

AMPLIFYING THE VOICE OF 'LIVED EXPERIENCE'



67%

OF NON-DISABLED PEOPLE REPORT FEELING UNCOMFORTABLE TALKING TO DISABLED PEOPLE

43%

OF NON-DISABLED PEOPLE SAY THEY DO NOT PERSONALLY KNOW ANYBODY WITH A DISABILITY

41%

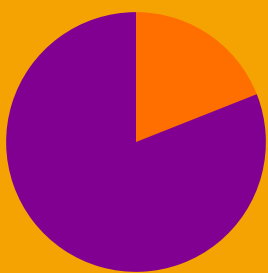
OF DISABLED PEOPLE FEEL THAT NON-DISABLED PEOPLE DO NOT UNDERSTAND THEIR DISABILITY

Over the last 20 years, greater equality legislation has meant that disabled people experience more opportunities and aspirations than ever before. Then why is there still a lack of communication and understanding about the reality of living with different disabilities?

TWO MODELS OF DISABILITY: MEDICAL VS. SOCIAL

% OF UK POPULATION LIVING WITH DISABILITIES:

disabled
19%



non-disabled
81%

The medical model suggests that disabilities are caused by medical impairments, whereas the social model suggests that disabilities are caused by socially-constructed barriers caused by ignorance, prejudice and/or stereotyping (disablism). Often, it is well-meaning, empathetic people that fall into these traps.

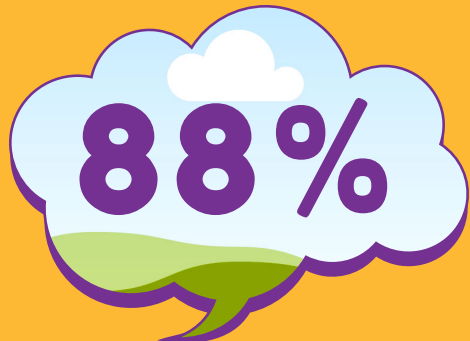
'Disablism' hinders society from engaging with disabled people's personal experience of disability, which results in The Disability Paradox: despite many disabled people reporting a high quality of life, many external observers wrongly assume that they live an undesirable existence.

THE MOST HARMFUL BARRIERS AREN'T MEDICAL, THEY'RE ATTITUDINAL!

WHAT ARE THE IMPLICATIONS OF EXCLUSION FOR BIOETHICS?

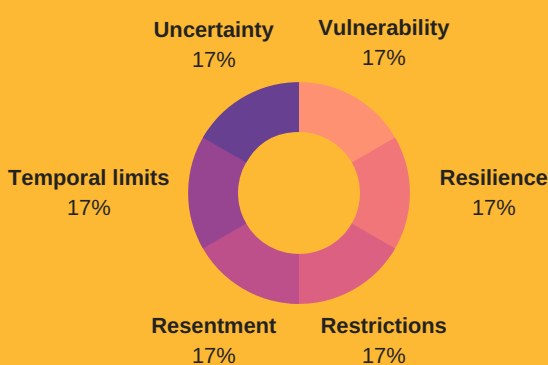
More than 10,000 conditions result from genetic abnormalities. Advancements in reprogenetic technologies such as genetic screening (e.g. NIPT), mean it is increasingly possible to permanently eradicate genetic conditions. Widespread 'disablism' in society has meant that we are failing to include disabled people's voices in bioethics debates, instead making simplifying and often false assumptions about the quality and value of a life that happens to deviate from the norm.

USING 'LIVED EXPERIENCE' TO ENRICH THE DEBATE:

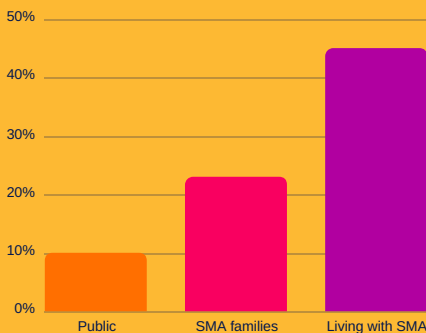


OF PEOPLE FEEL THAT THEY ARE BETTER PEOPLE BECAUSE OF THEIR SIBLING WITH DOWN'S SYNDROME

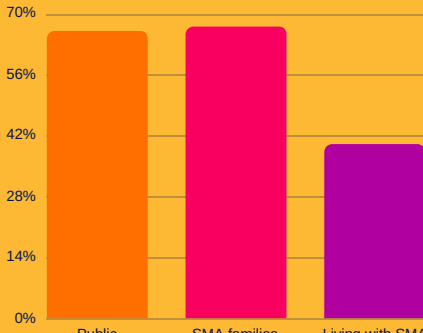
KEY THEMES IN THE EXPERIENCES OF PEOPLE LIVING WITH CYSTIC FIBROSIS:



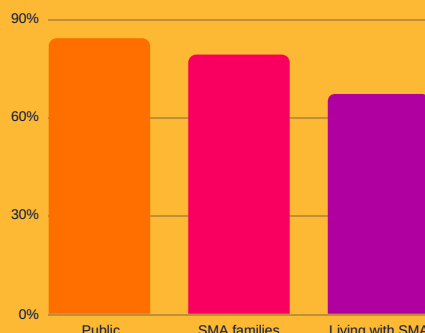
OF PEOPLE WITH DOWN'S SYNDROME FEEL HAPPY WITH THEIR LIVES



THINK IT WOULD BE A LOSS TO SOCIETY TO HAVE LESS PEOPLE BORN WITH SPINAL MUSCULAR ATROPHY (SMA)



THINK SCREENING FOR SMA WILL PREVENT UNNECESSARY SUFFERING



WOULD SUPPORT PRENATAL SCREENING FOR SMA

DO'S

- COMMUNICATE WITH DISABLED PEOPLE AND ASK ABOUT THEIR PERSONAL EXPERIENCES AND NEEDS
- OPPOSE DISABLISM AND FIND WAYS TO INCLUDE DISABLED PEOPLE'S VOICES IN SOCIETAL DECISIONS
- CONSIDER 'LIVED EXPERIENCE' WHEN MAKING PERSONAL CHOICES

Key Lessons:



DONT'S

- ASSUME THAT ALL DISABLED PEOPLE HAVE A LOW QUALITY OF LIFE
- ASSUME THAT YOU ARE IMMUNE TO BEING DISABLIST
- ASSUME THAT MEDICAL PERSPECTIVES GIVE A BALANCED VIEW OF DISABILITY

REFERENCES:

[HTTPS://GOO.GL/GFYIIB](https://goo.gl/gfyiib); [HTTPS://GOO.GL/21Y9NK](https://goo.gl/21y9nk); [HTTPS://GOO.GL/SCIXCE](https://goo.gl/scixce); [HTTPS://GOO.GL/ROUSU3](https://goo.gl/rousu3); [HTTPS://GOO.GL/5FUPC9](https://goo.gl/5fupc9); [HTTPS://GOO.GL/XBNM4S](https://goo.gl/xbnm4s)