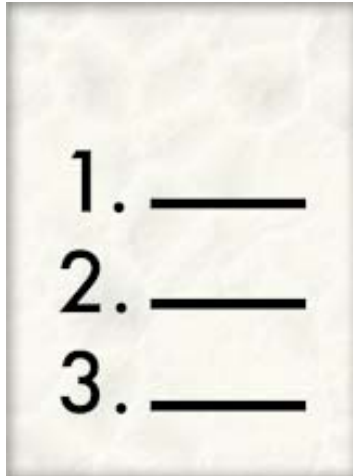


# Healthcare for people with a learning disability- Getting it right

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# What we will be talking about



- What is a **learning disability**?
- Why is health an **important** issue for people with a learning disability?
- What happens **when healthcare goes wrong** for people with a learning disability?
- What does **good healthcare** look like?
- What **change** is needed?

# What is a learning disability?



“a reduced intellectual ability and difficulty with everyday activities...which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.”

# What causes a learning disability?



- A learning disability occurs when the brain is still developing - before, during or soon after birth.
- Before birth things can happen to the central nervous system (the brain and spinal cord) that can cause a learning disability. A child can be born with a learning disability if the mother has an accident or illness while she is pregnant, or if the unborn baby develops certain genes.
- A person can be born with a learning disability if he or she does not get enough oxygen during childbirth, or is born too early.
- After birth, a learning disability can be caused by early childhood illnesses.

# Why do Mencap campaign on health?



- People with a learning disability are **at least twice as likely** as other people to go into hospital in a year
- Those who go into hospital are **twice as likely** to be admitted **three times or more** in that year
- Their hospital stays are roughly **25% longer**
- People with a learning disability are **58 times more likely** to die before their 50<sup>th</sup> birthday
- Mencap have had **almost 100 avoidable deaths** reported to us since 2002

# Associated medical conditions



- **Epilepsy:** 22% of people with a learning disability compared to 1% in the general population
- **Dementia:** 21.6% of people with a learning disability compared to 5.7% of the general population
- **Schizophrenia:** 3% of people with a learning disability compared with 1% of the general population
- **Visual impairments:** More likely (8.5 to 200 times) to have vision impairment
- **Hearing impairment:** 40% have hearing impairments
- **Poor dental hygiene and dental care** with 36.5% of adults and 80% of adults with Down's syndrome having unhealthy teeth and gums



# Common problems when accessing health services



# What happens when healthcare goes wrong for people with a learning disability?



- Where health care needs are greater, the response should be greater
- People with a learning disability have increased health needs but continue to receive poorer health care
- Mencap have heard many stories from families about NHS failures
- In some cases, poor healthcare was resulting in people dying “prematurely”





# Institutional discrimination

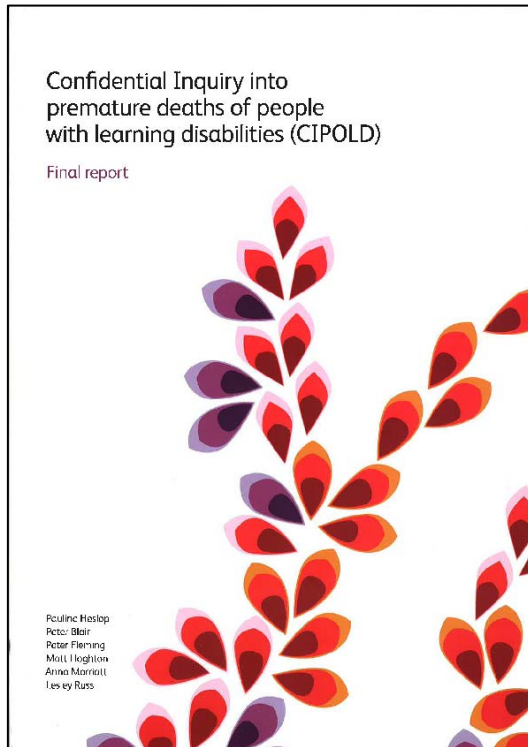
Institutional discrimination happens when the people working in a place or organisation **do not:**

- **value all people equally**
- **understand that different people have different needs**
- **change the way they deliver a service so that it meets different needs**

This happens for a long time and staff become used to it and do not notice it is wrong.



# Recent data: The Confidential Inquiry



- 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 **1,200 people** with a learning disability are dying prematurely every year. That's almost **25 people per week**.
- Lots of people had died because their illnesses were **not diagnosed or treated properly**



# What does good healthcare look like?



**mencap**

The voice of  
learning disability

# Getting it right charter



## See the person, not the disability

All people with a learning disability have an equal right to healthcare.

All healthcare professionals have a duty to make reasonable adjustments to the treatment they provide to people with a learning disability.

All healthcare professionals should provide a high standard of care and treatment and value the lives of people with a learning disability.

By signing this charter, we pledge to:

- ✓ make sure that hospital passports are available and used
- ✓ make sure that all our staff understand and apply the principles of mental capacity laws
- ✓ appoint a learning disability liaison nurse in our hospital(s)
- ✓ make sure every eligible person with a learning disability can have an annual health check
- ✓ provide ongoing learning disability awareness training for all staff
- ✓ listen to, respect and involve families and carers
- ✓ provide practical support and information to families and carers
- ✓ provide information that is accessible for people with a learning disability
- ✓ display the *Getting it right* principles for everyone to see.

