



Public Health
England

Health profile of *People with Learning Disabilities*



This Photo by Unknown Author is licensed
under CC BY

Dr Andrew Lee
Y&H PHE Centre Lead for Learning Disabilities
Andrew.lee@phe.gov.uk



Public Health
England

How many people are there with learning disabilities in England?

- ~1.2 million persons with learning disabilities in England (2011)
- 905,000 were adults (aged over 18 years)
- 530,000 were men
- 375,000 were women
- ~170,000 were children on school registers (2.5%)





Public Health
England

How many people are there with learning disabilities in England?

- **Boys** are more likely than girls to be identified with learning disabilities
- There were more people with learning disabilities in **poorer households**



This Photo by Unknown Author is licensed under [CC BY-NC-ND](#)

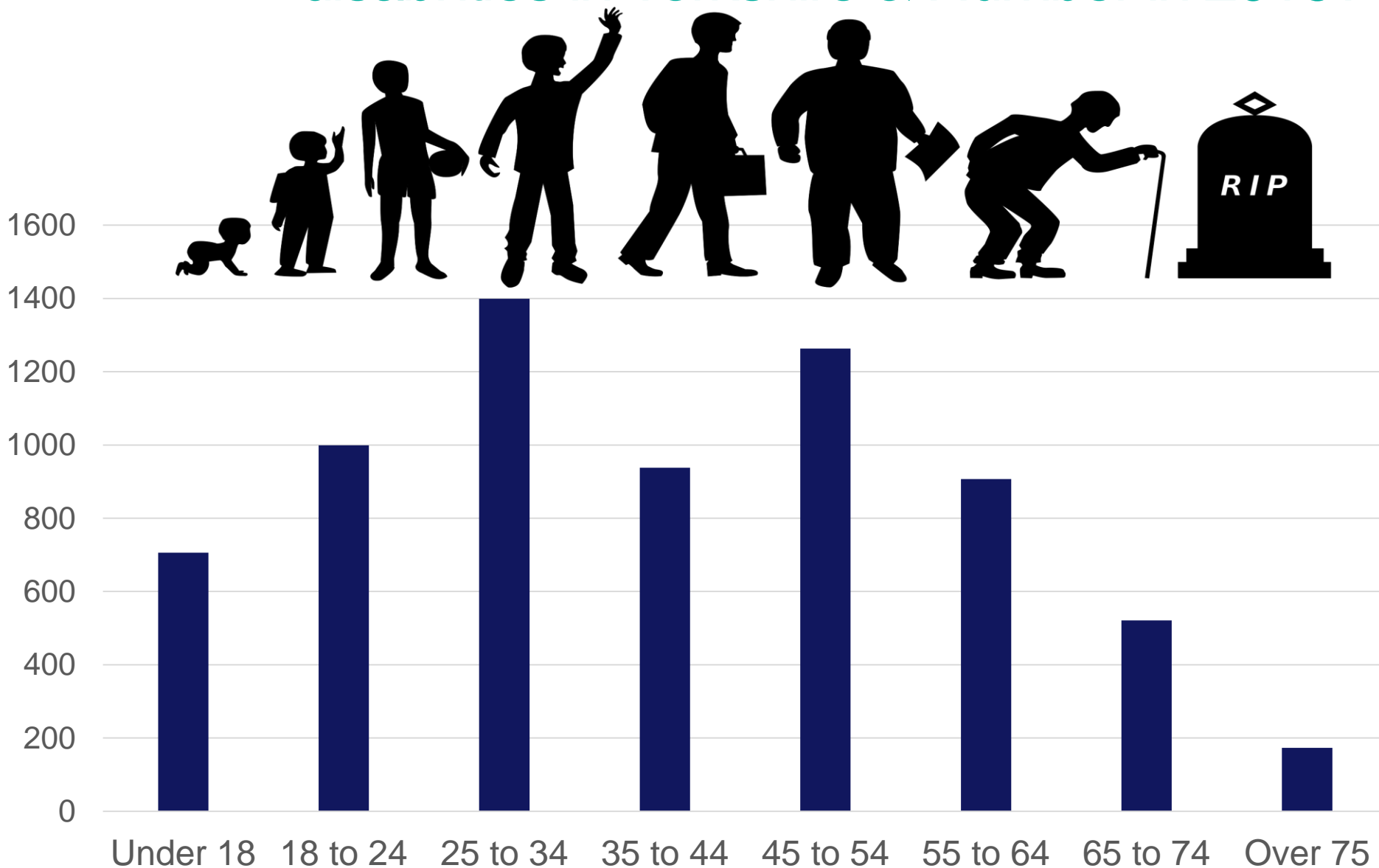


This Photo by Unknown Author is licensed under [CC BY](#)



Public Health
England

How old are people with learning disabilities in Yorkshire & Humber in 2016?





Public Health
England

How good is people's health?



- Not very good
- In many ways
- At every age



Public Health
England

They may have unhealthy lifestyles!

