

# Introducing the Humanising Healthcare Project



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**Nikita Hayden,**  
Bojana Daw  
Srdanović & Dan  
Goodley

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# Talk Outline

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- Introducing the Humanising Healthcare Project
  - Co-production with people with learning disabilities
  - Theorising Humanising Healthcare



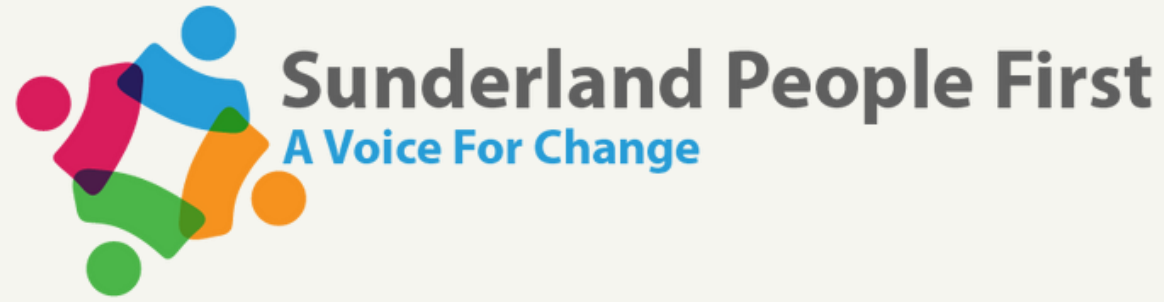
# Funding and Research Governance



University of  
**Sheffield**



**Economic  
and Social  
Research Council**



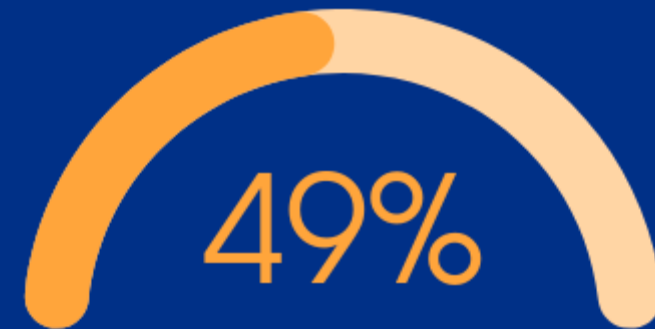
# LEARNING DISABILITIES & HEALTH INEQUALITIES

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Men with learning disabilities die on average 22 years younger than men in the general population<sup>1</sup>



Women with learning disabilities die on average 26 years younger than women in the general population<sup>1</sup>



**AVOIDABLE DEATHS –  
LEARNING DISABILITY<sup>2</sup>**



**AVOIDABLE DEATHS –  
GENERAL POPULATION<sup>2</sup>**

Avoidable deaths are those that could have been avoided through healthcare or public health intervention

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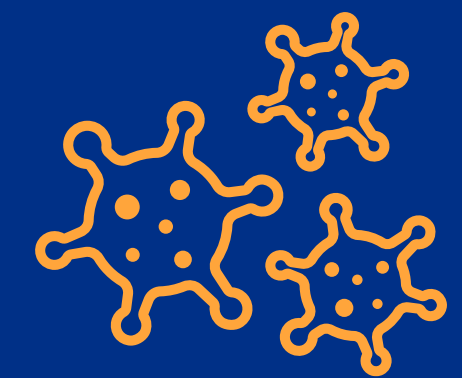
**33.6%** Of people with a learning disability have a psychiatric condition<sup>3</sup>



Almost half of people with learning disabilities have at least one other chronic health condition<sup>4</sup>



People with learning disabilities have high rates of risk factors associated with cardiovascular problems, e.g., metabolic syndromes (22.5%) & abdominal obesity (52%)<sup>5</sup>



People with learning disabilities had more COVID-19 infections, more severe infections, higher mortality, and case fatality<sup>6</sup>

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# Social determinants associated with poorer health in people with learning disabilities



Being from a Black, Asian, or minority ethnic group<sup>7</sup>

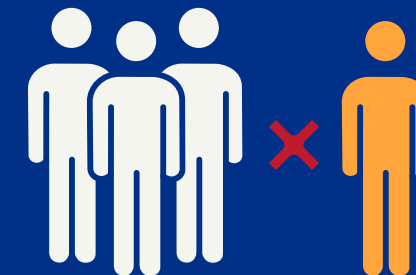


Low socio-economic status and poverty<sup>8</sup>



Unemployment<sup>9</sup>

Social exclusion<sup>10</sup>



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**References** 1. White et al. ([2021](#)); 2. O’Leary et al ([2018](#)); 3. Mazza et al., ([2019](#)); 4. Cooper et al., ([2015](#)); 5. Vancampfort et al. ([2020](#)); 6. Henderson et al. ([2022](#)); 7. Robertson et al. ([2019](#)); 8. McMahon et al., ([2022](#)); 9. Robertson et al. ([2019](#)); 10) Emerson et al. ([2014](#)).



