

# generate

opportunities for people with learning disabilities





# Leaving indifference behind

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Chief Executive of Generate

# Death by indifference





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opportunities for people with learning disabilities

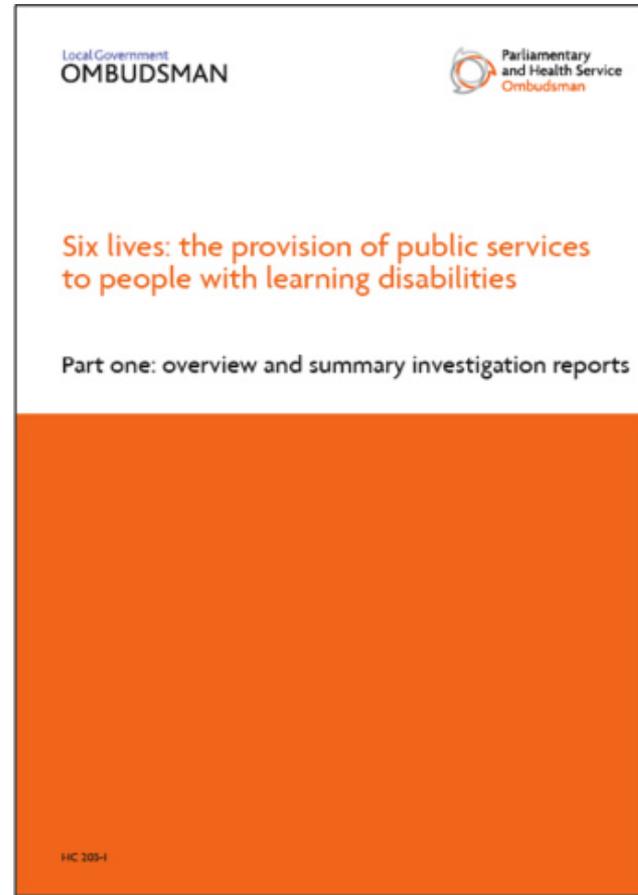
# Institutional discrimination



- Not valuing all people equally
- Not understanding that different people have different needs
- Not adjusting the way they services/treatment is delivered so that it meets different needs
- Becoming used to it and not noticing/realising it is wrong
- '*A fatal complacency*' DRC 2006

Death by ***indifference***

# Inquiries and investigations



# Death by indifference: 74 deaths and counting



# What the 74 deaths and counting showed



- People with a learning disability still dying in avoidable circumstances
- Common themes across the cases were:
  - poor communication
  - lack of basic care
  - delays in diagnosis and treatment
  - failure to recognise pain
  - not following guidance around mental capacity or resuscitation
- Evidence of progress but not enough had changed
- More change needed to improve healthcare

# Nicki's story

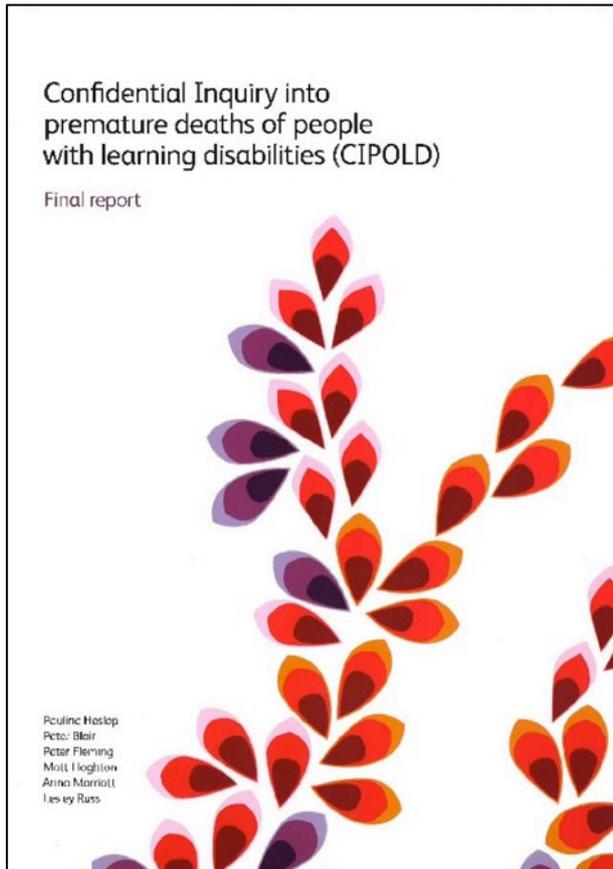


# Ombudsman findings



- Poor nutrition and rapid weight loss
- Hospital staff did not carry out vital tests
- Hospital staff did not follow the Mental Capacity Act
- Concerns raised by Nicki's family were ignored