Not enough exercise

Poor diets →



← Alcohol, Cigarettes & Drugs



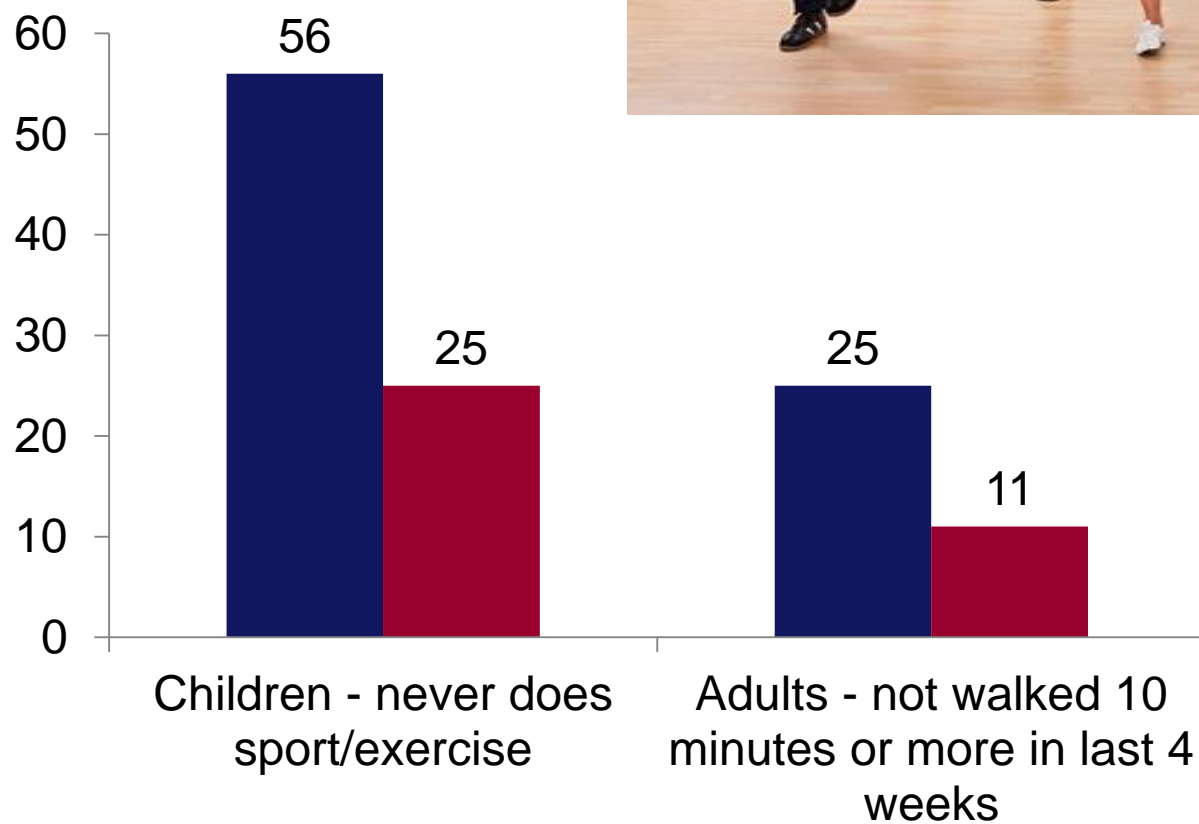
Sex →





Public Health
England

Exercise



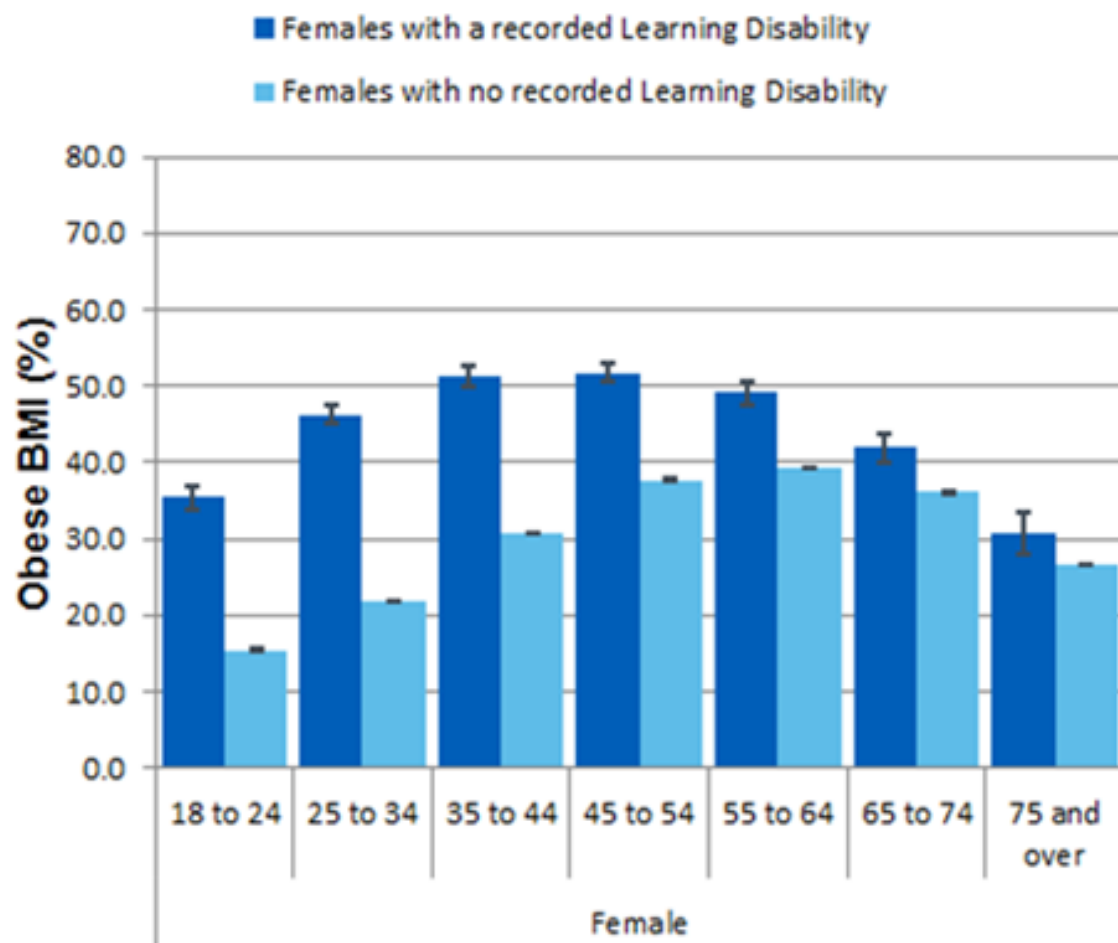
■ People with learning disabilities
■ Other people



Public Health
England

Obesity

Percentage of female patients with an obese BMI recorded in the 15 months to 31 March 2015 by age, sex and learning disability status



The most striking pattern is how much earlier obesity appears.



Public Health
England

Being very overweight

- Young adults with learning disabilities are twice as likely to be very overweight (obese)
- Increases with age
- Older people with learning disabilities twice as likely to be underweight





Public Health
England

People with learning disabilities (PwLD) at higher risk of developing Type 2 diabetes

- More sedentary lifestyle, low levels of exercise
- Consuming high fat diets
- Being prescribed high levels of antipsychotic medications which can contribute to obesity



This Photo by Unknown Author is
licensed under [CC BY-SA](#)

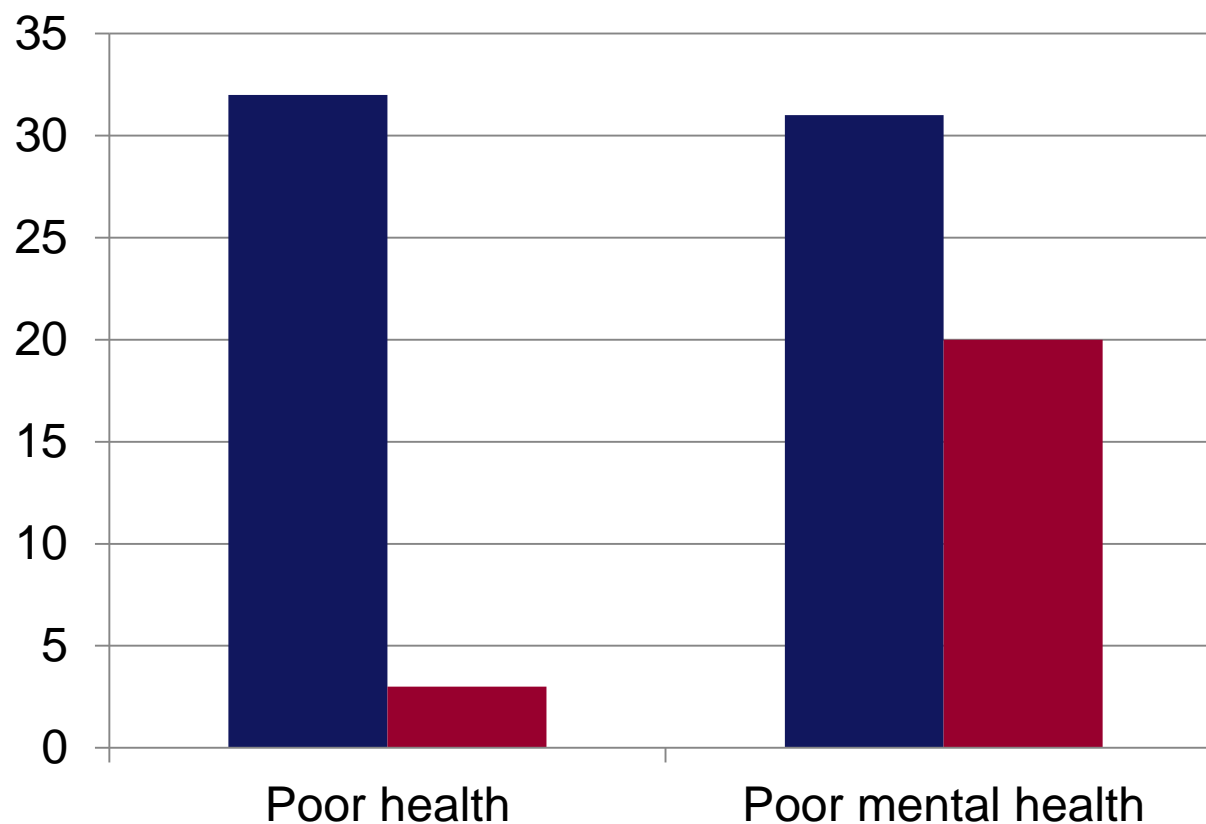


This Photo by Unknown Author is
licensed under [CC BY-SA](#)



Public Health
England

The health of the 'hidden majority'

