Views of societal interest groups

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Overview

• What is a societal interest group?
• Feminist approaches
• Disability issues
• Public involvement
What is a societal interest group?

• My brief
  • Disability/chronic illness
  • Women
  • Other

• Groups (usually non-professional) with particular interest in the topic, may or may not have representation in policy, ethics, governance discussions
  • Professional groups are also interest groups

• Individuals/groups may ‘have an interest’ in the topic without being directly affected by it
Feminist approaches: the obvious

• Issues that directly/disproportionately affect women
• Both initial research and ultimately treatment will involve intervention into early embryos or eggs
  • How are they acquired?
  • How are women best supported/protected in information and consent processes?
• Keeping in mind global disparities in women’s rights, autonomy, access to healthcare
• Downstream consequences of human gene editing targeting disability/disease
  • Women’s disproportionate care responsibilities (within and beyond families)
Feminist approaches: the less obvious

- Conceptual and methodological attentiveness to persistent disparities in authority/power/responsibility/‘voice’
- Not solely gendered disparities
- Empirically grounded
Disability issues

• A word about language
• Disability/chronic illness are highly diverse
• Disability/chronic illness are *experiential* (not just phenotypic or genotypic)
• Much disability is not genetically related
• Intervening steps between genotype, phenotype, impairment, disability
• Disabled/chronically ill people hold wide range of opinions
Disability issues

• Expressivist argument
  • Do policy choices ‘send out a message’?
• Is it clear what we mean by disability?
• Is it clear what we think about disability/diversity?
  • Where are lines drawn between variation, impairment, minor/severe disability?
Public involvement

• Societal interest groups are among many different ‘publics’
  • How do we ensure fair and appropriate access to ethics and governance debates?
  • Bearing in mind that some groups face special barriers
• Not all interested publics are obvious stakeholders
  • What place do non-stakeholders have in governance dialogue?
What does this suggest for governance?

- Discussion of governance and ethics should be informed by well grounded understanding of the views of multiple publics
- (Much easier to say than to do)
- Based on principles of
  - Fairness
  - Epistemic modesty