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 50th 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 healthcare include:

- Poor communication: I need an advocate, you're not talking to me.
- Lack of understanding: Training needed.
- Lack of engagement: Not enough information, I don't understand, not enough money.
- Personal Health Budgets: But what happens next?
- Information Posters: Not easy to understand.
- CP Annual Health Check: Why are these?
- Reasonable adjustment: Nothing! Doesn't get out of chair, no blood pressure taken.

Mencap: The voice of learning disability
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?
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.

For guidance on implementing this pledge, please visit www.mencap.org.uk/gettingitright
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?

- Personalised Health Plan
- Clear Signs
- Decisions
- Letters
- Open evenings & weekends
- EXPERTS
- GP Surgery

What needs to change?

- Area of Conflict of Interest
- Separate
- Funding
- Meetings
- WE WILL DO SOMETHING!
- WE WILL LISTEN

- National Forums
- We are human!
- Like Jim!
- More advocates!
- INDEPENDENT

Information
- Clear, easy to understand
- Change the process!

- Specialist Learning Disability Nurse
- Monitor Progress
- Training Programme

- Involve people with a
- Behaviour
- Attitudes
- Skills
- Learning disability & family

IT WILL SAVE LIVES!!

www.newpossibilities.co.uk

mencap
The voice of learning disability
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

- Confidential Inquiry- [http://www.bris.ac.uk/cipold/](http://www.bris.ac.uk/cipold/)
- GMC- [http://www.gmc-uk.org/learningdisabilities/](http://www.gmc-uk.org/learningdisabilities/)
- RCGP- [http://www.rcgp.org.uk/learningdisabilities](http://www.rcgp.org.uk/learningdisabilities)
- RCN- [https://www.rcn.org.uk/learning_disabilities](https://www.rcn.org.uk/learning_disabilities)
For more information

Visit our website
www.mencap.org.uk/deathbyindifference
www.mencap.org.uk/gettingitright

Or email
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Any questions?