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| <p><b>Institution: Lancaster University</b></p>  |
| <p><b>Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy</b></p>   |
| <p><b>Title of case study:</b> The establishment of the world's first specialist learning disabilities public health observatory, providing research to inform policy and commissioning</p>  |
| <p><b>1. Summary of the impact</b> (105 words)</p> <p>Lancaster research has highlighted the pervasive health inequalities and inadequate services experienced by people with learning disabilities (LD). Our 2005 report commissioned by the Department of Health (DH) proposed the establishment of a specialist LD observatory for England. This proposal was taken up by a government-commissioned independent inquiry and accepted.</p> <p>The same team is one of three partners who, through a competitive tender process, have since 2010 been operating the first specialist LD public health observatory in the world. The observatory collects, analyses and summarises health information to improve the data available to DH and other stakeholders thereby improving the health of people with LD.</p>   |
| <p><b>2. Underpinning research</b> (407 words)</p> <p>Emerson, Hatton (both Professors) and Robertson (Lecturer) moved to Lancaster University in 2000, and from 2000-2008 conducted a stream of research projects that were fundamental to making the case for a specialist LD public health observatory in England, including:</p> <p>2.1 A DH commissioned <b>first national survey</b> of 3,000 people with LD in England, including data on social determinants of health, access to health services, and health outcomes (with British Market Research Bureau 2002-2004; 3.13; 3.1), revealing the socio-economic and health inequalities experienced by people with LD compared to the general population.</p> <p>2.2 A DH funded project to collate and analyse existing national statistics concerning people with LD (2004-2006; 3.12, 3.2). A major proposal from this work was the establishment of a <b>specialist LD observatory</b>.</p> <p>2.3 Studies for councils, commissions from Mencap and DH and an NIHR study to develop national statistical models for <b>predicting the future population of adults with LD</b> in England requiring services (2000-2009; 3.8), which predict sustained increases in the population of adults with LD.</p> <p>2.4 A Disability Rights Commission funded study partly to analyse <b>inequalities in access</b> to primary care for people with LD (with Sainsbury Centre 2005; 3.11), revealing inequalities in access.</p> <p>2.5 Studies conducting secondary analyses of nationally representative population surveys (2006-2010; 3.9, 3.10, 3.3), again revealing <b>the scale of the socio-economic and health inequalities</b> experienced by people with LD, and the extent to which these inequalities could be accounted for by differences in socio-economic position rather than disability.</p> <p>All these projects were peer-reviewed, open competition tenders.</p> <p>From 2010, much of the Lancaster research (Emerson, Hatton, Robertson) has been conducted within the LD public health observatory commissioned by DH through open competitive tender and continuing as part of Public Health England (PHE). This collaboration involves public health experts within PHE, a third sector organisation (National Development Team for Inclusion, NDTi) and Lancaster University. Research led by the Lancaster group includes:</p> <p>2.6 Regular <b>systematic reviews of available evidence</b> concerning the health inequalities</p> |

experienced by people with LD and the uptake and/or effectiveness of health services (3.5).

- 2.7 Regular reports documenting **national statistics** concerning people with LD (3.4).
- 2.8 **Improved modelling of population projections** for adults with LD (also supported by NIHR).
- 2.9 **Secondary analysis** of datasets concerning services for people with LD (e.g. national inspections of inpatient services collected by the Care Quality Commission).
- 2.10 **Surveys of current practice** in relation to people with LD (e.g. reasonable adjustments in NHS acute trusts).

