

# From theory to practice. Co- production in public health

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Presenting on behalf of the study team.

## **NIHR Three Research Schools Prevention Research Programme**

A unique collaboration between the NIHR Schools for Primary Care Research (SPCR), Public Health Research (SPHR) and Social Care Research (SSCR) ("Three Schools") to collaborate on a programme of work funded through the National Institute for Health and Care Research (NIHR)

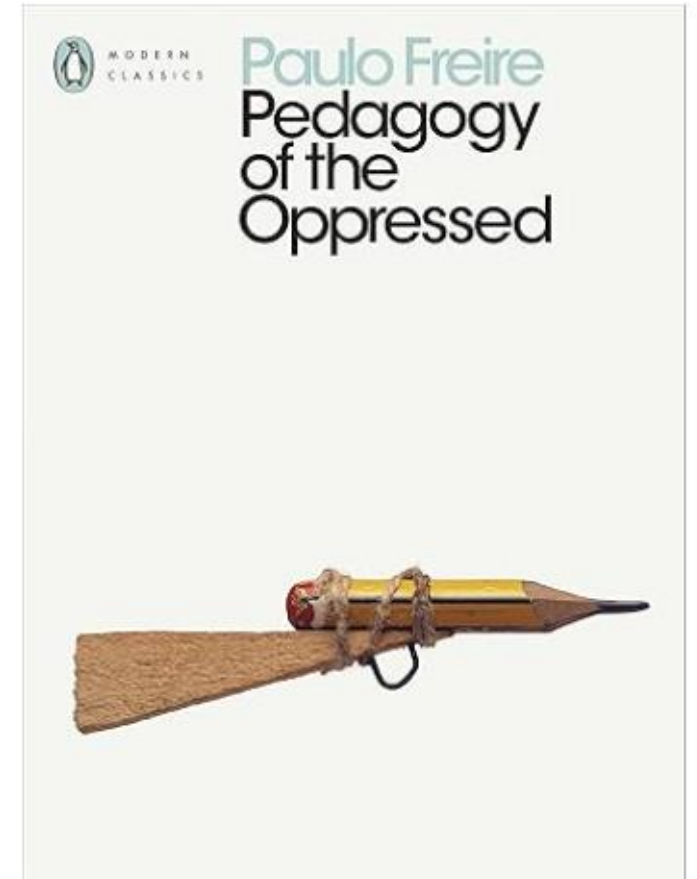


# Presentation Overview

- Paulo Freire and his impact on the way I view, understand, and live research in adult social care.
- Oppressive practice in research.
- Applying Freirean principles to my own research; a case study.
- Lessons learned and reflections to share.

# Paulo Freire

- The purpose of being human is to become more human. Being more human is to be more self-determining, autonomous and free.
- 'With freedom comes responsibility' Satre.
- For Freire, to hold such limiting beliefs as part of your worldview is to him, dehumanising. In other words, they are a class of ideas that prevent people as being as self-determining or as human as they could be.
- These limiting beliefs are a type of *oppression* that is being inflicted upon an individual's existence.
- For Freire, to move past these beliefs involves a turn towards what he termed a development of 'critical consciousness', a process of recognising that these situations are not unchangeable but can be transformed through dialogue and action.



# Freire and me, experiences as an early-career researcher

- Began research career on projects that sought to improve paediatric palliative care before developing a focus on adult social care for disabled young people with progressive life-limiting conditions.
- On the surface, my participation in such projects was meaningful, with several going on to deliver changes in practice.
- Yet, I was troubled to an extent about how this research was undertaken...

# 'Oppressive' research practice

Oppression in research practice occurring at two levels:

1. Oppression by virtue of exclusion.
2. Oppression by virtue of restricted opportunity for participants to be their fully autonomous selves.

# But is it oppressive?

- Freire; research that is ‘anti-dialogical’; does not seek genuine dialogue or communication but seeks to define and contain people within strict parameters.
- Parochial view of a person’s capability delineates their true value and potentialities.

“...the means used are not important; to alienate human beings from their own decision making is to change them into objects”  
(Freire, 1968, p.58).

# Freire and Disablism



**Disabled woman put in nursing home against her will says she feels 'betrayed'**

- Historical and current practice of oppressing disabled adults.
- Research practice then, should at the very least, not add to such feelings of oppression.

# Freire and research values

- Does the project consider **participation** in its widest and broadest sense within the scope of the project?
- Is it underpinned by **egalitarianism**?
- Is it **dialogical** by design?
- Is it **accessible**?

# Freire applied to my own research practice; a case study

# Enhancing social care for young adults with neuromuscular conditions as a preventative approach

- Collaboration between [Pathfinders Neuromuscular Alliance](#), Bradford LA, and Northumbria, Bristol and UoEL Universities.
- Two-year project (April 25-March 27)
- Funded by the NIHR Three Schools Prevention Programme.



‘We will not be part of  
another project that merely  
describes the problem.’

