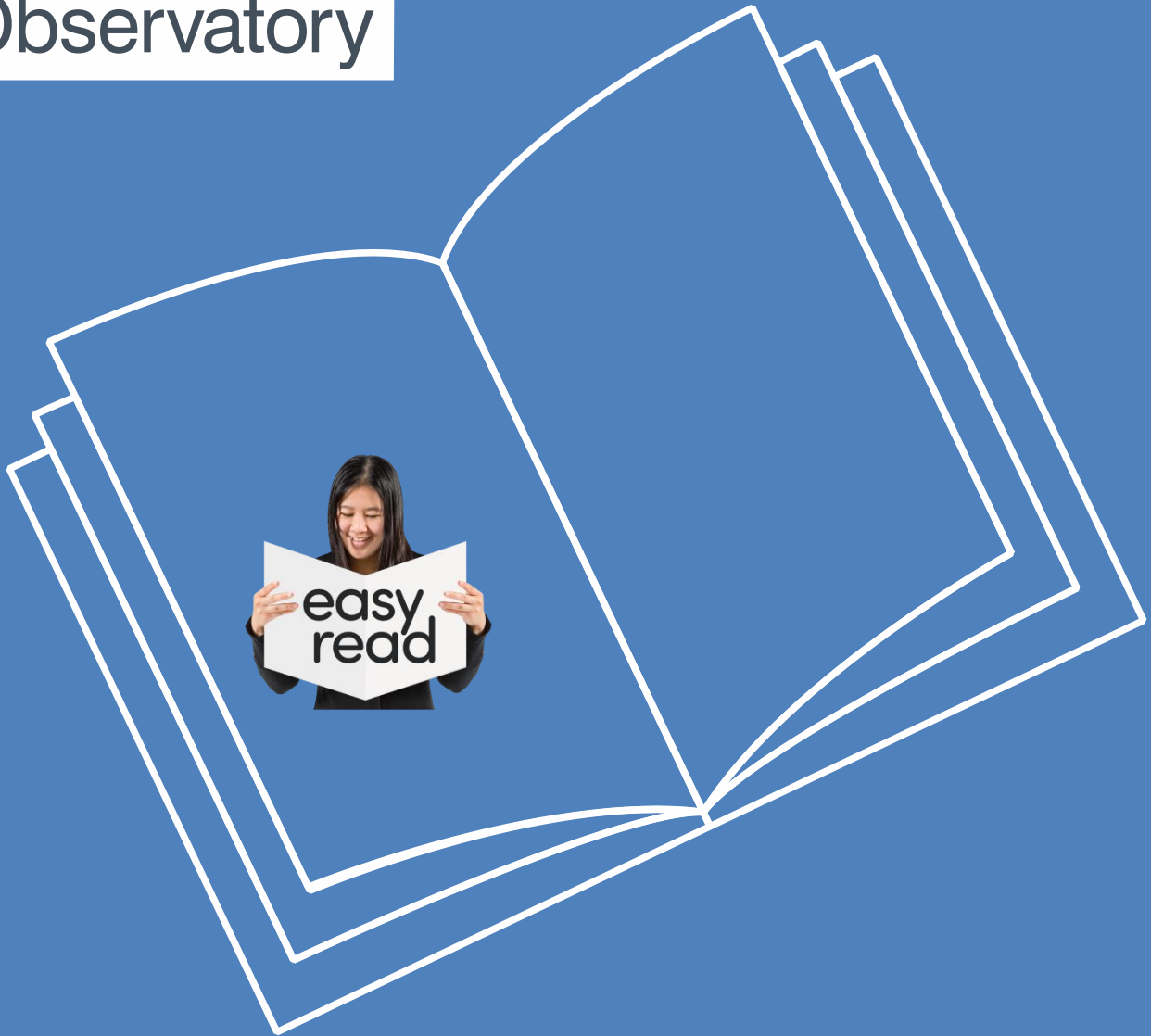


Scottish

Learning Disabilities

Observatory



**Deaths in children and young people
with and without learning disabilities
in Scotland 2009 to 2015**

What words used in this report mean

Cause of death	The reason that somebody dies. It might be an illness, like cancer.
Cerebral palsy	Is a health condition. It affects everyone differently. It can affect body movement, and how you speak.
Epilepsy	Is when you have seizures because of something happening in your brain.
Medical journal	A type of magazine about medical research.
Premature death	When someone has died at a younger age than they should have done.
Prevented	This is when something could be stopped from happening.
Reasonable adjustments	These are the changes that help make services more accessible for people with learning disabilities.
Treatable conditions	These are health conditions that can be treated and made better.

