

UNRAVELLING DISABILITY'S DNA

EXPERIENCE & IDENTITY IN A GENOMIC AGE



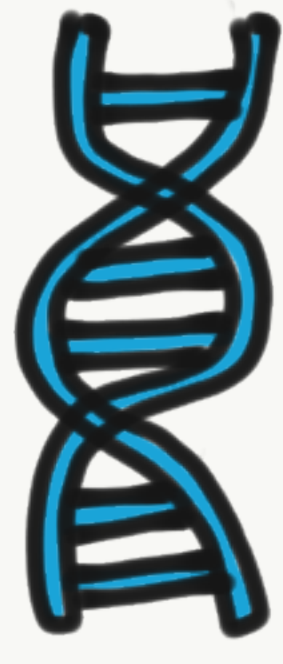
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DISABILITY → social experience of a medical condition

New technologies



tests



Whole genome sequencing in NHS

What ~~can~~ be done

What should be done



Disabled people have

EXPERIENTIAL KNOWLEDGE

↓
they should be included in the debate



WHY ASK AFFECTED FAMILIES?

→ impact on them

- public profile of disease
- expressivist objections
- ↓ research funding
- ↓ peer support

FINDINGS FROM TALKING WITH AFFECTED FAMILIES

① Genetic condition = transformative experience for parents



② Attitude vary across impairment groups



③ The meaning of the experience & identity politics

④ Diseased classifications ≠ lived experience (do not match)

→ deterioration is harder, even if the level of disability is not as high

⑤ The limits of lived experience

EXPERIENCE

HOW WE COULD MAKE GOOD USE OF **LIVED EXPERIENCE** OF FAMILIES WITH DISABILITIES?