Institution: University of Bristol		
Unit of Assessment: 20) Social Work and Social Policy		
Title of case study: Evidence of premature deaths in people with learning disabilities informs major reform of health policy and practice in England		
Period when the underpinning research was undertaken: 2010 - 2013		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Pauline Heslop Anna Marriott	Professor of Intellectual Disability Studies Research Fellow	12/1999 - present 03/2007 - 09/2014
Period when the claimed impact occurred: 1st August 2013 – 2020		
Is this case study continued from a case study submitted in 2014? No		

1. Summary of the impact

The University of Bristol led Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), provided vital new evidence into both the numbers and causes of avoidable and premature deaths of people with learning disabilities in England. Evidence and recommendations from CIPOLD prompted reform of both health policy and practice in England including the establishment of a national mortality review programme, the first of its kind in the world. Expansion of GP registers, a learning disabilities indicator, and a 'reasonable adjustment flag' system have increased identification of patients with learning disabilities and contributed to a 12% increase in annual health checks and an increase in flu vaccinations.

2. Underpinning research

Longstanding concerns about the care of people with learning disabilities within the NHS were brought into focus in 2007 with Mencap's 'Death by Indifference' report, and a subsequent independent inquiry in 2010, which recommended the urgent need to understand the extent of the problem of premature deaths and establish guidance on prevention. The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) (2010-2013) [1] was commissioned from University of Bristol (UoB) by the Department of Health [i] and led by Prof Pauline Heslop.

CIPOLD investigated the deaths of 247 people with disabilities and 58 matched comparator cases (people without learning disabilities but similar in age, gender, geographical location etc), over a two-year period in one region of England. The inquiry developed a unique methodology to reviewing deaths that took account of multiple health and care service providers as well as the family carers' perspectives. Each review included collation, analysis and synthesis of core data, case note reviews, individual interviews with family members, a panel meeting of all those involved in supporting the deceased and external anonymous scrutiny by an Overview Panel [1].

The inquiry provided robust research evidence of the significant reduction in life expectancy, 13 and 20 years for men and women respectively, for people with learning disabilities compared to the general population. 'Avoidable' deaths from causes amenable to change by good quality health care were more common in people with intellectual disabilities (37%) than in the general population of England and Wales (13%).The most common reasons for premature deaths were revealed to be delays or problems with diagnosis or treatment, often associated with the lack of provision of 'reasonable adjustments' for their care, and problems with identifying needs and

providing appropriate care in response to changing needs, particularly in cases of a deteriorating condition. The findings and 18 recommendations were published in a report to government [1], and subsequently in *The Lancet* [2].

A subsequent study by Prof Heslop with academic colleagues at Public Health England (PHE) linked data from GP registers of people with learning disabilities with English mortality data [4]. This nationally representative linked data confirmed the findings of CIPOLD and highlighted the disparity in life expectancy between people with learning disabilities and the general population as 19.7 years [4]. Similar disparities were identified by Heslop and co-authors for the USA [5].

CIPOLD research also identified concerns about the coding used for underlying cause of death on Medical Certificates of Cause of Death (MCCD), which were echoed nationally and internationally [6]. The research highlighted inaccuracies in the coding of routinely collected data, such that it was difficult to extract accurate national data on the age and causes of death of people with learning disabilities. This has led to national and international work to understand 'hidden' causes of premature and avoidable death.

3. References to the research

[1] **Heslop P**, Blair P, Fleming P, Hoghton M, Marriott A & Russ L. (2013) *The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Final report Bristol: University of Bristol. www.bristol.ac.uk/cipold/

[2] **Heslop P**, Blair P, Fleming P, Hoghton M, Marriott A & Russ L. (2014) The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*. 383, 9920, p889–895. DOI:10.1016/S0140-6736(13)62026-7

[3] **Heslop P** & Marriott A. (2015) Making a difference - the impact of the Confidential Inquiry into premature deaths of people with learning disabilities. *British Journal of Learning Disabilities* 43, 142-149. DOI:10.1111/bld.12114

[4] Glover G, Williams R, **Heslop P**, Oyinola J & Grey JM. (2017) Mortality of people with intellectual disabilities in England. *Journal of Intellectual Disability Research* 61, 1, 62–74. DOI:10.1111/jir.12314

[5] Lauer E, **Heslop P**, Hoghton M. (2015) Identifying and addressing disparities in mortality: US and UK perspectives. In: Hatton C, Emerson E (eds) *International review of research in developmental disabilities*. Vol 48. ISBN: 9780128022917. [Available from HEI]

[6] Dunwoodie Stirton F & **Heslop P.** (2018) Medical Certificates of Cause of Death for people with intellectual disabilities: A systematic literature review. *Journal of Applied Research in Intellectual Disabilities* 31, 5, 659-668. DOI:10.1111/jar.12448

Key research grants

[i] **Heslop P,** *Confidential Inquiry into premature deaths of people with learning disabilities,* Department of Health 2010 – 2013, GBP1,900,000

[ii] **Heslop P,** *Learning Disabilities Mortality Review Programme.* NHS England/HQIP, 2015 - 2019, GBP2,100,000 (2015-2018) and GBP899,000 (2019).