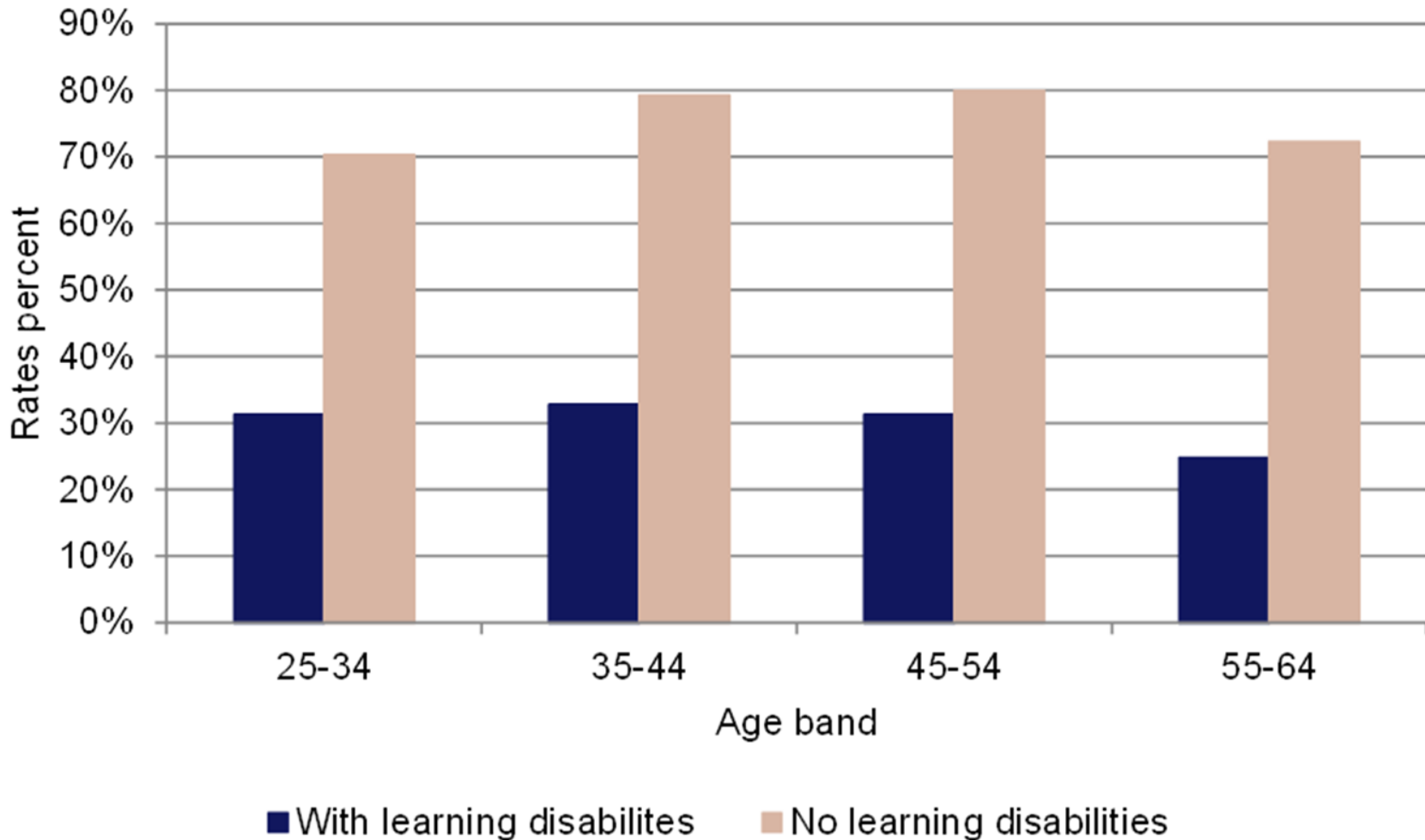


- Adults with learning disabilities
- Other adults



Cervical cancer screening

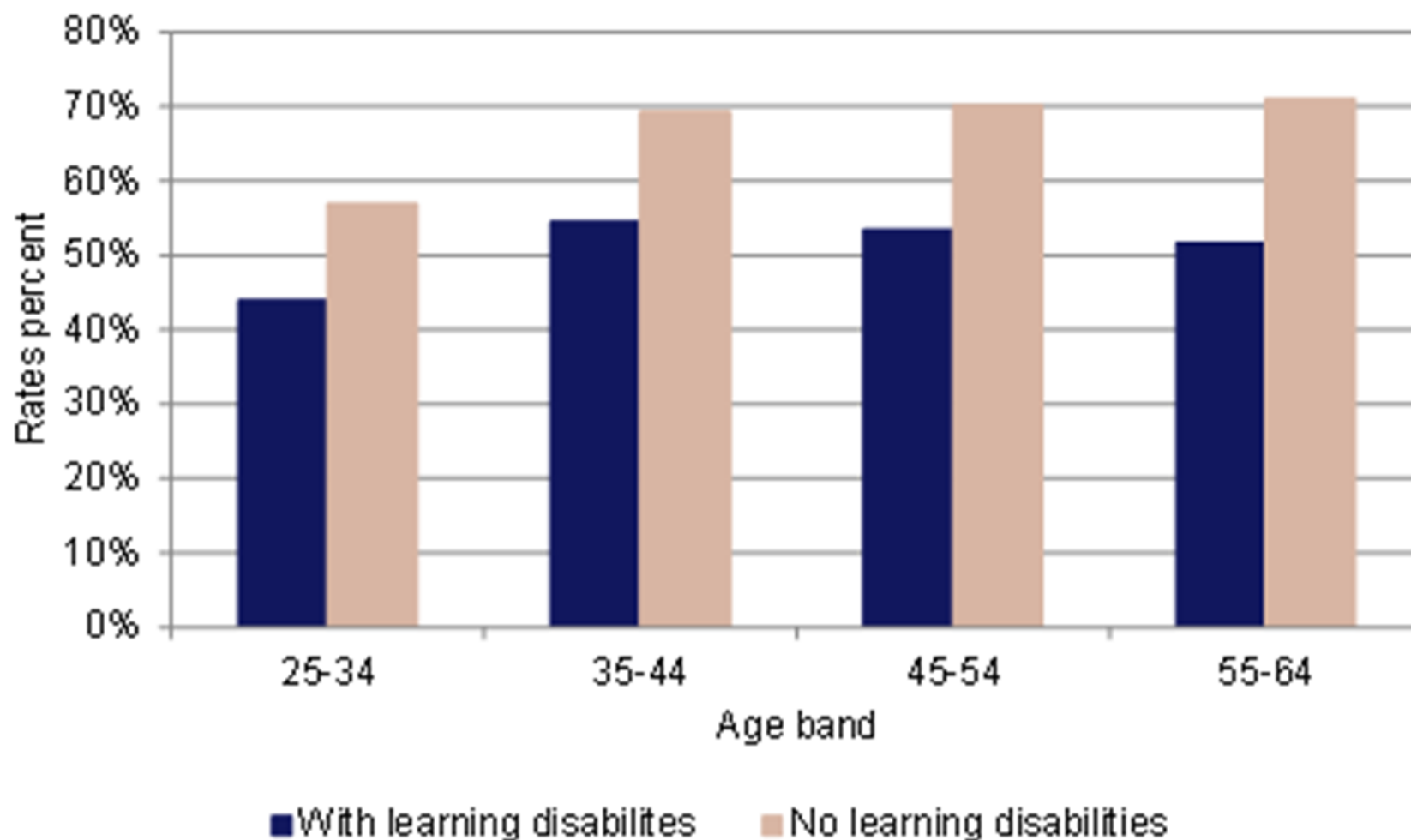
Cervical cancer screening - Age stratified rates 2016/17