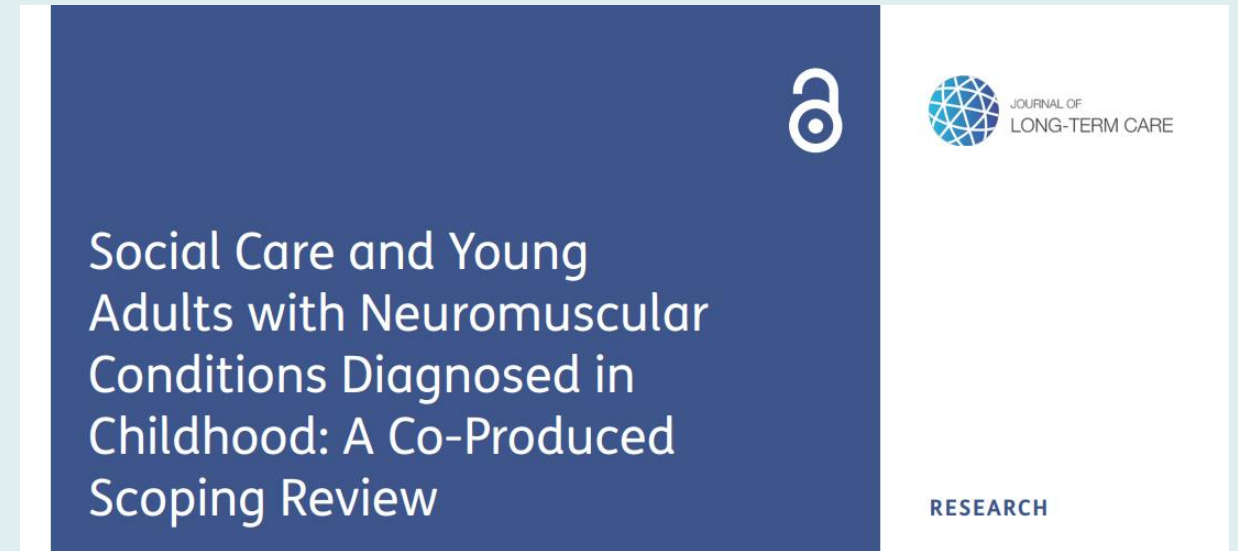


Dr Jon Hastie. CEO Pathfinders Neuromuscular Alliance.



# Adult Social Care in 2026 Overview

- As part of building the foundations for the described project, Pathfinders with input from me and other academics produced several outputs, each of which reflect a system that consistently fails to meet the needs of adults with NMCs diagnosed in childhood.
- These findings of course reflect the prognosis of adult social care more broadly, described by Baroness Casey as, 'something creaking, inconsistent and impenetrable'.

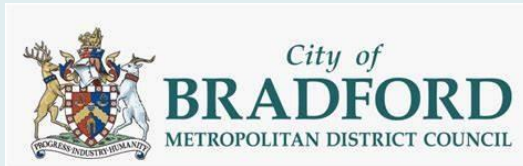


# Project Overview

- Aims to co-design solutions to common adult social care challenges experienced by adults with neuromuscular conditions.
- Uses Experience-Based Co-Design as its guiding methodology.



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# Through the lens of Freire

- **Egalitarian:** PNA receives majority of funding to recruit staff to project as co-apps and co-researchers.
- **Dialogue/Participation:** Co-researchers recruited from PNA community to not just 'advice' but engage and take ownership of all stages of the project.
- **Accessible:** Paying and training co-researchers and working with crip-time.

# Where we are up to.

- Interviews with N=30 adults, informal carers, and professionals.
- Co-analysis with co-researchers and project advisory group, including training.
- 3x workshops provided by the Picker Foundation n Experience-Based Co-Design attended by all co-applicants, co-researchers, and advisory group members.
- Planned feedback events and workshops beginning in July 26 through to Feb 27 to co-design solutions to priorities identified.
- Film editing (launch Sept) depicting adult social care as experienced by adults with NMCs.



# Reflections and lessons learned...

# Participation includes you (as PI)

- It means being more involved and often leading tasks that may otherwise have been handed to 'research associates'. (E.g. HRA ethics).
- It means greater involvement in all aspects of study design and delivery, specifically data collection and analysis.
- It means ensuring time and resource to appropriately train co-researchers in relevant methods.
- It means meeting people when suits them (evenings and weekends).

# Trust and Faith

“...they almost always bring with them the marks of their origin: their prejudices and their deformations, which include a lack of confidence in the people’s ability to think, to want, and to know”  
(Freire, 2017, p. 34).

# Balancing epistemologies

- Valuing diversity of knowledge via 'EBCD'.
- People as Beings beyond a predetermined 'use' (e.g. interview participant) but as autonomous selves who are able to impart and have **continued ownership** of their knowledge in ways that feel meaningful to them.
- Importance of dialogue.
- Transparency and honesty.
- An ethics of care and responsibility not found on an IRAS form.

# ‘The Correct Method Lies in Dialogue’

“It is not our role to speak to the people about our own view of the world, nor to attempt to impose that view on them, but rather to dialogue with the people about their view and ours”.

# Plan accordingly...

- Crip time refers to the relationships between disability and time.
- Alison Kafer says (in Liddiard, 2026) of Crip time (Kafer 2013: 27): ‘Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen on time, recognising how expectations of “how long things take” are based on very particular minds and bodies....’

To find out more about our project please visit our webpage [here](#).

You can also stay up to date with the project by following Pathfinders Neuromuscular Alliance on:

- [Facebook](#)
- [Instagram](#)
- [LinkedIn](#)



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# Any Questions?

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