

Institution: Lancaster University		
Unit of Assessment: 3, Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Working towards elimination of health and care inequalities experienced by people with learning disabilities		
Period when the underpinning research was undertaken: 2000 - 2020		
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:
Hatton, Chris	Professor	2003 – August 2020
Emerson, Eric	Professor / Emeritus	2000 – present
Robertson, Janet	Research Fellow	2000 – 2019
Baines, Susannah	Research Associate	2018 – present
Period when the claimed impact occurred: 2013 - 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact <p>There are approximately 1.5 million people with learning disabilities in the UK. People with learning disabilities experience substantial and pervasive health inequalities throughout their lifetime, with a lifespan 20 years shorter on average than the general population. The team at Lancaster University (Hatton, Emerson, Robertson, and Baines) carried out an extensive research programme that has documented these health inequalities, their causes, and the ways in which they can be changed to improve health. This research has underpinned the following impacts, being used to:</p> <ol style="list-style-type: none"> 1) Hold public bodies in the UK to account for inadequate services (through work with the Equality and Human Rights Commission and the Parliamentary Joint Committee on Human Rights) 2) Promote an accurate and clear awareness of the health inequalities experienced by people with learning disabilities in the public consciousness (via work with TV, radio and print media; blogging; and the use of social media) 3) Enable change to tackle these inequalities through policy by providing evidence and guidance for national and local health policies and training standards 4) Provide mental health interventions and healthy living resources for people with learning disabilities 		
2. Underpinning research <p>Most of the 1.5 million people with learning disabilities in the UK rely heavily on existing health and care systems as part of their day-to-day lives; however, they are subject to distinct inequalities within these systems. A review of 2011-2012 Care Quality Commission's (CQC) [R1] of 145 assessment and treatment units in England found that only one in seven residents were supported in a unit that was compliant with inspection outcome standards for care and welfare (such as safe discharge planning) and safeguarding (such as staff competency and the use of physical restraint).</p> <p>In 2010, Hatton and Robertson founded the Learning Disabilities Public Health Observatory at Lancaster University to help reduce, and hopefully eventually eliminate, the health and care inequalities experienced by people with learning disabilities in England. This observatory was one of the world's first specialist learning disability public health observatories.</p> <p>Since the observatory's inception, the Lancaster team has published over 100 peer-reviewed journal articles on the health inequalities experienced by people with learning disabilities, and has contributed close to 100 other outputs including policy reports, guidance, and mental health tools. The following research employing rigorous methodologies has been conducted to directly target this previously neglected area of health research:</p> <ul style="list-style-type: none"> • Systematic reviews were conducted to highlight the wide range of health issues that people with learning disabilities face, including by collating evidence on the prevalence of specific health conditions (e.g. dysphagia, constipation, epilepsy), mortality (e.g., epilepsy [R2]), interventions and service responses to health issues (e.g., postural care interventions, health checks) and health inequalities (e.g., paid employment, BAME communities). 		

- **Secondary analyses of nationally representative cohorts** were undertaken to investigate health disparities between people with and without learning disabilities across their lifespans with respect to a wide range of factors. Secondary analysis was performed with survey data on cardiovascular, rheumatic, endocrine, malignant, and respiratory illnesses; obesity rates; polypharmacy; and self-rated/self-awareness of health [R3]. Additional survey data on the social determinants of health inequalities (e.g., poverty and hardship, social connectedness, paid employment and bullying) and on equitable access to services (e.g., cancer screening) were also analysed.
- **Secondary analysis of administrative data**, with additional analysis of CQC inspections [R1] and Joint Strategic Needs Assessments, was also performed, providing valuable insight into the living circumstances, support and services that people with learning disabilities experience.
- **Research on the mental health needs** of people with learning disabilities was conducted, including systematic reviews of mental health assessment tools, secondary data analysis of nationally representative cohort surveys focusing on the mental health of children and young people with learning disabilities [R4], and a world-first definitive Randomised Control Trial of psychological interventions for adults with learning disabilities and co-morbid depression [R5].

