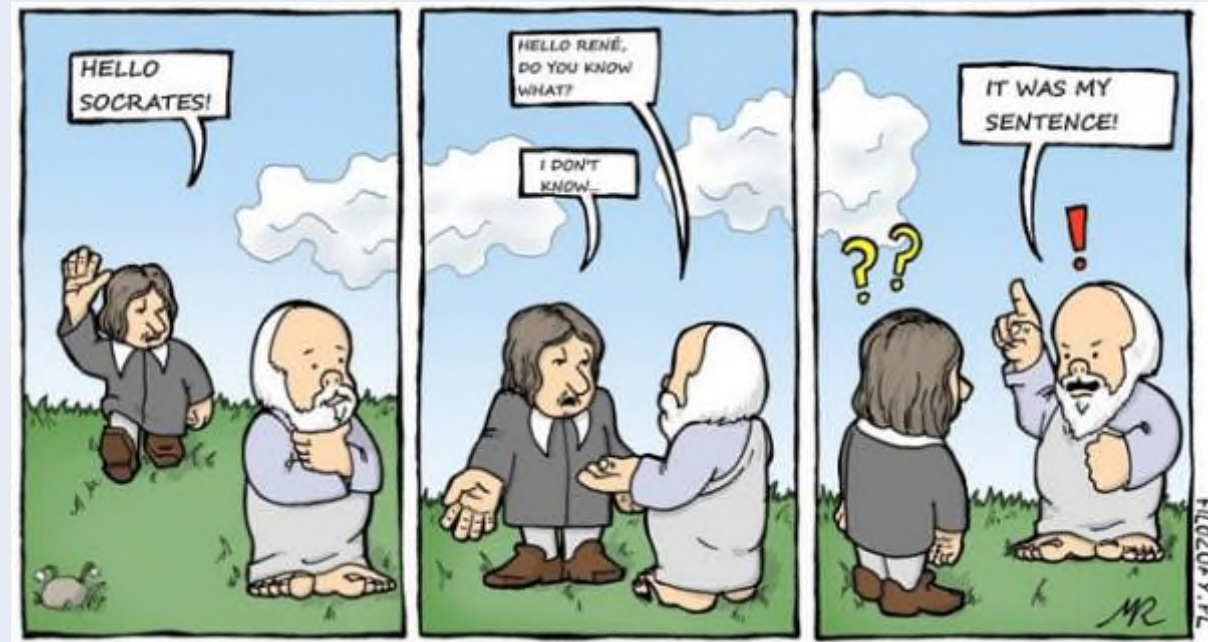
-> **How to right these wrongs?**



Ethical underpinnings

4 fundamental guiding principles:

- *Epistemic responsibility*: know the person
- *Epistemic modesty*: know what you don't know
- *Humility*: don't impose your own values on others
- *Accountability*: pay attention to the consequences of your actions -> methods and tools



(Parmenter, 2011)

Knowledge production

Inclusive and collaborative actions

- Object AND subject: in all phases of the treatment/project: 'Nothing about us, Without us'
- Acknowledge situated knowledge: experiential knowledge is an equally important source of knowledge
- Adaptive and creative (non-conventional) methods and tools
- Flexibility in time/space



Working towards Epistemic Justice (in a Robotics Project as example)

- communicative practices tailored to families (e.g. working with flash cards instead of 'traditional' information sheets) -> **avoid misinterpretations**
- experiential knowledge as equal information source-> changes **power structures**
- co-researchers are able to gather valuable data and information -> **added value** in knowledge production



Disclosure of speaker's interests

I declare no conflicts of interest

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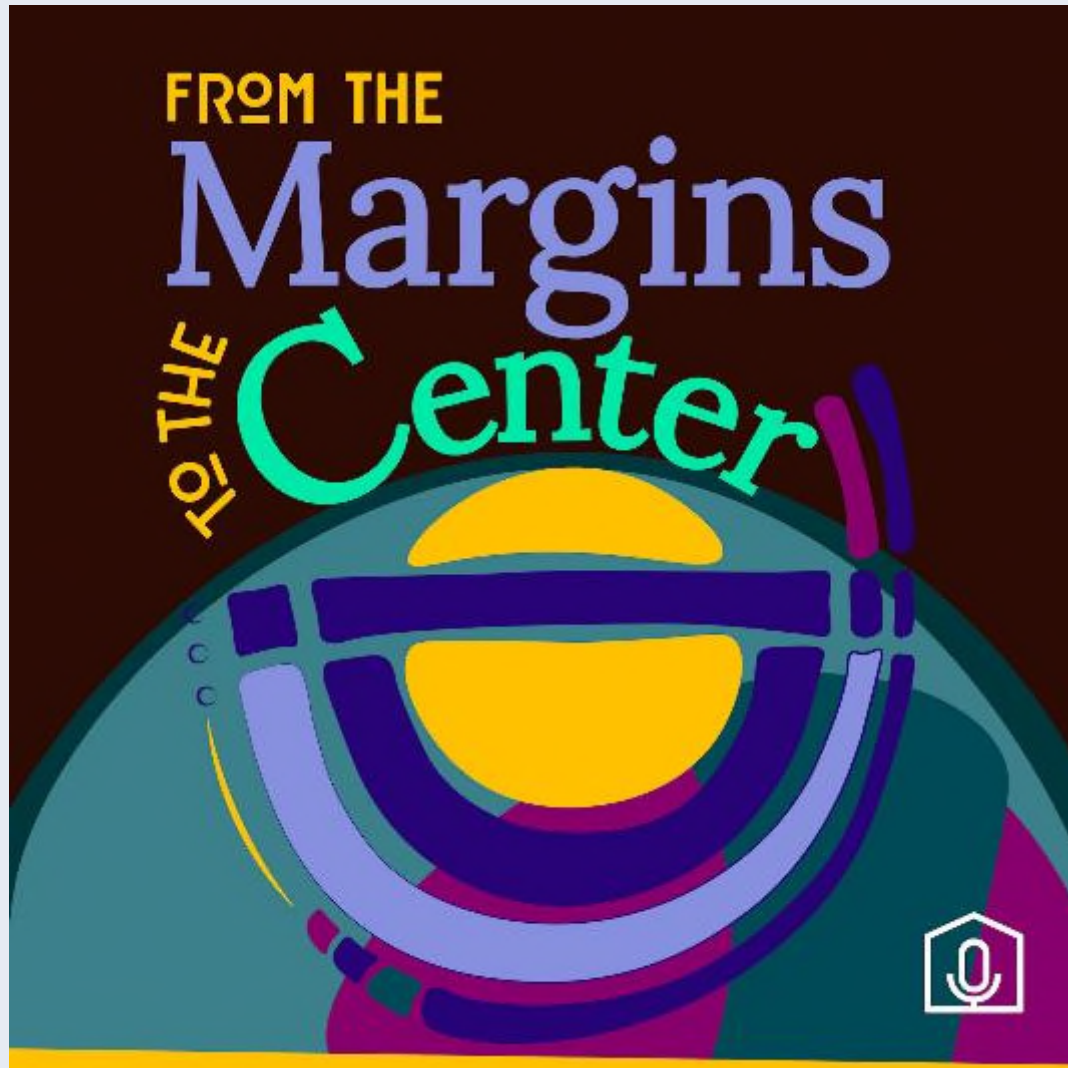
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Thank you!