

# Appoint a Learning Disability Commissioner for Wales

Y Pwyllgor Deisebau | 9 Gorffennaf 2019  
Petitions Committee | 9 July 2019

## Research Briefing:

**Petition number:** P-05-892

**Petition title:** Appoint a Learning Disability Commissioner for Wales.

**Text of petition:** We call on the National Assembly for Wales to appoint a Learning Disability Commissioner for Wales. This must be a person with a learning disability.

They are more reports of abuse of people with a learning disability in England again. Research also shows that people with a learning disability get unequal healthcare and die up to 20 years earlier than others. It's 50 years since the Ely Hospital report showed abuse and led to the closure of these institutions. As the organisation set up by people leaving Ely, we believe it is time that we had someone to champion our rights for us at a Welsh level.

## Background

The petition has been submitted by [Cardiff People First](#) which is a self-advocacy organisation run by and for people with a learning disability. There are a number of [People First groups across Wales](#) and elsewhere in the UK.

The petitioners are calling for the appointment of a learning disability commissioner for Wales and cite recent reports in a [BBC Panorama programme](#) of the abuse of residents at Whorlton Hall, a learning disability hospital in Durham. [Sir Stephen Bubb](#), author of two reports on the abuse of people with learning disabilities at Winterbourne View, Gloucestershire in 2011 has also urged the UK Government to set up an office of a Commissioner for People with Learning Disabilities.

## Welsh Government action

In its response to the petition the Welsh Government highlights the work it has been undertaking in recent years, including its 2017 review of learning disability services and the development of the [Improving Lives programme](#). The programme, launched in 2018, focuses on improving services in five key areas:

- early Years – reducing adverse childhood experiences and improving the ability of parents with a learning disability to bring up their children
- housing – new models of supported housing will be developed, helping people to live closer to their friends and families
- social care – making sure everyone who needs it has access to good quality care and support which is focused on their needs
- health – through reasonable adjustments to mainstream services and access to specialist services when needed. To address health inequalities, making sure people with a learning disability receive the annual health checks they are entitled to and health boards ensure they meet the needs of people with a learning disability when in hospital
- education, skills and employment – supporting young people to make the most of their potential, and when they become adults ensuring they have the right support to allow them to live successful lives, through providing targeted careers advice and making sure more people with a learning disability have paid jobs.

Implementation of the programme is supported by a Learning Disability Ministerial Advisory Group, whose membership includes people with a learning disability, families and carers, key professionals from local authorities, the health sector and charities. It is chaired by Gwenda Thomas (former AM and Deputy Minister for Social Services), and co-chaired by Sophie Hinksman, a representative of All Wales People First.

## Health inequalities

The petitioners refer to health inequalities experienced by people with learning disabilities, an issue which has been recognised for some time. The [Mencap website](#) has a summary of the evidence of the [\*Confidential Inquiry into premature deaths of people with learning disabilities \(CIPOLD\)\*](#). The inquiry investigated the sequence of events leading to all known deaths of people with learning disabilities (aged 4 years and older) over a 2-year period in 5 Primary Care Trust (PCT) areas of South West England. The report was published in 2013:

### **Poor quality healthcare causes health inequalities and avoidable deaths**

#### **Premature deaths**

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found an average age of death of 65 for men and 63 for women in a sample of 247 people with a learning disability in the UK. This is significantly less than the average age of death of 78 for men and 83 for women in the general population (Heslop et al. 2013). In other words, on average women with a learning disability died 20 years sooner than women in the general population, and men with a learning disability died 13 years sooner than men in the general population.

CIPOLD also reported the average age of death for different levels of impairment:

- 67.5 for people with a mild learning disability
- 64 for people with a moderate learning disability

- 59 for people with a severe learning disability
- 46 for people with profound and multiple learning disabilities

### **Poor quality healthcare causes avoidable deaths**

The Confidential Inquiry into premature deaths of people with a learning disability also found that 38% of people with a learning disability died from an avoidable cause, compared to 9% in a comparison population of people without a learning disability (Heslop et al. 2013, p. 92). Note: Mencap uses the term avoidable death for deaths that could have been avoided by the provision of good quality healthcare.

Allerton and Emerson (2012) analysed large-scale data to investigate the access to good quality healthcare for British adults with a chronic health condition or impairment. 309 people in the sample had a learning disability. The research found:

- 40% of people with a learning disability reported a difficulty using health services, compared to 18% of people with no chronic health condition or impairment
- 12% of people with a learning disability reported a lot of difficulty using health care services, compared to just 3% of people with no chronic health condition or impairment.

The CIPOLD report also found lower rates of take up of health promotion initiatives (e.g. cancer screening) by people with learning disabilities.

The Welsh Government introduced annual health checks in 2006 for people with a learning disability. The health checks are available to people over 16. However, the [report](#) of the Learning Disability Improving Lives Programme found that individual experience of accessing the health check, and of accessing secondary healthcare varied across Wales (e.g. see p11). The Equality and Human Rights Commission 2018 report *Is Wales Fairer?* stated that “most people with learning disabilities are not receiving an annual health check”, and highlighted the difficulties disabled people in general experience in accessing healthcare.

### **Accommodation**

The [report](#) of the Learning Disability Improving Lives Programme also highlights the problem of people being placed outside Wales due to a lack of accommodation and services in Wales (see p3). A [Care Inspectorate Wales/Healthcare Inspectorate Wales survey of local authorities](#) in 2015 found that 547 people had been placed out of county, 172 out of region and 142 out of country (see p17).

A Welsh Government [Statistical Release](#) shows that at 31 March 2018 there were 117 people with a learning disability resident in hospitals and units in Wales, a similar number to the previous nine years.

The Minister for Health and Social Services, Vaughan Gething AM, recently provided the following response to a [Written Assembly Question](#) from Janet Finch Saunders AM on people with learning disabilities who are placed in hospitals outside Wales:

**WAQ78410**

*Tabled on 13/06/2019*

What target has the Minister set for reducing the number of mental health and learning disability patients who are placed in hospitals outside of Wales, and why are only 20 of the approved units in Wales?

**Answered by Minister for Health and Social Services**

*Answered on 18/06/2019*

Whilst there is no target, we are committed to ensuring people can access mental health and learning disabilities services closer to home and the number of out of Wales placements, via the National Collaborative Framework Agreement for Mental Health and Learning disabilities (the Framework), continue to reduce.

For those patients placed outside of Wales, we continue to have robust arrangements in place to monitor the quality and safety of specialist inpatient settings.

The Framework aims to enable all parts of NHS Wales to procure and performance-manage services under pre-agreed standards, costs and the terms and conditions of a contract in a compliant manner. It is the responsibility of providers to apply to be included on the Framework and the NHS Collaborative Commissioning Unit has confirmed that that all independent hospitals in Wales are included on the Framework.

The Wales CAMHS and Eating Disorders Network recently established a task and finish group to undertake a clinically informed option appraisal to consider the provision and capacity of specialist tier 4, low secure and learning disability inpatient care currently provided by out of area placements for children and young people. This work will inform the review of the existing Framework prior to new arrangements being introduced on 1 April 2020.

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.