3. References to the research

- [R1] **Emerson, E.** (2012). [A review of the results of the 2011/2012 focused CQC inspection of services for people with learning disabilities](#). Improving Health and Lives Learning Disabilities Observatory.
- [R2] **Robertson, J., Hatton, C., Emerson, E., & Baines, S.** (2015). Mortality in people with intellectual disabilities and epilepsy: A systematic review. *Seizure - European Journal of Epilepsy*, 29, 123-133. <https://doi.org/10.1016/j.seizure.2015.04.004> (36 citations Google Scholar, Altmetric 37)
- [R3] **Emerson, E. B., Hatton, C. R., Baines, S. M. J., & Robertson, J. M.** (2016). The physical health of British adults with intellectual disability: Cross sectional study. *International Journal for Equity in Health*, 15 (11). <https://doi.org/10.1186/s12939-016-0296-x> (90 citations Google Scholar, Altmetric Score: 13)
- [R4] **Emerson, E. & Hatton, C.** (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, 191, 493-499. <https://doi.org/10.1192/bjp.bp.107.038729> (510 citations Google Scholar, Altmetric score: 52)
- [R5] Jahoda, A., Hastings, R., **Hatton, C.**, et al. (2017). Comparison of behavioural activation with guided self-help for treatment of depression in adults with intellectual disabilities: A randomised controlled trial. *Lancet Psychiatry*, 4, 909-919 [https://doi.org/10.1016/S2215-0366\(17\)30426-1](https://doi.org/10.1016/S2215-0366(17)30426-1) (27 citations Google Scholar, Altmetric Score: 131)
- [R6] **Emerson E, Hatton C.** (2004). *Estimating the Current Need/Demand for Supports for People with Learning Disabilities in England*. Institute for Health Research, Lancaster University. (102 citations Google Scholar)

G1: Public Health England Learning Disability Observatory (PHELD0), 01/04/2010 - 31/02/2019, Public Health England. PI: C. Hatton, GBP1,497,383.

G2: [BEAT IT: RCT of behavioural activation for adults with learning disabilities and depression](#), National Institute for Health Research, 01/01/2013 - 328/02/2017, National Institute for Health Research, PI: A. Jahoda (University of Glasgow), Lancaster PI: C. Hatton, GBP207,432 to LU, GBP1,207,487.00 to consortium.

G3: Estimating future need for adult social care, 01/11/2010- 30/10/2011, National Institute for Health Research, PI: E. Emerson, Co-I: C. Hatton, GBP 86,362.

4. Details of the impact

At Lancaster University, Hatton, Emerson, Robertson and Baines have produced research that not only ensures public and political awareness of the health inequalities that people with learning disabilities face, but also helps service commissioners, policymakers and providers

improve the equality of people with learning disabilities in physical health, mental health and social care.

1) Holding public bodies to account for the unequal treatment of people with learning disabilities by working in advisory roles

The Lancaster team has used their research findings [R1] to hold public bodies in the UK to account for the inadequate treatment of people with learning disabilities within health and social care systems.

Hatton was appointed Specialist Advisor to the [2019 Joint Parliamentary Human Rights Committee Inquiry](#) on the detention of children and young people with learning disabilities and/or autism within inpatient units, providing evidence based on the underpinning research [S1(a, b, c)]. This inquiry resulted in the recommendation of a number of changes to the legal framework for detention, the strengthening of the legal rights of those with learning disabilities, and improvements to the CQC's inspection process. These advisory activities also contributed to a much-needed CQC review of restraint, seclusion and segregation practices in facilities that provide care for people with mental health issues, learning disabilities and/or autism. This review began in 2018 and is on-going [S2]. Further pressure was applied to the UK government when Hatton's work with the Equality and Human Rights Commission (EHRC) led to the EHRC using the Lancaster team's research as part of their legal challenge filed in February 2020 against the Secretary of State for Health and Social Care on their failures to deliver appropriate accommodation services for people with learning disabilities and/or autism [S3(a)]. EHRC made earlier use of Lancaster research in their 2016 *Is England Fairer* reports [S3(b)]. Finally, the research supported the launch of a [NHS England Taskforce](#) in October 2019 to reduce the number of young people with learning disabilities and/or autism in inpatient units.

2) Bringing health inequalities to the public consciousness via the media

To ensure that any impacts of the research on improving conditions for people with learning disabilities are far-reaching and long-lasting, Hatton pushed the issue of health inequalities into the public consciousness by working with television, radio and print media to provide evidence-based reports of research findings to broad audiences. Hatton provided reports that included background briefings to help journalists find and use relevant data in their reporting to highlight the issues faced by people with learning disabilities. A reporter from BCC Breakfast said, *"These are issues which traditionally haven't been given airtime on mainstream media. Today they absolutely are given prominence and I can categorically say that the team in Lancaster has made that happen."* [S4(a)].