Breast cancer screening

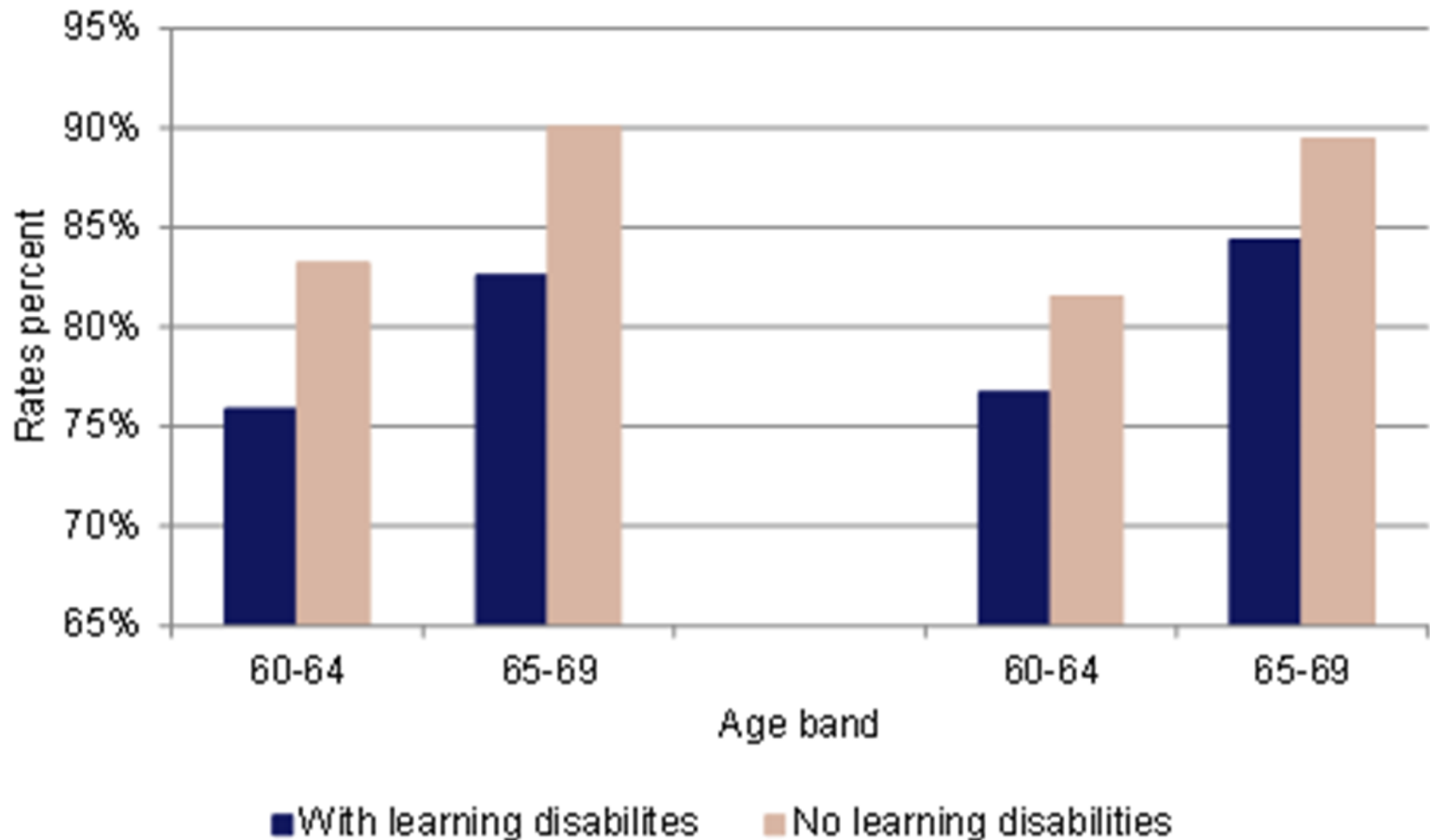
Breast Cancer screening - Age stratified rates 2016/17



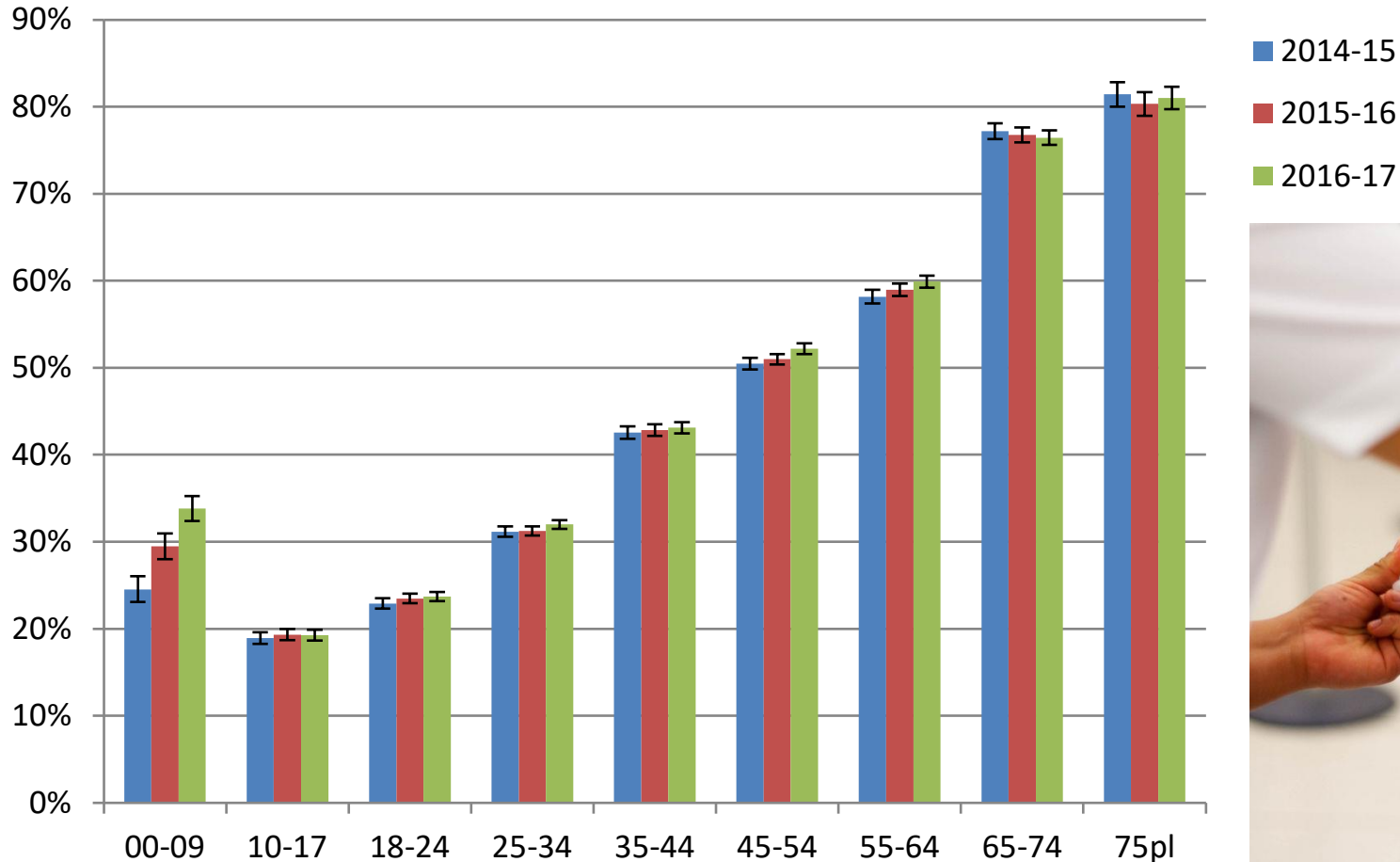


Colorectal cancer screening

Colorectal cancer screening - age/sex strat. rates 2016/17



Flu immunisation coverage for people with learning disabilities by age group and year



Source: NHS Digital, Learning disabilities health and care dataset

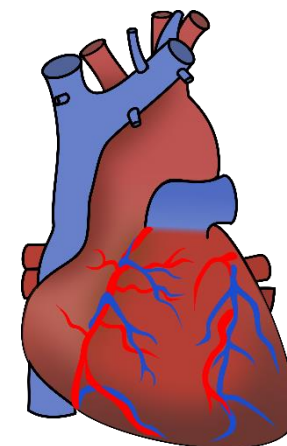
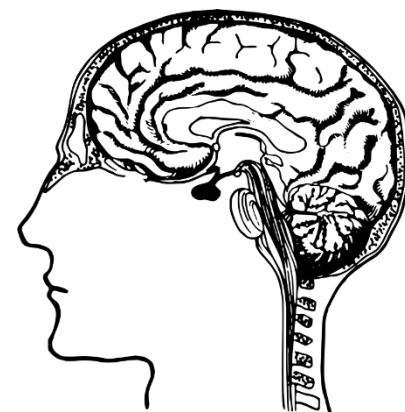
This Photo by Unknown Author is licensed under [CC BY-NC-ND](#)



Public Health
England

What health problems may people with learning disabilities have compared to other people?