Charity number 212277 (England, Northern Ireland and Wales), 10241079 (Scotland) 2015207\_0410 407280407

For guidance on implementing this pledge, please visit [www.mencap.org.uk/gettingitright](http://www.mencap.org.uk/gettingitright)



getting it right ✓





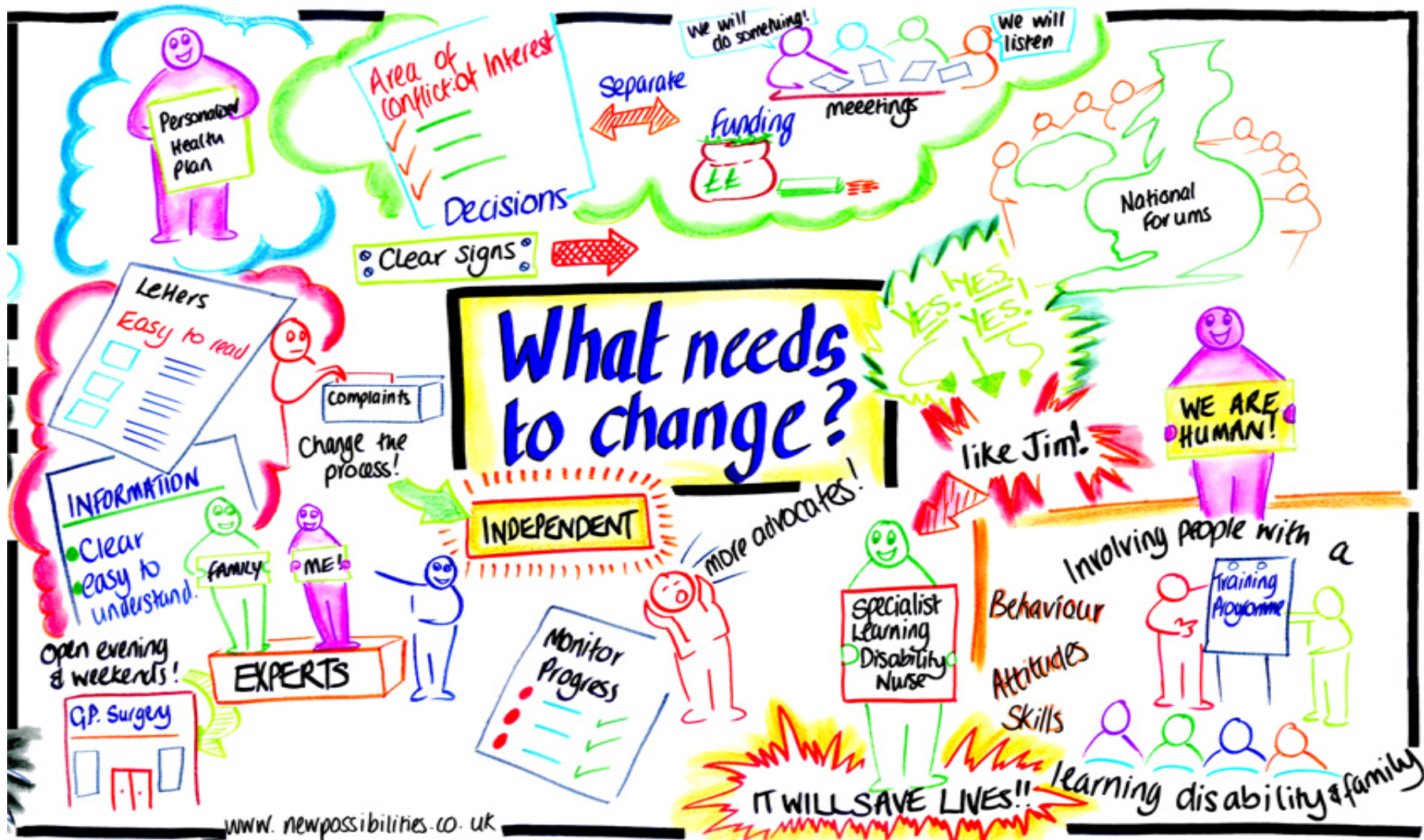
## See the person – not the disability

- ✓ Find time to:
  - listen to the person
  - listen to the family.
- ✓ Find the best way to communicate.
  - Pay attention to facial expressions.
  - Notice gestures and body language.
  - Try pointing to pictures.
  - Try signing.
- ✓ Keep information simple and brief.
- ✓ Avoid using jargon.

## Don't make assumptions about the person's quality of life

- ✓ People with a learning disability feel pain too.
- ✓ People with a learning disability get ill too.
- ✓ Don't confuse a learning disability with illness.
- ✓ Be suspicious about serious illness – act quickly!
- ✓ Get to know some of the health conditions that are more common for people with a learning disability.

# What needs to change?



# Other things we want to see...



- Standardisation of annual health checks
- Better healthcare planning
- Wider use of hospital passports; they save lives!

# Other things we want to see...



- Better data collection and the introduction of a flagging system for patients with a learning disability



- Better monitoring and regulation of healthcare settings



- Continued funding for the Public Health Observatory and a Mortality Review

# Kyle's Story





# What nurses and midwives can do?



- Take the time to **get to know their patients** as people; see the person, not the disability
- Think of any **reasonable adjustments** that can be made
- Check if patients have a **hospital passport** or **health action plan**
- Use **accessible** language in written and spoken communication
- **Listen** to the person and their family/carers
- Learn about **Mental Capacity Laws**



## 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/>

# For more information



Visit our website

[www.mencap.org.uk/deathbyindifference](http://www.mencap.org.uk/deathbyindifference)

[www.mencap.org.uk/gettingitright](http://www.mencap.org.uk/gettingitright)



Or email

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# Any questions?

