Public Health England

Protecting and improving the nation's health

Early death in people with learning disabilities

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Mencap: Death by Indifference

Two major reports
by Beverley Dawkins

Prompted the setting up of the learning disabilities observatory and the Confidential Inquiry into Premature Deaths of People with Learning Disabilities

Death by indifference (2007)

74 deaths and counting (2012)

Death of Connor Sparrowhawk (2013)

1. Dying younger - Introduction

- Numerical measures of higher mortality – how much younger do people with learning disability die?
- Causes of death and premature death
- An NHS outcomes framework indicator

How much younger do people with learning disabilities die?

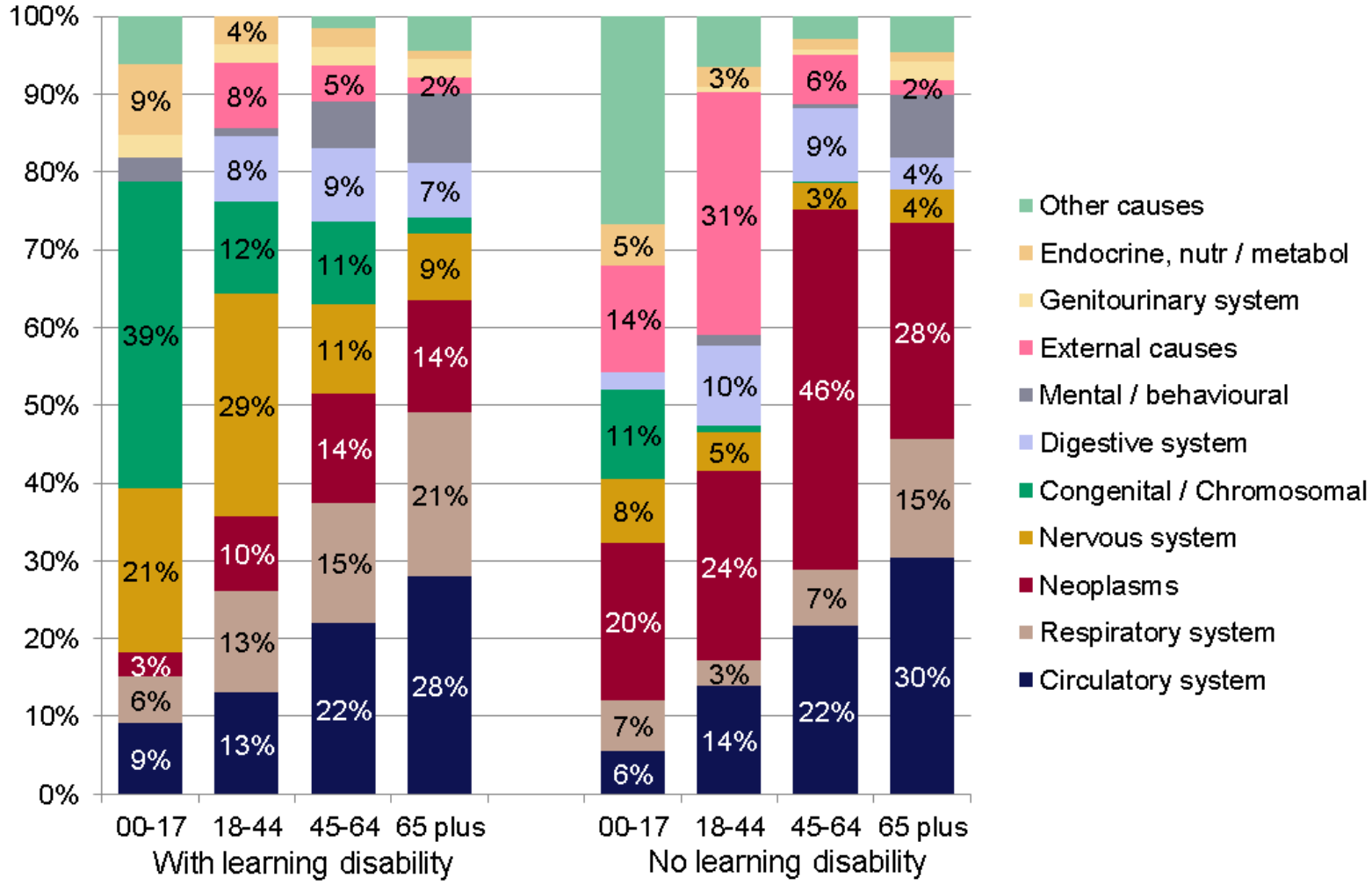
- Difficult question
- Measuring death rates:
  - Numbers of deaths – by age, sex and preferably cause
  - Numbers of people in the population
- Unfortunately
  - No comprehensive population register giving age and sex
  - Death certificates do not systematically record learning disabilities
- Sources:
  - Death certificates which do mention learning disabilities
  - Data from a GP research database linked to the mortality register
  - Data from our new national General Practice Extract the Learning Disability Health and Care dataset

