



NAS/NAM Committee on Human Gene
Editing: Scientific, Medical and Ethical
Considerations
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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