Deaths of children and young people with and without learning disabilities in Scotland

Scottish
Learning Disabilities
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Introduction

The Scottish Learning Disabilities Observatory was set up in 2015 and is part of the University of Glasgow.

We are funded by the Scottish Government.

About this report



This report looks at the health of children and young people with learning disabilities in Scotland between the years 2009 and 2015.

People with learning disabilities often die earlier than people without learning disabilities. We wanted to understand why this can happen?



We wanted to know how many children and young people with learning disabilities died in Scotland?



We wanted to know what children and young people with learning disabilities died from?

Could their deaths have been prevented?



We looked at lots of different information to tell us how many children and young people had learning disabilities in Scotland.

We found that 18,278 children and young people had learning disabilities.

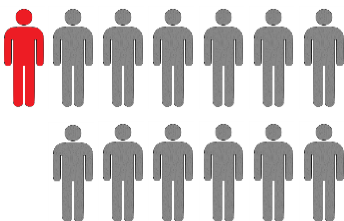
How many people died?



We found 106 children and young people with learning disabilities had died.



We compared the number of children and young people with learning disabilities against the number of children and young people without learning disabilities.

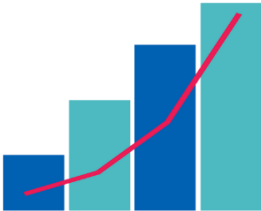


For every child or young person without a learning disability who died, there were 12 with learning disabilities who had died.



More children and young people died with a learning disability, than those who did not have a learning disability.

For every girl without a learning disability who died, there were 17 girls with learning disabilities who had died.



For every boy without a learning disability who died, there were 10 boys with learning disabilities who had died.



Children and young people with learning disabilities died at a younger age than children and young people without learning disabilities.

What did people die from?

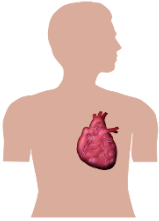


For each child or young person who died we looked at the underlying cause of death. This is the reason why someone had died.

We found people with learning disabilities had died from many different causes.



- About 1 in 3 children and young people died from nervous system diseases, including cerebral palsy and epilepsy.



- About 1 in 5 children and young people died from lifelong conditions, including heart or brain problems.

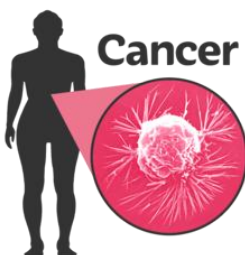


- Around 1 in 10 children and young people died from problems with lungs or breathing like chest infections or flu.

Or problems caused by food or drink going down the wrong way or choking.

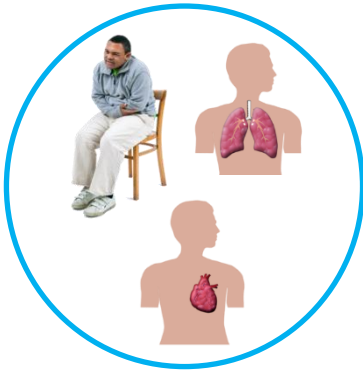


- About 1 in 20 children and young people died from having an accidents like falls, trips and slips.



- About 1 in 20 children and young people died from cancer.

What diseases made their health worse?



When someone dies, the doctor should report all their health problems that may have made their health worse. Things like:

Stomach and digestive problems

Lungs and breathing problems

Heart problems



Some children's deaths due to epilepsy and chest infections could have been prevented because they are treatable conditions.

There were some limits to this study



We were not able to look at the different causes of death in boys and girls.



We can't see important details about people who died, like:

where they lived,

their health across their whole lives



Sometimes doctors don't share enough information about why a person died.

What will we do now?



Everyone has the right to the best health.

Premature death amongst children and young people with learning disabilities is not acceptable.



We need to improve access to good healthcare for children and young people.

We need more reasonable adjustments.



We need social care and health services to work together to prevent health problems.

What changes do we need to make to prevent deaths?



Epilepsy

We need to help people find out if they have epilepsy or seizures so they can look after their health.



We need more reasonable adjustments, to make sure people with epilepsy get the best treatment.

Chest infections

We need to help people with learning disabilities who have chest infections get treatment quickly.



We need to help more people get the flu jab each winter, including supporting staff and health workers.



Choking

We need to help people find out if they have swallowing problems.

Who will we share this report with?



The Scottish Learning Disabilities Observatory will work with:

The Scottish Government



doctors and nurses



support workers



people with learning disabilities and their families



the public, through newspapers and social media



We will also send this study to a medical journal for researchers and health workers to read.

The researchers who did this study are:

Gillian Smith

Mike Fleming

Deborah Kinnear

Jill Pell

Craig Melville

Sally-Ann Cooper

Angela Henderson



People First
(Scotland)

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