Health problem	How many times more	More or less?
Epilepsy	22.5	MUCH MUCH MORE
Mental health	7.6	Much more
Dementia	4.5	Much more
Underactive thyroid	2.6	More
Diabetes (Type 2)	1.8	More
Kidney disease	1.6	More
Heart failure	1.5	More
Stroke	1.4	More
Asthma	1.3	More
High blood pressure	0.9	A little less
Cancer	0.8	Less





Public Health
England

How much younger do people with learning disabilities die?

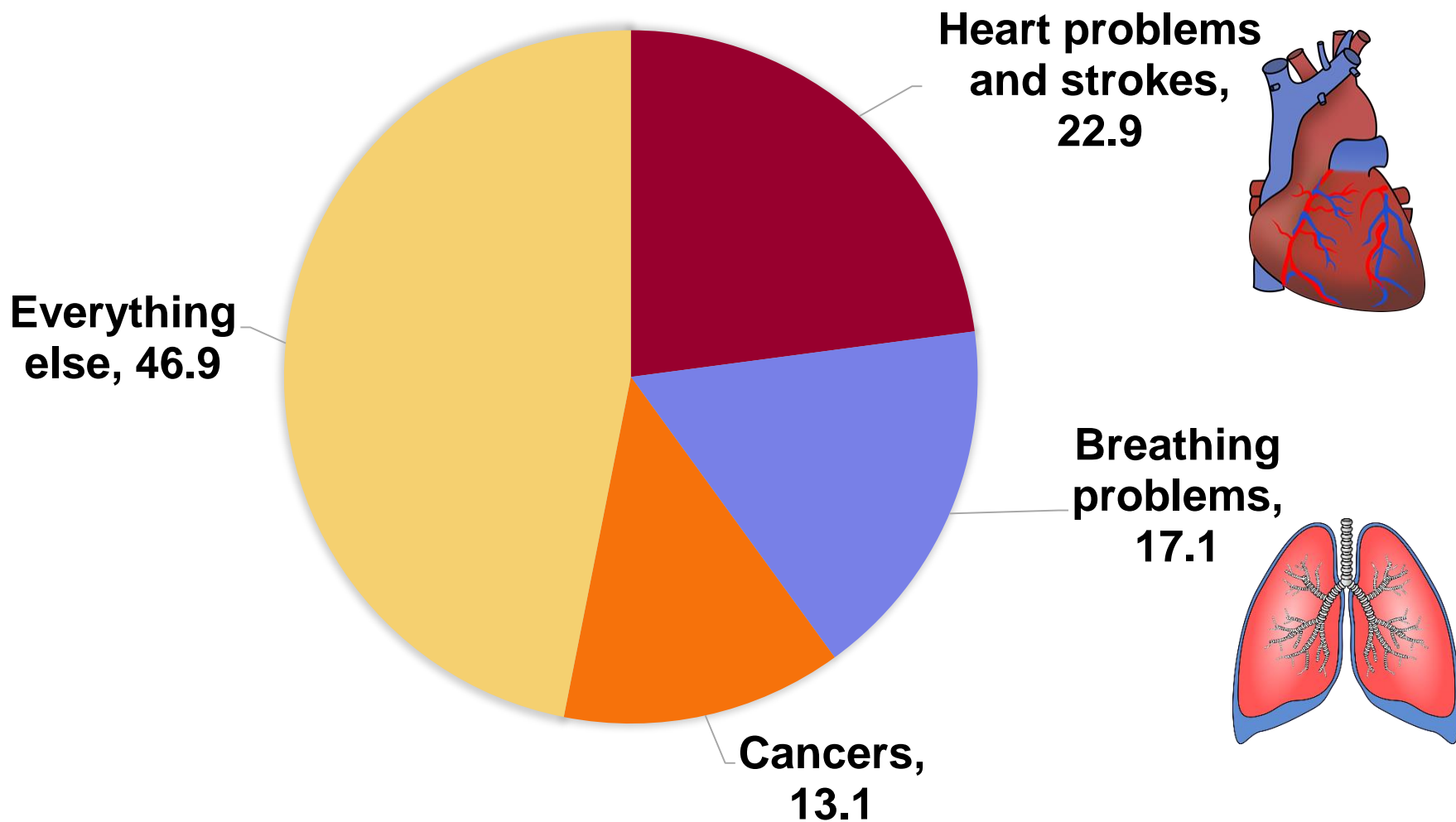
	Male	Female
Compared to people without learning disabilities how many times more likely are people with learning disabilities to die? (Standardized mortality ratio)	3.0 times	3.4 times
How long can people with learning disabilities live on average? (Life expectancy)	63.8 years	66.7 years
How much shorter is the length of life for people with learning disabilities?	19.8 years	20.2 years



Public Health
England

What are the common causes of death in people with learning disabilities?

PROPORTION OF DEATHS (%)





People with learning disabilities have a higher chance of dying from...

Causes	Chance of death x
Epilepsy	34.4
Lung disease	21.8
Flu and chest infections	7.7
Strokes	3.3
Heart disease	2.2



This Photo by Unknown Author is licensed under [CC BY](#)



This Photo by Unknown Author is licensed under [CC BY-SA](#)



This Photo by Unknown Author is licensed under [CC BY-NC](#)



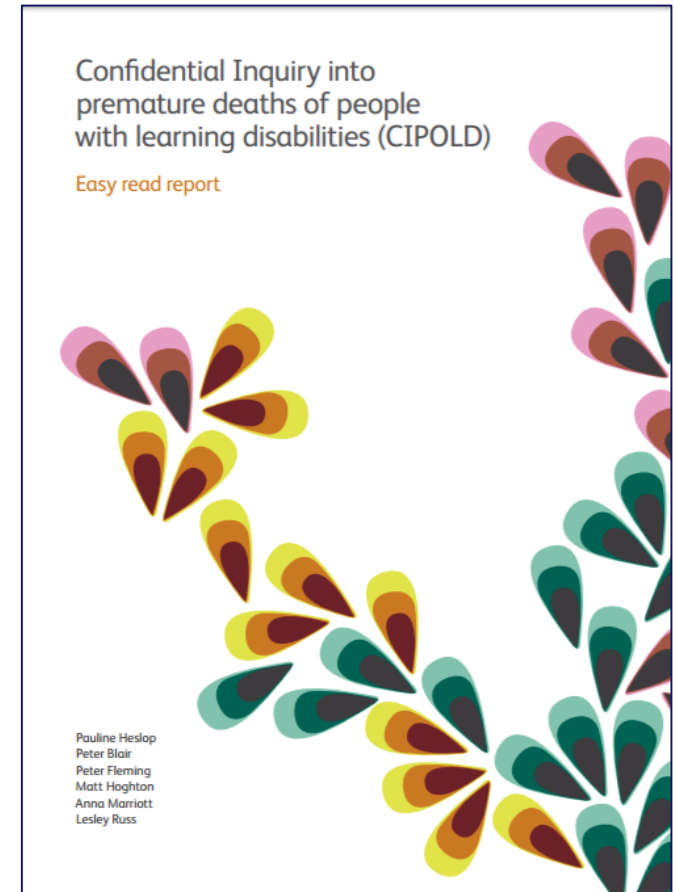
Public Health
England

Avoidable deaths

Nearly half of deaths of people with learning disabilities were avoidable

Common problems:

- Delays in diagnosis and treatment
- A lack of reasonable adjustments to healthcare





Public Health
England

Contributing factors

☐ **Communication problems** during the consultation.



This Photo by Unknown Author is licensed under CC BY-NC-ND

☐ Patient inhibitions because of previous **negative encounters**



☐ **Lack of time** to conduct an adequate consultation.



☐ **Delays or problems with diagnosis or treatment**

SOURCE: CIPOLD & McCarthy M. Exercising choice and control—women with learning disabilities and contraception. British Journal of Learning Disabilities. 2010 Dec 1;38(4):293-302.