Hatton's research has also been used directly by journalists since 2018 across a wide range of print media and audiences to highlight the ongoing poor conditions affecting people with learning disabilities. These pieces include work by Saba Salman (*The Guardian*), Ian Birrell (who won the 2020 George Orwell prize for his work on the detention of people with learning disabilities and autistic people in inpatient units; *Mail on Sunday*, *Daily Mail*, *The Independent*, and *Tortoise*), Shaun Lintern (*The Independent*), and Nick Cohen (*Spectator*) [4(b)]. Hatton also facilitated access to highly relevant data for a *BBC Radio Current Affairs* piece on assessment and treatment units that was broadcast in October 2018. This brought the use of restraints in these units – apparently without the knowledge of the CQC or NHS England – to the public's attention [S4(b)]. BBC Current Affairs producer added that while this program *"had enormous immediate media impact, this impact was continued by a range of other newspapers and broadcasters, specifically Sky and the Daily Mail and The Times"* [S4(c)]. Since October 2013, Hatton has also been writing a blog [S5(a)] on issues relating to people with learning disabilities. This blog focuses on making evidence and statistics available to the general public and highlights their policy and practice implications; it has had over 320,000 page views between October 2013 and December 2020 and has resulted in knowledge exchange with over [6,000 Twitter followers](#). Hatton's analysis in this blog is cited in the Joint Committee on Human Rights report 'COVID-19: The detention of young people who are autistic and/or have learning disabilities' [S5(b)].

3) Engineering change by providing robust evidence for policies and guidance

As a key member of the PHELODO (Public Health England Learning Disability Observatory) Improving Health and Lives (IHaL) collaboration, the Lancaster team has made clearly identifiable contributions to the following impacts. The team produced the authoritative online [People with Learning Disabilities in England series](#) of updates of national statistics (August 2019) for commissioners and health and social care providers; this series is one of the most viewed (over 8,000 page views by August 2020) and downloaded resources from the PHELODO collaboration [S6(a)]. The Lancaster team has also produced [summaries of evidence related to health inequalities](#) (2018), as well as contributions to regular [national autism self-assessments](#) (2016, 2018) conducted in accordance with the Autism Act 2009 [S6(a)]. These valuable resources are hosted by Public Health England and are used by policymakers, service commissioners, service practitioners, the voluntary and charitable sector, family members and self-advocates to make a strong case for implementing changes in health and care for people with learning disabilities and to plan and deliver improved services [S6(a)]. A 2016 online survey of PHELODO IHaL users [S6(b)] reported that 94% of 304 respondents (mainly service managers, professionals and commissioners) found the information provided by PHELODO to be useful/quite useful, and 73% had used PHELODO information in their own work for strategic planning, benchmarking, service development and commissioning, and providing training or teaching. Comments included the following, *“So much of the work we do is dependent on statistics, if I need to prove a point, seek additional funding, or inform myself about how my Team needs to adapt to changes then I need up to date facts and figures; [PHELODO] provide these”* and *“I get all my information/evidence from [PHELODO] for my training I deliver”* [S6(b): pp. 14-15].

At the national level, the research *“directly contributed to multiple specific commitments being incorporated”* [S6(a)] into the January 2019 NHS England Long-Term Plan, which includes a section devoted to learning disabilities and autism. It also informed the Public Health England guidance [‘All Our Health’](#) (April 2015) and was used by the NHS Learning Disability Team to inform metrics within the national learning disability improvement standards [S7]. The Lancaster team’s research is also cited in the [Skills For Health 2019 Core Capabilities Framework](#), which is designed to standardise and improve education on learning disabilities for workers in the health and care sector. At the local government level, the underpinning research led to the inclusion of learning disabilities in the strategic planning of health needs that is conducted in every locality in England. The percentage of Joint Strategic Needs Assessments including a section on adults with learning disabilities increased from 48% in 2013 to 65% in 2017, with 57% of these assessments directly referencing PHELODO’s work [S8(a)]. Further to this, their research [R6] was the basis for the creation in October 2008 of the [Projecting Adult Needs and Service Information \(PANSI\)](#) learning disability information resource. PANSI is for use by local authorities and service commissioners, as well as providers to explore the impacts that demography and certain conditions may have on populations aged 18 to 64. With regard to the use of PANSI, a Principal Consultant from the Institute of Public Care confirmed that *“the vast majority, if not all, LAs in England have used these tools”* between August 2013 and December 2020 [S8(b)], suggesting that all local authorities in England have used the resource in some aspect of local planning between August 2013 and December 2020. Many local authorities also cite [R6] directly as the basis for PANSI, e.g. [Central Bedfordshire Council](#), [Hillingdon Council](#), and [Blackpool Borough Council](#).