# The Confidential Inquiry



- The Confidential Inquiry came about after Death by *indifference*
- It was set up by the Government to look at deaths of people with a learning disability
- They wanted to know how many of the deaths could be avoided

# Confidential Inquiry- findings



- The Confidential Inquiry looked at the deaths of **247 people** with a learning disability
- On average, men with a learning disability died **13 years earlier** and women with a learning disability died **20 years earlier**
- **37% of the deaths** could have been avoided with good healthcare
- Scaling up, this means **1200 people** with a learning disability are dying prematurely every year in England
- Lots of people had died because their illnesses were **not diagnosed or treated properly**



# Confidential Inquiry- recommendations



- More reasonable adjustments
- Clear identification of people with learning disabilities
- Patient held health records like hospital passports

# Confidential Inquiry- recommendations (cont)



- Better understanding and protection of people's rights
- Standardisation of annual health checks
- Better healthcare planning

# Confidential Inquiry- recommendations (cont)

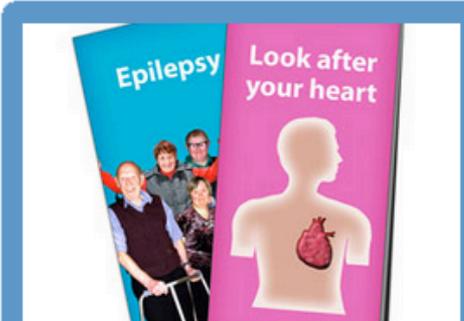


- More learning disability specialists



- Continued monitoring of deaths of people with a learning disability; a **National Learning Disability Mortality Review Body**

# easyhealth.org.uk



Health Leaflets

The image shows two health leaflets. The left one is blue and titled 'Epilepsy' with a photo of a group of people. The right one is pink and titled 'Look after your heart' with a diagram of a human torso showing the heart.



Food and Exercise

The image shows a man in a yellow and blue athletic outfit with his arms raised in a celebratory gesture. In front of him are various fresh fruits and vegetables, including a red bell pepper, a red apple, and a glass of water.



Health Videos

The image shows a man in profile, holding a professional video camera up to his eye as if filming.



Useful Things for your Health Care

The image shows a woman smiling while holding an open book titled 'My NHS Health'.



Useful Organisations

The image shows a blue rotary telephone.



About this website

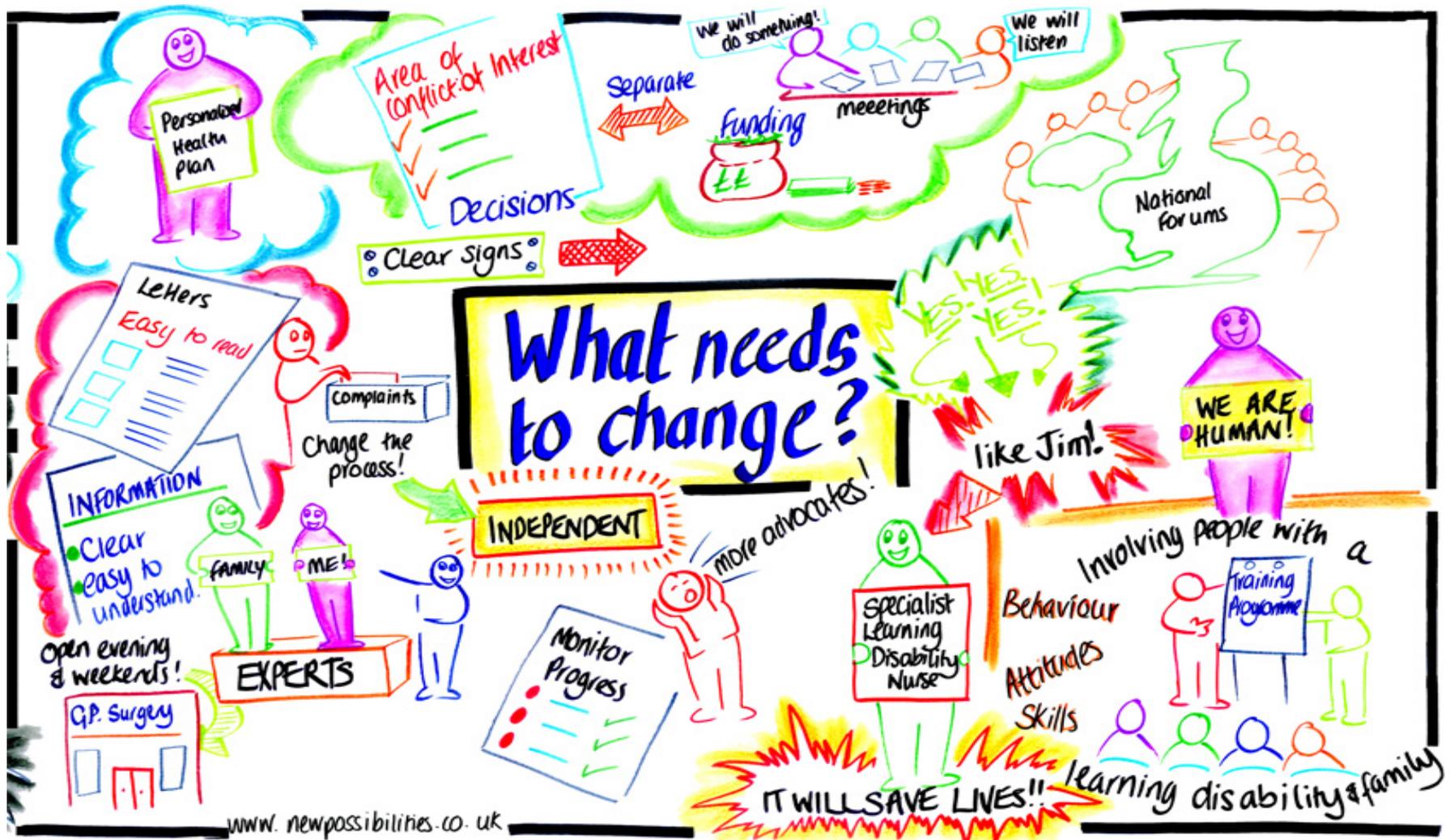
The image shows a video player interface with a play button in the center. The video title is 'Home page film white cuts - maste'. The player shows a progress bar at 0:00 / 1:19 and the YouTube logo.