Conditions with specific relevance to people with intellectual disabilities

	Constipation	Dysphagia	Reflux
2014-15	1.6 (1.5 to 1.7)	2.6 (2.5 to 2.7)	6.8 (6.7 to 7.0)
2015-16	1.7 (1.6 to 1.8)	2.9 (2.8 to 2.9)	7.3 (7.2 to 7.5)
2-16-17	13.1 (12.9 to 13.3)	3.0 (3.0 to 3.1)	7.8 (7.7 to 7.9)

- Notable rise in rate of identified constipation
- Dysphagia is underdiagnosed - rate should probably be at least 8%



Public Health
England

Contributing factors

- ☐ **Lack of awareness** of their health needs amongst health care staff.
- ☐ Problems with **identifying needs**
- ☐ Difficulty providing appropriate care in response to **changing needs**.
- ☐ Lack of **coordination of care** across and between different disease pathways and service providers.

TRANSITIONS ARE PROBLEMATIC





Public Health
England

Contributing factors

❖ *Diagnostic overshadowing*



This Photo by Unknown
Author is licensed under [CC BY-NC](#)

❖ *Overmedication*



This Photo by Unknown Author
is licensed under [CC BY-SA](#)

❖ Low take-up for national
screening programmes



This Photo by Unknown Author is
licensed under [CC BY-SA](#)



Public Health
England

Contributing factors

- ❑ Lack of **effective advocacy** for people with multiple conditions and vulnerabilities.
- ❑ **Lack of priority** given in the NHS generally
- ❑ Lack of **reasonable adjustments** to help people to access healthcare services.

Source: CIPOLD (2011)

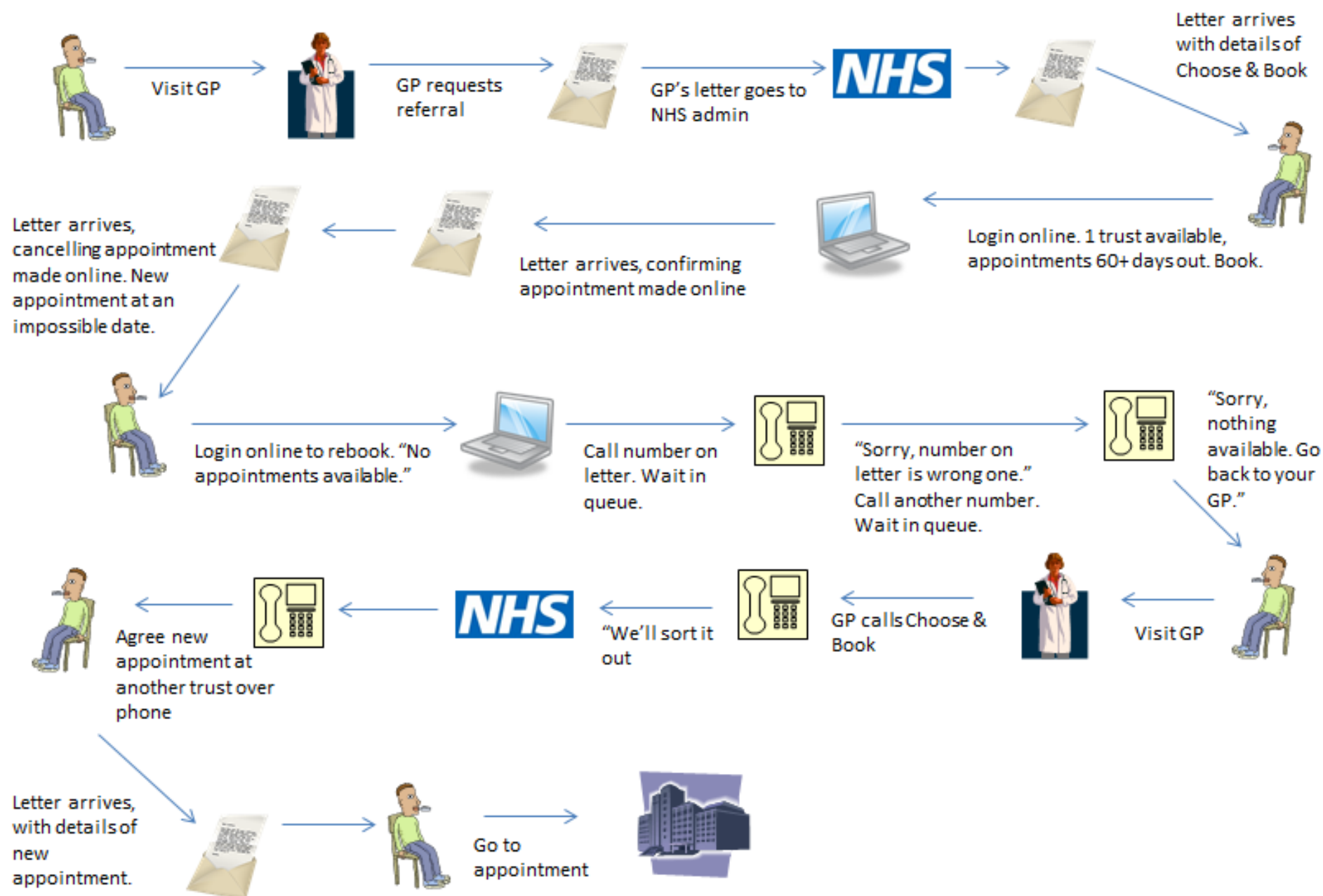


This Photo by Unknown Author is licensed under [CC BY-NC](#)



This Photo by Unknown
Author is licensed under [CC
BY](#)

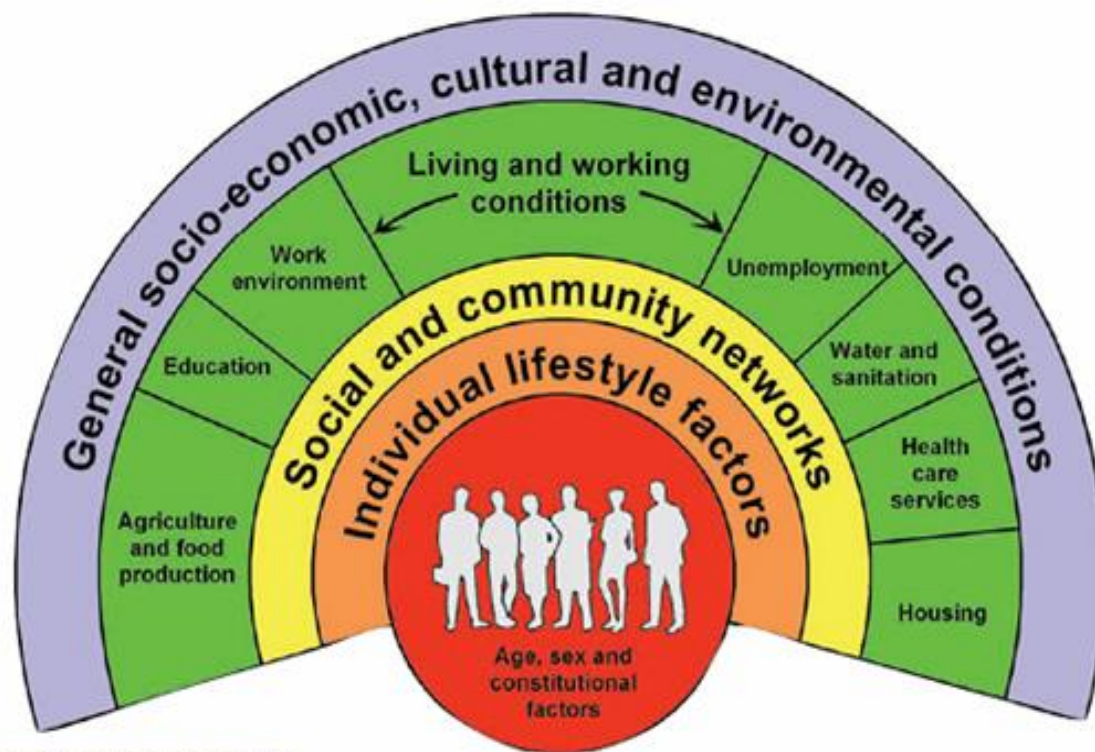
Choose and Book: How it Works (Patient Perspective)





Public Health
England

What other reasons are there for their bad health?