GP database statistics

Measure	With learning dis.		Without learning dis.	
	Male	Female	Male	Female
Crude death rate (deaths per 1000 population per year)	10.9 (9.9 to 12.1)	11.6 (10.3 to 13.0)	8.5 (8.4 to 8.5)	9.1 (9.0 to 9.1)
Standardised Mortality Ratio (observed /expected allowing for age/sex)	3.0 (2.7 to 3.4)	3.4 (3.0 to 3.8)	1.0 (1.0 to 1.0)	1.0 (1.0 to 1.0)
Life expectancy (life table method)	63.8 (57.7 to 69.9) Difference: 19.8 years	66.7 (63.4 to 70.0) Difference: 20.2 years	83.6 (83.4 to 83.7)	86.9 (86.8 to 87.0)

- Source: Clinical Practice Research Datalink. April 2010 to March 2014
- Patients divided into those with and without learning disability by on GP register or other dependably associated condition recorded
- 95% confidence intervals in brackets

Causes of death at different age groups



Key causes of death

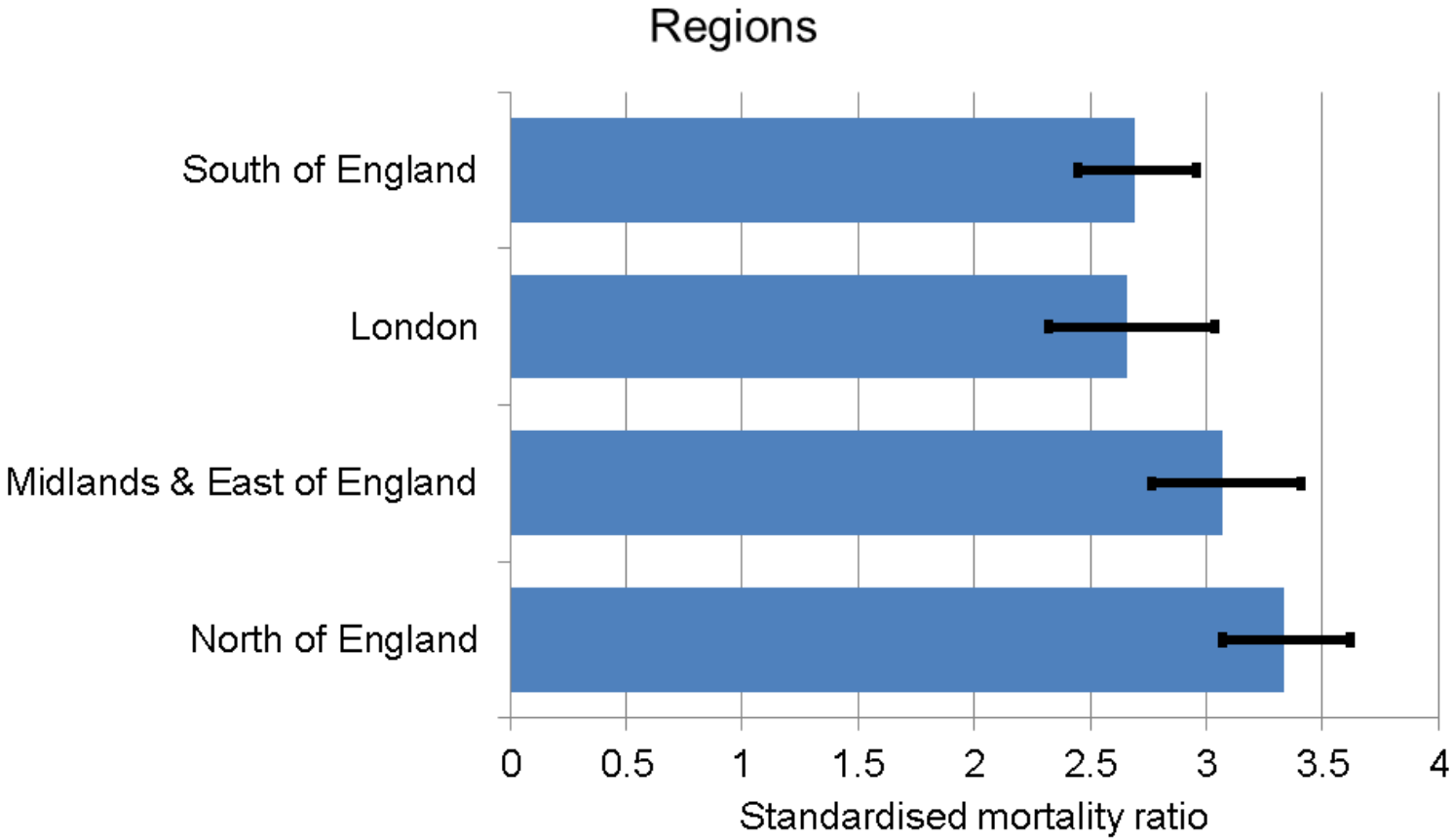
- Higher rates for people with learning disabilities, potentially avoidable causes
  - Ischaemic heart disease (SMR 2.2)
  - Cerebrovascular disease (SMR 3.3)
  - Phlebitis and thrombophlebitis (SMR 6.8)
  - Influenza and pneumonia (SMR 7.7)
  - Lung disease due to external agents (SMR 21.8)
  - Colorectal cancer (SMR 2.4)
  - Epilepsy (SMR 34.4)

NHS Outcomes Framework Indicator

- Since the 2012 to 2013 edition the NHS Outcomes Framework includes 'placeholder' indicator:
- '**Reducing premature death in people with learning disabilities** '
- As yet no measure has been published
- The new Learning Disabilities Health and Care dataset provides a possible way to do this.
  - Data requested from all general practices – (Voluntary participation)
  - First year achieved just over 50% completeness
  - Provides numbers on learning disabilities registers by age and sex
  - Numbers of deaths occurring to them
- Standardised mortality ratio – first year – 2.98. (Males 2.74, Females 3.33)
- Potentially large enough numbers fro regional comparisons taking years together
- Source: NHS Digital: Health and Care of People with Learning disabilities 2014-2015

SMRs for people with learning disabilities: 1 - Regions

Single year of data with only 50% coverage not enough.
Potentially important differences not statistically significant.



Source: NHS Digital Learning Disabilities Health and Care dataset, 2015

CIPOLD

We reviewed :

All known deaths of people with learning disabilities

From 5 PCT areas

From 1st June 2010 – 31st May 2012.