### 3. References to the research

Key outputs:

- 3.1 Emerson, E., Malam, S., Spencer, K., & Davies, I. (2005). Adults with Learning Difficulties in England 2003/4. Leeds: Information Centre for Health & Social Care.  
[http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/ListOfSurveySince1990/Generalsurveys/DH\\_4081207](http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/ListOfSurveySince1990/Generalsurveys/DH_4081207)
- 3.2 Hatton, C., Emerson, E. & Lobb, C. (2005). Evaluating the Impact of Valuing People. Report of Phase 1: A review of existing national datasets. Institute for Health Research, Lancaster University.
- 3.3 Emerson, E., & Hatton, C. (2007). The mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry* 191, 493-499. doi: 10.1192/bjp.bp.107.038729
- 3.4 Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S., & Glover, G. (2011). People with Learning Disabilities in England 2010. Durham: Improving Health & Lives: Learning Disability Observatory.  
[http://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_9244\\_IHAL2011-02PWLD2010.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9244_IHAL2011-02PWLD2010.pdf)
- 3.5 Robertson, J., Roberts, H., Emerson, E., Turner, S., & Greig, R. (2011). The impact of health checks for people with intellectual disabilities: a systematic review of evidence. *Journal of Intellectual Disability Research* 55, 1009-1019. doi: 10.1111/j.1365-2788.2011.01436.x

Key grants (total £3.36 million):

- 3.6 Learning Disabilities Public Health Observatory (PI Glover, ERPHO; Hatton, Emerson, Robertson), 2013-2014, PHE, £550,000.
- 3.7 Learning Disabilities Public Health Observatory (PI Wilkinson, NEPHO; Emerson, Hatton), 2010-2013, DH, £1.7 million.
- 3.8 Estimating future need for social care services for younger disabled adults (PI Emerson, Hatton, Robertson), NIHR School for Social Care Research, 2010-2011, £98,000.
- 3.9 The association between child disability and poverty dynamics in British families (PI Emerson), ESRC, 2008-9, £74,000.
- 3.10 Factors associated with well-being and distress in parents of infants and young children with delayed development in the Millennium Cohort Study (PI Emerson), Nuffield Foundation, 2007-8, £10,000.
- 3.11 Health inequalities faced by people with mental health problems and people with learning disabilities (PI: Chiara Samele, Sainsbury Centre for Mental Health; Emerson), Disability Rights Commission, 2005, £100,000
- 3.12 Evaluating the impact of Valuing People (PI Hatton; Emerson), Department of Health, 2004-2006, £230,000.
- 3.13 The English National Survey of adults with intellectual disabilities (PI: Sally Malam, BMRB; Emerson), Department of Health, 2002-2004, £600,000.

All the grants (3.6 to 3.13) were awarded through open competition nationally, and all the

**Impact case study (REF3b)**

references above (3.1 to 3.5) have been peer-reviewed. These studies apply rigorous quantitative methodologies (including sampling, question development, data extraction and data analysis) to the population of people with learning disabilities. This research represents an original body of work empirically investigating the population of people with learning disabilities through a health inequalities lens, with significance for other researchers beginning to adopt similar perspectives and more broadly (the topic of this impact case study).

**4. Details of the impact (774 words)**

From 2000 research by the Lancaster group has revealed the scale and nature of the health inequalities experienced by the **1.2 million people with LD in England**, the inadequacy of services for this population, and the potential utility of national statistics (3.1-3.4, 5.1). Our report from a DH commissioned study concerning national statistics on people with LD (3.2) stated: "*The establishment of an Observatory for Learning Disability Statistics could provide a major ongoing resource for all stakeholders*" (p. 52).

A government commissioned independent inquiry into healthcare for people with LD (5.2) recommended the establishment of a specialist learning disabilities observatory: "*The Inquiry believes (as suggested by Hatton et al., 2005) that public health experts have a crucial role to play in helping to strengthen data and information*" (p. 43) and "*Recommendation 5. To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory*" (p. 44).

The Government report Valuing People Now (5.3) accepted this recommendation and tendered for **the first national specialist LD observatory in the world**, to operate from 2010. The Lancaster University group, with a public health observatory (now in PHE) and NDTi, won the tender and manage the observatory (known publicly as Improving Health and Lives; IHaL), which is now located within PHE (5.4, 5.5).

**IHaL collects, analyses and summarises information** for policy makers, service commissioners, service practitioners, the third sector, family members and self-advocates. As IHaL is collaborative, certain impacts are not attributable to a specific partner – therefore, in this section we describe impacts where there are clearly identifiable contributions from Lancaster researchers.