Source: Dahlgren and Whitehead, 1991



Public Health
England

Social and economic factors

- Children and adults with learning disabilities more likely to be:
 - Living in poverty/hardship
 - Living in inadequate housing
 - Experiencing adverse life events
 - Unemployed (as adults)
 - Restricted in their social networks
 - Experiencing discrimination and violence

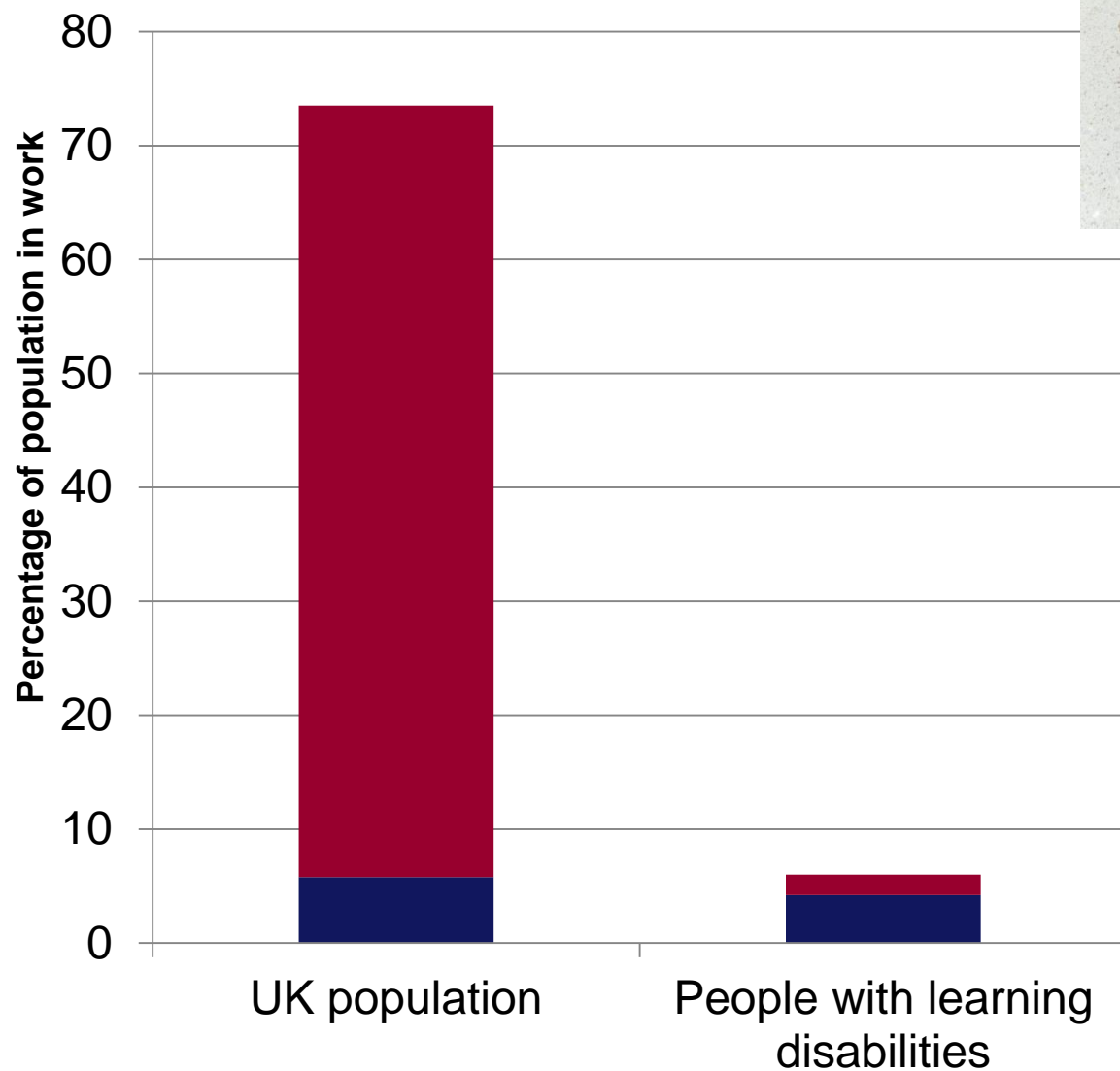


This Photo by Unknown Author is
licensed under [CC BY-NC-ND](#)



Public Health
England

Paid job



This Photo by Unknown Author is licensed under [CC BY](#)

- More than 16 hrs per week
- Up to 16 hrs per week

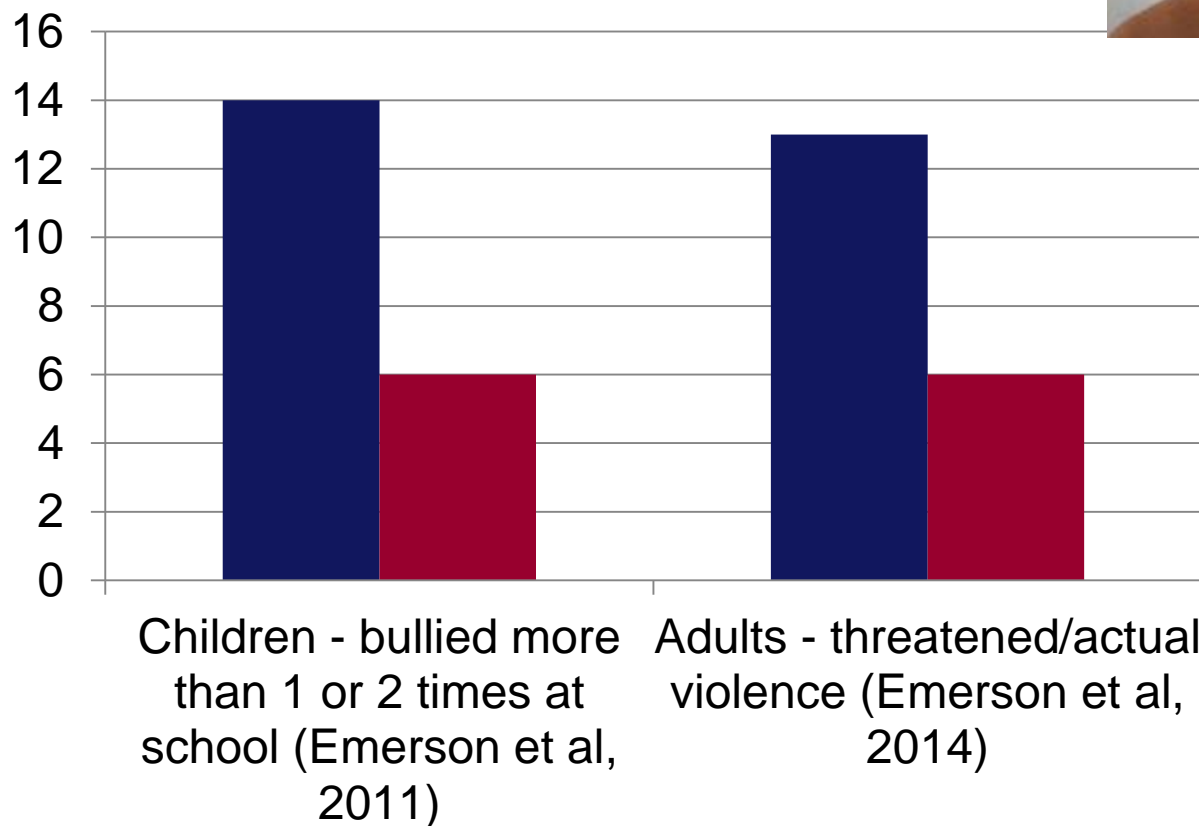


Public Health
England

Exposure to violence



This Photo by Unknown Author is
licensed under [CC BY-NC-ND](#)



■ People with learning disabilities
■ Other people



Public Health
England

Equality Act 2010

When we're making decisions, the Equality Act 2010 gives us a duty to take into account the need to:

- eliminate discrimination, harassment and victimisation
- advance equality of opportunity
- foster good relations between different parts of the community

This covers **disability**





Public Health
England

What Can We Do?