4. Details of the impact

Reform of Health and Social Care Policy in England

The Government response to the CIPOLD report [1] agreed that *"much more still needs to be done to ensure people with learning disabilities have the same rights and access to the same health benefits as the rest of the population"* (p.2).

Launching *The Lancet* paper (December 2013) [2], Prof Heslop criticised the lack of urgency in acting on the recommendations in the CIPOLD report [1]. Pressure from MENCAP and the Health Service Ombudsman was followed by a strongly critical Lords debate which drew extensively on CIPOLD findings. A delayed Department of Health progress report [A] summarised action taken on each of the CIPOLD recommendations (*R*) and confessed that *"…we now need to step up the pace and make a concerted national effort"* [A]. Key initiatives included: a commitment to increasing annual health checks (*R6*), BMI checks and cancer screening (*R7*); targeting people with learning disability for flu immunisation (CIPOLD showed they were more vulnerable to respiratory disease [1]); improving access to palliative care; and improving adherence to the Mental Capacity Act (*R15*) [A]. Significantly, the government committed to the CIPOLD recommendation (*R18*) to establish a learning disability mortality review body (LeDeR). This was delivered by UoB [ii] and commissioned for five years (2015-2020) by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, and directly by NHS England from 2020-2021.

Since 2014, there have been five debates in the Lords and eight in the Commons which have discussed CIPOLD or LeDeR. In 2016, the Secretary of State announced that the LeDeR programme would provide support to families and all local NHS areas in England to enable reporting and an independent, standardised review of all learning disability deaths [Ci]. In 2018 the Minister for Care, responding to the First LeDeR report [Bi], announced a new legal requirement for every NHS Trust in England to publish data on avoidable deaths and provide evidence of learning and improvements (*R17*), and a learning disability annual health checks scheme (*R6*) was introduced to help ensure that undiagnosed health conditions can be identified early [Cii].

A LeDeR recommendation on the need for better training and awareness of learning disability in the health and social care sector (*R6* [Bii]), was recognised in the Government's response to the consultation on learning disability and autism training for health and social care staff [D]. The government subsequently proposed to amend the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 accordingly (para 79), with planned changes coming into force in April 2021 [D]. Health Education England and Skills for Care are now co-ordinating the development of the training in health and social care.

The CIPOLD [1, 2] and LeDeR [Bi-iii] reports have presented uncomfortable findings and challenges. Nevertheless, in the preface to the government's response to the 3rd LeDeR report [Biii], the Minister wrote: "*The University of Bristol has played a hugely important role since the beginning of the LeDeR programme, setting out the learning and recommendations from the LeDeR reviews in their annual reports. We are grateful for the significant contribution they have made*." The Minister continued, *"I… reiterate our ongoing commitment to the mortality reviews themselves being undertaken as set out in the NHS's Long Term Plan [2019]"* [E].

Learning from Mortality Reviews in England

LeDeR is the world's first national programme of mortality reviews of people with learning disabilities aged 4 years and over. More than 5,000 deaths of people with learning disabilities have now been reviewed: in 2018 this was 86% of the estimated number of deaths of people with learning disabilities in England that year. Three annual reports have been published by the University of Bristol identifying key learning and making recommendations to the NHS and social care sector [Bi-iii]. The case record review methodology developed by CIPOLD [1] and adapted for use by LeDeR has been recognised by, and recommended for use in, the national *Learning from Deaths programme* [F] which requires a LeDeR review of *'all in-patient, out-patient and community patient deaths of those with learning disabilities'* [F].

A *Learning into Action* collaborative was established by the NHS England and NHS Improvement learning disability programme to co-ordinate the national response to learning from LeDeR. It involved NHS trusts, social care, charities and the independent sector, practitioners, people with a learning disability and their families. The collaborative's work was guided by recommendations made in the 2018 and 2019 UoB LeDeR reports [Biii, Biv]. Work streams have tackled respiratory problems, sepsis, constipation, cancer, the failure to recognise physical deterioration and the application of the Mental Capacity Act [G]. The most recent Action from Learning report [Gii] demonstrates impact for people with learning disabilities in relation to improvements to cancer screening services, the development of a reasonable adjustment 'flag' on case records, the use of the NEWS2 (National Early Warning Score) to improve the detection and response to clinical deterioration, changes to the flu vaccination eligibility criteria to include all people with learning disabilities, the provision of advice to Trusts about DNACPR (Do not attempt cardiopulmonary resuscitation) decisions, and improvements to the NHS111 service [Gii]. Most recently (Nov 2020), findings of LeDeR reviews of deaths from COVID-19 have been presented to the government Scientific Advisory Group for Emergencies (SAGE). NHS Action from Learning have responded to these data with specific actions for GP practices, as well as health and care organisations [Giii].

