



Columbia Precision Medicine Initiative
Precision Medicine: Ethics, Politics and
Culture

Columbia University

9 March 2017

Precision medicine and disability

(with some gestures towards embodiment and self)

Jackie Leach Scully

Professor of Social Ethics and Bioethics

Policy, Ethics and Life Sciences Research Centre

Newcastle University

jackie.scully@ncl.ac.uk



Overview

- Background
- Precision medicine and disability
- Theorising disability
- Disability critiques
 - Discrimination
 - Diversity
- Embodiment and identities
- Regulation, expressivism and responsibilities
- Central question

Precision medicine and disability

- What's actually new?

1)

- **Scope** of PM and
- **Regulatory frameworks** of PM

-- have the potential to alter cultural discourse about variation and disability

2) **New version** of longstanding question about disability/variation

NAS/NAM Human Genome Editing

- Somatic genome editing
 - Limit clinical trials or therapies to treatment and prevention of **disease or disability** at this time
- Germline (heritable) genome editing
 - Permit clinical research trials only for compelling purposes of treating or preventing **serious disease or disabilities...**

Theorising disability

- Context of disability rights activism
- UN Convention on the Rights of Persons with Disabilities 2005
- Biomedical model
 - Disability as a nominative pathology
- Social or social-relational models
 - Disability as result of environmental, social, cultural, political, economic factors interacting with anomalous phenotype

What's the *bad thing* about disability?

- Suffering due to particular subjective experiences of pain, disadvantage, difficulty, exclusion
- Phenotypic deviation from statistical norm does not necessarily cause impairment
- Impairment does not necessarily lead to disablement
- Genomic information is a further step back from the *bad thing*

Diversity and its value

- ?reduction in disability incidence?
- Genomic diversity has biological benefits
- ...and some people think social benefits to
- Can genomic diversity that leads to disabled embodiment also be considered a good?

Embodiment and identity

- Genetic/genomic imaginery
- Medicalization, geneticization, genomicization...
- Destabilizing lines or increasingly rigid and constrained norms?
- Genomic categories as new categories of person
- Reifying genomic categories as identities

Responsible biocitizens

- Citizens as rational, responsible consumers and choosers, with right/power/obligation to take control of health/identity
- Transfer of responsibility from collective to individual
 - Ontology of disability
 - Access to healthcare and support

Regulation and expressivism

- Regulatory challenges
- Expressivist/symbolic function of regulation
 - Individual choices
 - Policy and regulation
- Justificatory expressivism

Old ethical question in a new form

- Moral balance of selective/eliminatory interventions is different from that of editing or restoration
- ***What do we really think about human variation and disability?***