Improve health services,
by making *reasonable
adjustments*

Reasonable adjustments are changes or additions to existing services designed to make them more accessible and effective for disabled people.

Their aim is to ensure that disabled people are not excluded from services, and can achieve the same outcomes as those who are not disabled.



Public Health
England

What are reasonable adjustments?

IS IT ACCESSIBLE?

- ❖ Does the service have all the components it needs to ensure accessibility to and effectiveness for people with learning disabilities



DOES IT MEETS NEEDS?

- ❖ Are there systems in place to ensure individuals are assessed and the appropriate adjustments are made to meet their personal needs?

ARE THE STAFF TRAINED?

- ❖ Do the people in the service have the right knowledge and skills?





Public Health
England

Practical priorities for public health?

- ✓ Annual health checks for people with learning disabilities
- ✓ Flu immunisation
- ✓ Cancer screening
- ✓ Mental health
- ✓ Paid jobs



This Photo by Unknown Author is licensed under [CC BY-SA](#)



Public Health
England

Annual Health Checks

Whole series of health checks including:



← **Dental health**

Eye checks →



This Photo by Unknown Author is licensed under CC BY-ND



This Photo by Unknown Author is licensed under CC BY-NC-ND

← **Hearing**

Feet →



This Photo by Unknown Author is licensed under CC BY-SA

← **Screening tests**



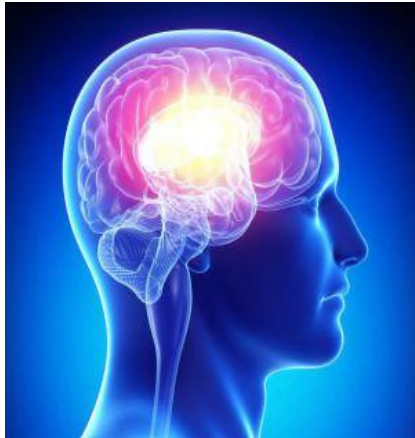
Flu jabs →





Public Health
England

Detect longer term health problems



Epilepsy

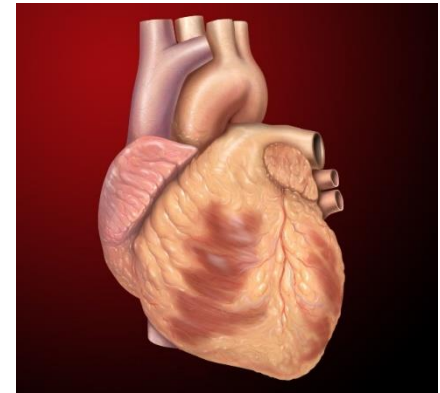
Mental health

Dementia

Thyroid problems

Diabetes

Heart disease & strokes



Dysphagia

Asthma / respiratory problems



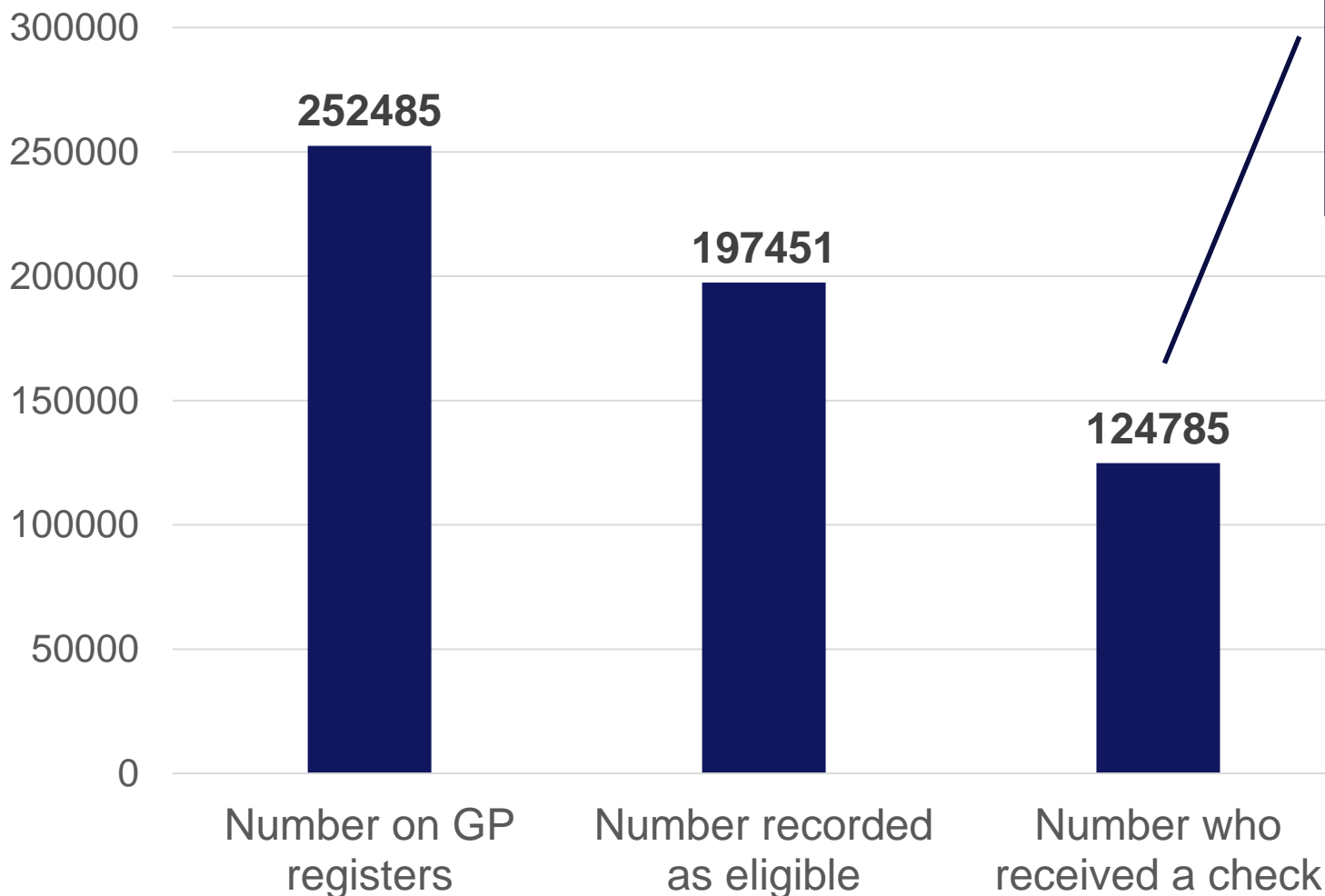
Mobility



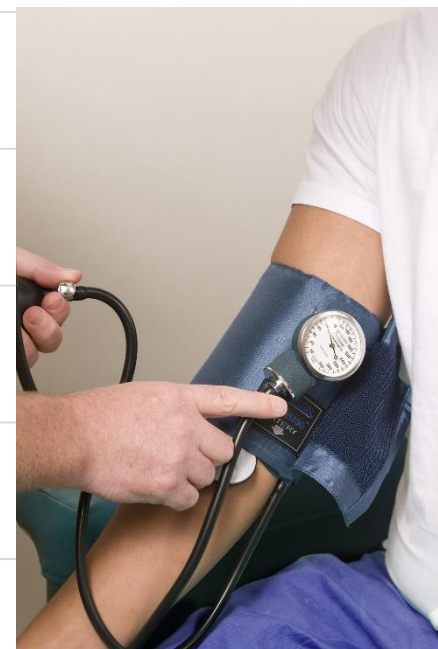


Public Health
England

How many people with learning disabilities get an annual health check in England in 2014/15



Less than
half!





Issues

For annual health checks, flu immunisation and cancer screening, issues of...

- Geographical **variation**
- Awareness of **eligibility** (people with learning disabilities, families, support workers, health professionals)
- **Reasonable adjustments** to ensure meaningful access
- **Follow up**





Public Health
England

Health, social and economic inequalities

Attributable to the external environment and conditions mainly outside the control of the individuals concerned

Unnecessary, avoidable, unjust and unfair





Public Health
England

Acknowledgements

- Many thanks to Professors Gyles Glover and Chris Hatton from the PHE Learning Disabilities Observatory for sharing their slides