# Affirmative and Overt Research



# Research aims



- (1) To qualitatively investigate the cultures, conventions, systems, relationships and practices of a neurology service and a learning disability service through co-production, ethnography and narrative interviews.
- (2) To identify the ways in which two distinct services and their practitioners deliver humanising healthcare for people with learning disabilities and/or autism.

# Empirical work

Field work at two NHS sites:

- Neurology service in South Wales
- Learning Disability service in Cornwall

Health ethnography

Narrative interviews, creative methods

Supplementary interviews with self-advocates



# Conceptualising Humanising Healthcare



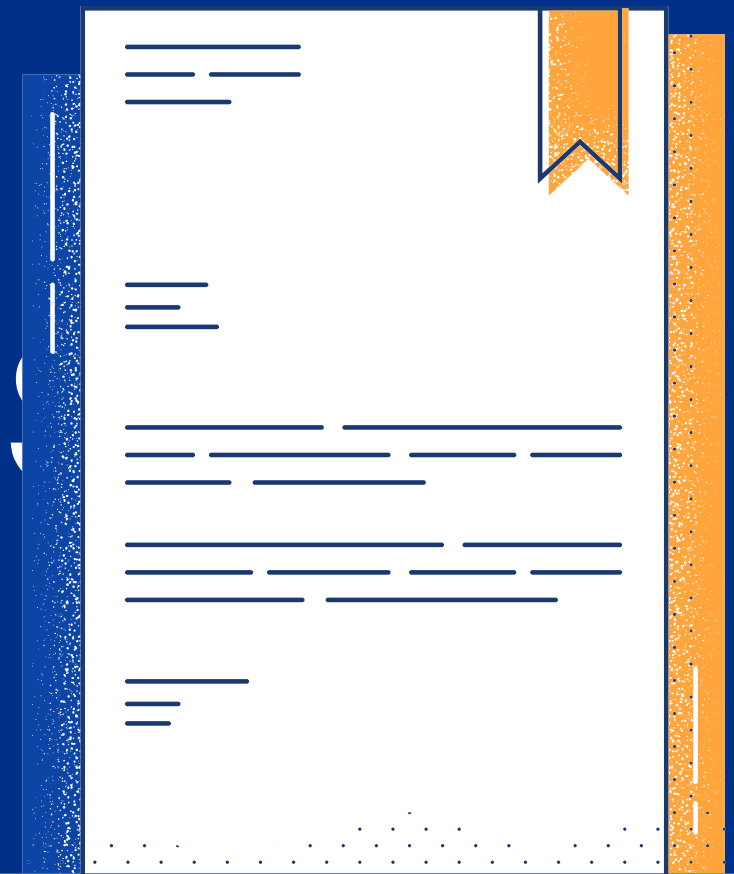
# CO-PRODUCTION

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Working in co-production with our advocacy-based organisations' researchers - to lead, plan, design, implement and review the research and contribute to the analysis and dissemination of findings of our fieldwork.



# PARTICIPATORY ETHICS GOOD PRACTICE GUIDELINES



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Guideline 1. Pay our research partners for their time.  
Guideline 2. Always start a research meeting with some friendly introductions.  
Guideline 3. Always use Plain English and supporting images. We use Photosymbols.

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Guideline 4. Always start a research meeting with a reminder of what the research is.  
Guideline 5. We remind people that they can leave research projects if they no longer want to be involved.  
Guideline 6. Spend time explaining consent.

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Guideline 7. Always recap on previous meetings.  
Guideline 8. Explain the research context.  
Guideline 9. Spend time together understanding and co-producing research methods.  
Guideline 10. Make sure Information Sheets and consent forms are co-produced in accessible ways.



# Sharing Good Practice



**Thank you**  
for listening!



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Contact details:

Twitter/X: @esrchumanhealth

Nikita – n.hayden@sheffield.ac.uk

@nikitahayden

Bojana –

bojana.dawsrdanovic@plymouth.ac.uk

@bdawsrdanovic

Dan – d.goodley@sheffield.ac.uk

@dangoodley