What is asthma?	Chronic Obstructive Pulmonary Disease ('COPD')	Epilepsy	Diabetes type 2
 <p>Asthma is when the tubes that carry air in and out of your lungs tighten and become swollen. Symptoms of Asthma are:</p>	 <p>You have COPD when you have one or more of the following lung diseases:</p>	 <p>Epilepsy is a brain condition. It can make a person have seizures ('fits' or 'attacks').</p>	 <p>Diabetes Type 2 happens when your body can't control how much sugar there is in it.</p>
 <p>Coughing.</p>	 <p>Chronic bronchitis.</p>	 <p>People often only find out that they have epilepsy when they have had a 'fit'.</p>	 <p>It usually affects people over the age of 40. However, it can affect anyone.</p>
 <p>Wheezing (breathing noises).</p>	 <p>Emphysema.</p>	 <p>There are different kind of fits.</p>	 <p>If you think you might have diabetes you should see your doctor straight away.</p>
 <p>A tight feeling in your chest.</p>	 <p>Chronic asthma.</p>	 <p>Some people can have a 'trance-like' state for a few seconds or minutes.</p>	 <p>Diabetes needs treatment. If you do not treat diabetes it can body damage your body.</p>
 <p>Finding it hard to breathe.</p>		 <p>Other people may faint or fall to the ground and their body may shake.</p>	 <p>Diabetes is a long-term condition. This means it won't go away.</p>

# What does good healthcare look like?



# What needs to change?



# Complain for change

Home

Advice on complaining

Our resources

## Complain for change

Many people don't complain because they find it hard or think it won't make a difference. We want to help people who want to complain about government or health services.



### If you have a learning disability or know someone who has

Currently, our campaign focuses on people with a learning disability and their families, friends and carers. We want to give them the confidence to complain to the NHS if they are unhappy with the service they have received.



### Joe faces problems getting an appointment

Watch our video about a young man with a learning disability who might want to complain.



### Advice on complaining

You can complain if you are unhappy with the service you have received from the NHS. Click here to read our tips on complaining.



### Our resources

Click here for our range of campaign materials including leaflets, posters and Easy Read information.



## Louise

“She had no means of telling them what was the matter. There was no indication from her of what was the matter. She’s so terrified of things like blood tests, there was no way people could get near her”

Brenda (Louise’s mum)

# Better health for people with a learning disability!





# Useful resources

- **IHAL-** <http://www.improvinghealthandlives.org.uk/>
- **Confidential Inquiry-** <http://www.bris.ac.uk/cipold/>
- **GMC-** <http://www.gmc-uk.org/learningdisabilities/>
- **RCGP-** <http://www.rcgp.org.uk/learningdisabilities>
- **RCN-** [https://www.rcn.org.uk/learning\\_disabilities](https://www.rcn.org.uk/learning_disabilities)
- **EasyHealth-** <http://www.easyhealth.org.uk/>