4) Providing and improving access to help for mental health problems and better social care

In recognition of the underpinning research, Hatton was appointed a member of the NICE Guideline Committee for ‘NG54: Mental Health Problems in People with Learning Disabilities: Prevention, Assessment, and Management’ (2016). Moreover, research from the Lancaster team was used as evidence in the creation of NICE NG54 [S9], a guideline that not only helps people with learning disabilities who have mental health problems identify what health, social and educational care they should be receiving, but also establishes the definitive standard for healthcare professionals to adhere to. More recently, an RCT investigating depression in people with learning disabilities [R4] resulted in a [Health Education England e-learning programme](#). This was developed by the authors to enable professionals to learn how to conduct the two types of therapy researched in the RCT – behavioural activation and guided self-help, and includes a manual written by the authors. This resource was launched in April 2019 and it reached more

than 10,000 enrolments by December 2020 [S10(a)]. The Lancaster team also adapted guided self-help materials to support the mental health of people with learning disabilities during the COVID-19 crisis, making them freely available [online](#). A first print run of 12,000 hard copies was also distributed between April and November 2020 with very positive feedback [S10(b)].

Research conducted by the Lancaster team for PHELD0 also directly underpinned the [Health Charter for Social Care Providers](#) (October 2017), which was jointly created with the Voluntary Organisations Disability Group (VODG). A total of 140 organisations pledged to use this charter, and a 2016 [evaluation](#) by the VODG found it provided a useful focus for providers to improve their care and other practices, for example supporting people to access mainstream healthcare and influencing practice in the NHS to ensure people with learning disabilities get a better deal [S11(a)]. The Lancaster team also worked with the VODG to help produce numerous resources for improving care [S11(b)], such as a resource for providing [healthier diets](#) in social care settings. Research conducted by the Lancaster team for PHELD0 also directly informed the 2019 British Association for Social Workers [Essential Capabilities Statement](#) for people working with adults with learning disabilities, which provides a statement of the core competences expected. In 2020, Hatton was invited to be a member of the Social Care Sector COVID-19 Support Taskforce Learning Disability and Autism Advisory Group.

5. Sources to Corroborate the Impact

- [S1] Evidence provided to the 2019 Joint Parliamentary Human Rights Committee Inquiry: a) Report together with formal minutes relating to the report: [The detention of young people with learning disabilities and/or autism](#), November 2019 b) [Summary of evidence available to CQC as part of the Inquiry](#), c) [Analysis of independent sector and NHS inpatient settings](#), 2019.
- [S2] Care Quality Commission (CQC) (2019), '[Segregation in mental health wards for children and young people and in wards for people with a learning disability or autism](#)'.
- [S3] Evidence of impact on The Equality and Human Rights Commission a) Testimonial from a lawyer at the EHRC, 2020, b) [EHRC report on the experiences of people with learning disabilities](#), 2016.
- [S4] Evidence of the use of Hatton's research by journalists: a) Testimonial from reporter for BBC Breakfast, 2020; b) Articles by Saba Salman ([The Guardian Jan 19](#)), Ian Birrell (Daily Mail and Mail on Sunday, [Oct 18](#) and [Jan 19](#), [The Independent, July 2020](#), [Unherd, April 2020](#), and [Tortoise, May 2020](#)); Shaun Lintern ([The Independent, May 2020](#)), and Nick Cohen ([Spectator, May 2020](#)): c) [BBC Radio 4: File on 4](#) piece, October 2018 and testimonial from the producer, 2020.
- [S5] a) [Professor Chris Hatton's online blog](#), quoted in b) the Joint Committee on Human Rights report "[Human Rights and the Government's response to COVID-19: The detention of young people who are autistic and/or have learning disabilities](#)", 2020, p.16.
- [S6] Evidence from Public Health England: a) Testimonial from Programme Lead, Health Intelligence, Public Health England, 2020, b) [Public Health England Learning Disabilities Observatory: Results of User Survey](#), 2015.
- [S7] Testimonial from Head of Learning Disability Nursing, National Nursing Directorate, NHS England & NHS Improvement, 2020.
- [S8] Evidence regarding local authority impact: a). PHELD0 Internal Analysis for Public Health England, 2018. b). Email February 2021 from a Principal Consultant at the Institute of Public Care confirming use of PANSI data by local authorities.
- [S9] Impact on NICE NG54: [Evidence used for NICE Guidance, NG54: Mental Health Problems in People with Learning Disabilities: Prevention, Assessment, and Management](#), 2016, Tools and Resources: [Resource impact report: Mental health problems in people with learning disabilities: prevention, assessment and management](#), 2016.
- [S10] Evidence of the reach of a) "The Intellectual Disability and Depression: Talking Therapies Programme" and of b) the "COVID-19 Guided Self-help Booklet Series".
- [S11] Evidence of impact through the Voluntary Organisations Disability Group (VODG): a) Evaluation "[Health charter in practice](#)", 2016 (pp.15 and 13) b) Testimonial from Chief Executive at VODG, 2020.