Changes to NHS policy

CIPOLD [1] was instrumental in NHS England acknowledging premature mortality of people with learning disabilities as an area of concern and was identified as a key priority in the 2019 NHS Long Term Plan [Hi], as well as the NHS Operational Planning and Contracting Guidance (2019/20) and the Learning Disability Improvement Standards for NHS trusts (2018). Having a learning disability is not a cause of death. CIPOLD identified concerns about the coding used for underlying cause of death on MCCDs [6]. LeDeR reiterated these concerns [B] and in response the National Medical Director for NHS England wrote to NHS Trusts and Clinical Commissioning Groups reminding them that the terms 'learning disability' and 'Down syndrome' should never be used to describe the underlying, or only, cause of death on the MCCD [Hii].

Improved identification of people with learning disabilities and their needs

CIPOLD [1, 2] recommended identification of people with learning disabilities in health and social care settings (*R1*) so that practitioners make '*reasonable adjustments'* to ensure that services are fully accessible and meet their needs (*R2*). Furthermore, these reasonable adjustments should be recorded, implemented and audited (*R2*). In response, GP registers of people with learning disabilities were expanded from adult-only to all-age registers and form the basis for annual Learning Disability Health Checks included in the *General Medical Services Contract 2014/15* [Ii].

NHS England and NHS Digital, with input from the UoB, developed a 'reasonable adjustment flag' to add to a person's health record on the NHS Spine to inform health and care staff when an adjustment to services needs to be made. This is currently being piloted, pending national implementation, to gather feedback from staff, patients and carers about the impact on care when information is readily available to staff from the first point of contact onward [Iii].

Healthcare benefits for patients with learning disabilities

In 2019, NHS Digital reported indicators of health promotion activities recommended by CIPOLD and LeDeR and adopted by the NHS England [J]. Notably, the proportion of people with learning disabilities receiving an annual health check (*R6*) has increased from 43% (2014/15) to 55% (2017/18) and BMI assessments increased from 58% to 62% in the same period [J]. This is important because they are more likely to be obese (30%) than those without learning disability (23%) [1, 2]. The proportion of people with learning disabilities receiving a flu vaccination (*R9*) has risen from 40.8% to 44.7% (2014/15 to 2017/18); 83% of those over 75 had been vaccinated [J]. Rates of cancer screening were lower for people with learning disability than those without, e.g. for breast cancer 53% vs 68%, and for colorectal cancer 78% vs. 84%, although 78% was an increase from 67% in 2014-5. There had been a 60% increase in the proportion of patients with learning disabilities receiving palliative care at end of life; more than those without learning disabilities at all age bands [J].

5. Sources to corroborate the impact

[A] DoH (2014). Premature Deaths of People with Learning Disabilities: Progress Update

[B] UoB (2018). LeDeR Annual Reports (i) 2016, (ii) 2017, (iii) 2018, (iv) 2019

[C] i) Hansard (2016). CQC: NHS Deaths Review, 13 Dec 2016, Vol 618
ii) Hansard (2018). Learning Disabilities Mortality Review, 8 May 2018, Vol 640

[D] i) DHSC (2019). 'Right to be heard': The Government's response to the consultation on learning disability and autism training for health and care staff
ii) NHS Health Education England (2020). The Oliver McGowan Mandatory Training in Learning Disability and Autism

[E] DHSC (2020). The Government response to the third annual Learning Disabilities Mortality Review (LeDeR) Programme report

[F] National Quality Board (2017). National guidance on learning from deaths

[G] i) NHS (2019). Learning Disability Mortality Review (LeDeR) Programme: Action from Learning
ii) NHS (2020). Learning Disability Mortality Review (LeDeR) programme: Action from Learning Report 2019/2020
iii) NHS (2020). Action from learning: deaths of people with a learning disability from COVID-19

[H] i) NHS England (2019). The NHS Long-term Plan (*p.52.)*
ii) NHS National Medical Director (2019). Learning disability, death certification and DNACPR orders

[I] i) NHS Employers (2014/15). Summary of Changes to QOF 2014/15 England. LD001 Learning Disabilities
ii) NHS Digital (2019). Reasonable adjustment flags to be integrated with patient record systems

[J] NHS Digital (2019). Health and Care of People with Learning Disabilities, Experimental Statistics: 2017 to 2018