Our website (5.5) is a major vehicle for sharing information, attracting approximately **40,000 user hits per month** as of 31 March 2013. Examples of reasonable adjustments in health services (set up and maintained by Lancaster, and cited by DH in 5.6, p. 36) have been viewed 17,459 times. Lancaster-led reports on the IHaL website are also popular; e.g. the 2011 annual report of statistics (downloaded 4,380 times) and the 2011 report of health inequalities evidence (downloaded 5,866 times) (5.7).

Another major vehicle for sharing information are regionally based training and learning events (25 events to 31 March 2013; all with input from Lancaster staff), with approximately 1,200 people attending. IHaL has also run two national conferences – our recent conference in March 2013 included a speech from the **DH Minister of State, Norman Lamb**, who was highly enthusiastic about IHaL's work (5.7).

An online survey of potential IHaL users in September 2012 reported that 89%-94% of service managers, professionals and commissioners (total n=263) found the information provided by IHaL to be useful/quite useful and **92%-100% of these professional groups reported using IHaL information in their own work** (5.6 p. 29, 5.7).

## Impact case study (REF3b)

A recent DH progress report identified IHaL as one of its **four specific priorities for improving the healthcare** of people with LD (5.6 p. 28), and stated “*The Observatory has dramatically improved the quality of information available on the health of people with a learning disability and the health inequalities they experience. As a result, it has helped promote sustainable good practice, becoming a key source of evidence for local commissioning, benchmarking and accountability*” (5.6 p. 30).

IHaL, in conjunction with the Royal College of General Practitioners (RCGP) and the Royal College of Psychiatrists has produced **evidence-based guidance for health service commissioners** (Oct 2012). Dr Matt Hoghton, the LD Champion for RCGP has stated: “*The Public Health Observatory has made a significant impact on the health of people with a learning disability across all public services. At a time when the NHS is undergoing a significant reorganisation it is essential they continue their work in raising these important issues, ensuring there is a robust evidence base and translating the research into practical advice for all health and social care workers*” (5.7, 5.8).

**Accessible versions of IHaL information** are also highly valued by family members and self-advocates, illustrated by this family carer: “*The IHaL Public Health Observatory work has been very important at strategic and national level with its excellent guides, research and conference activity. However I have found it really useful on a personal level. I frequently use the website for info but more often I quote it when liaising with health professionals and use it to signpost them.*” (5.7).

**At a national level**, IHaL (including Lancaster) staff have regular meetings with DH policy makers (5.9). IHaL (including Lancaster) staff have also been invited to report to two meetings of the All Party Parliamentary Group on Learning Disabilities.

## 5. Sources to corroborate the impact

5.1 Policy Manager, MENCAP

5.2 Michael, J. (2008). *Healthcare For All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities* (pp. 43-44). Independent Inquiry: London.  
[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_106126.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf)

5.3 HM Government (2009). *Valuing People Now: a new three-year strategy for people with learning disabilities*. HM Government: London.  
[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_093375.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf)

5.4 Chief Knowledge Officer, Public Health England

5.5 Improving Health and Lives website. <http://www.improvinghealthandlives.org.uk/>

5.6 Department of Health (2013). *Six Lives: Progress report on healthcare for people with learning disabilities*. DH: London.  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212292/Six\\_lives\\_2nd\\_Progress\\_Report\\_on\\_Healthcare\\_for\\_People\\_with\\_Learning\\_Disabilities\\_-\\_full\\_report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212292/Six_lives_2nd_Progress_Report_on_Healthcare_for_People_with_Learning_Disabilities_-_full_report.pdf)

5.7 Improving Health and Lives Learning Disabilities Observatory (2013). *Final Report to the Department of Health*. IHaL: North East Public Health Observatory.

5.8 Clinical Champion Learning Disabilities, Royal College of General Practitioners

5.9 Deputy Director, Disability, learning and autism policy, Department of Health