UNRAVELLING DISABILITY'S DNA
EXPERIENCE & IDENTITY IN A GENOMIC AGE

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Disability: Social experience of a medical condition

New technologies and whole genome sequencing in NHS

What can be done vs. What should be done

Severe disease: Penetration of genetic variance, age onset, symptoms & impact, treatment, quality of life, variability & range of symptoms

Disabled people have experiential knowledge: They should be included in the debate

Why ask affected families? Impact on them: Public profile of disease, expressive objections, research funding, peer support

Findings from talking with affected families:

1. Genetic condition = transformative experience for parents
2. Attitude vary across impairment groups: Screening
3. The meaning of the experience & identity politics
4. Disease classifications ≠ lived experience (do not match)
5. The limits of lived experience

Experience: How we could make good use of lived experience of families with disabilities?