233 adults with learning disabilities

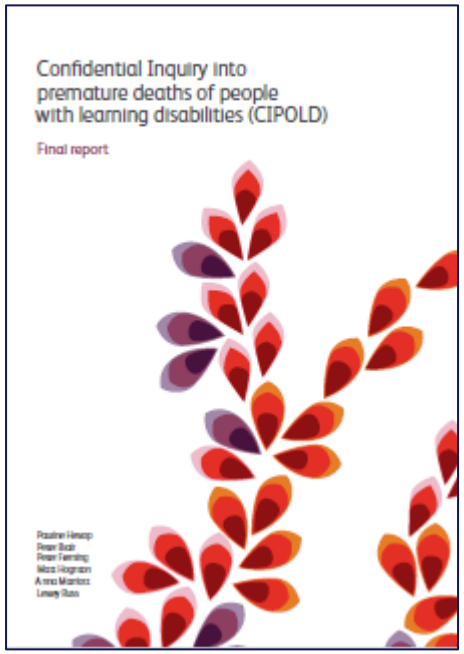
14 children with learning disabilities

58 comparator cases

Premature deaths

- CIPOLD deaths were considered to be premature: ‘if, without a specific event that formed part of the ‘pathway’ that led to death, it was probable (i.e. more likely than not) that the person would have continued to live for at least one more year.’
- 42% of deaths considered to be premature
- The most common reasons for premature death were problems with:
  - investigating or assessing the cause of illness
  - treating their health problems

Contributing factors



- A lack of reasonable adjustments to help people to access healthcare services.
- A lack of coordination of care across and between different disease pathways and service providers.
- A lack of effective advocacy for people with multiple conditions and vulnerabilities.

Robert's story

- He lived with his mother until his 50s when he 'temporarily' was moved into a generic care home
- He was still living there 10 years later
- He had minimal vocabulary but those who knew him well could tell if he was happy or not
- His mobility and general health deteriorated and he was diagnosed with tuberous sclerosis
- Mobility problems increased
- Physio raised concerns about positioning and pain
- Two hospital admissions over three days, diagnosed with aspiration pneumonia

Learning from Robert's story

- His case was reviewed at two panel meetings
- His death was categorised as premature

There were a number of concerns about the care and support Robert had received:

- Care home did not meet physical or social needs
- Poor quality care
- Previous signs of aspiration that were not addressed
- Lack of postural care and appropriate wheelchair
- Lack of an informed patient advocate
- Lack of reasonable adjustments
- There was no referral to a specialist service

Resources

- Joint guidance with NHS England about effective interventions and reasonable adjustments to reduce premature mortality
- Series of reasonable adjustment guides
- Systematic reviews and factsheets
- Stopping Over-Medication of People with learning disabilities (STOMP) campaign and related report
- Reasonable adjustment database
- Acute liaison nurse map

Learning Disabilities Mortality Review (LeDeR) Programme

Key aims:

1. To drive improvement in the quality of health and social care service delivery for people with learning disabilities
2. To help reduce premature mortality and health inequalities in this population

- Funded by NHS England
- Commissioned by Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England
- Runs from June 2015 for initial 3-5 years
- Led by the Norah Fry Research Centre at the University of Bristol

Scope of the programme

- Support reviews of deaths of people with learning disabilities aged 4 and upwards
- An initial review of each death
- A fuller multi-agency review of deaths that meet the criteria for this
- Priority Themed Reviews (year 1):
  - young people with learning disabilities aged 18-24
  - those of people from Black and Minority Ethnic communities
- An action planning process
- Monitoring of action plans to ensure practice improvements are taking place
- Further information at http://www.bristol.ac.uk/sps/leder/about/reviews-of-deaths/

Roll out of the programme

- North East and Cumbria were first pilot site
- Regional steering group set up and local reviewers identified and trained
- Building on existing structures and work wherever possible
- Programme is aligned with other investigations and mortality reviews
- NHS England has just appointed 4 Regional Programme Managers
- Pilot site in each of the 4 regions
- Regional ‘learning and sharing’ event prior to wider roll-out

Additional projects

- Data linkage project

- Mapping the provision of reasonable adjustments for people with learning disabilities

- Improving death certification in relation to people with learning disabilities

- Repository for anonymised reports pertaining to people with learning disabilities

Questions