



## Introduction

The Learning Disability Partnership Board's goal is to help adults with a learning disability:

- Stay healthy
- Live their best life
- Keep safe



We do this by working together. Self-advocates working with a wide range of health, social care and community organisations.

We are doing well when the voice of people with a learning disability is heard and included in health and social care decisions.



The Board believes that people with learning disabilities have the right to the same opportunities as anyone else:

- A place to live, a job and included in the community you live in.
- Involved in the design and delivery of any support you get.

A factsheet about the Board can be found [here](#).



We are pleased to talk to the Health and Wellbeing Board.

We hope that this will lead to the Board thinking about what people with learning disability have said when making their decisions.



## What things has the Learning Disability Partnership Board talked about?

The Board has been meeting 6 times a year since 2001.

The things we talk about come under these themes:

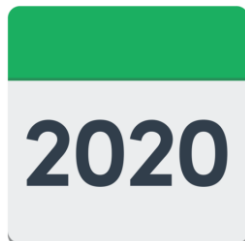


- Employment
- Friends, Relationships and Community
- Good Health
- Independent Living



In 2019 the Board talked about:

- Money
- Loneliness
- Mental health medication (STOMP)
- Support to people in mental health hospitals.



In 2020 we talked about:

- Supported Living
- Employment
- Safeguarding, Covid-19 and LeDeR
- Digital Inclusion
- Access to Primary Care – GP services

The Board looks for good practice and how more people can benefit from this.

It is important to share examples of how people and organisations are working in a way that includes people with learning disabilities.



Minutes are posted on the [WSCC website](#).



## What do we want to talk about today?

2 topics that we talked about in 2020 were chosen by the Board to talk to you about today:

- Preventing people with a learning disability dying earlier than the general population.
- Digital inclusion - nobody is excluded due to a lack of digital access, confidence or skills.

## Preventing people with a learning disability dying younger than the general population



Here are some reports to read:

1. [Learning Disability Mortality Review \(LeDeR\) programme annual report.](#)

In July 2020 the 4<sup>th</sup> LeDeR report was published. Here is a [film](#) about its findings.

The NHS has written a report about what improvements are being made it is called action from learning and here is the [easy read version.](#)



2. [LeDeR Sussex Annual Report](#)

Published in June 2020.  
Includes the Sussex LeDeR Covid Response.



### 3. [LeDeR national report into Covid-19 deaths](#)

This report tells us that people with learning disabilities are more likely to die if they get Covid-19.

This [easy read report](#) says what is being done about this.



### 4. Reasonable Adjustments

A reasonable adjustment is changing the way we usually do things to make sure people can use services.

Making reasonable adjustments is very important to help prevent poor health.



In Sussex there has been lots of work to make sure that easy read information about Covid-19 is available.

Agencies have worked together to make sure they understand how to support people with learning disabilities who have Covid-19. This includes GPs and hospitals.



[Government information](#) on reasonable adjustments for people with a learning disability.

Communicating with people with a learning disability and autism, dementia and mental health needs – [COVID-19 guidance](#)



## 5. Living together in a fair way

[Easy read report](#) (2019) by Institute of Health Equity about why social factors, for example employment, lead to people with a learning disability not living as long as other people.



## 6. Annual Health Checks for People with a Learning Disability and Hospital Passports

Annual Health Checks are carried out by Doctors. This link takes you to [Guidance](#) including details of online appointments.



## Example 1 - the Flu Jab

Flu prevention was more important than ever because of Covid-19.

Public Health England said in November that people with learning disabilities were 6 times more likely to die from COVID-19 than the general population. Breathing difficulties was a major cause of these deaths.



We know that there were some reasonable adjustments for the flu jab program:

- Targeted invites sent via the GP's Learning Disability Registers
- Easy read information
- Promotional films made by people with a learning disability.
- Information for Providers about consent.
- Nasal spray alternative to injection.
- Support from the Learning Disability Health Facilitation Team.



*The Health and Wellbeing Board could check the success of the program including the:*



- *Number of people with a learning disability who had a flu jab compared to other years.*
- *If there are any lessons to be learnt that will help the Covid-19 vaccination and next winters flu.*
- *Whether organisations are preparing to Covid-19 vaccinate people with a learning disability.*

## **Example 2 – NHS national focus on older people in Care Homes**

We have seen during the Covid-19 pandemic a national response that has mostly focussed on registered care homes.

An example is the Enhanced Health in Care Homes (EHCH) Approach. This is where each care home has a named GP who leads on weekly home visits and a multi-disciplinary way of working with people in the care home.

70% of people with a learning disability do not live in registered care home. Many people with complex health needs live in supported living accommodation, Shared Lives or with their families.

About half of the deaths of people with a learning disability from COVID-19 were in people aged 50-69 years. Between March – June 2020 (first lockdown) 615 (46%) of deaths of people with a learning disability were from Covid-19.



*The Health and Wellbeing Board could advocate that clinically vulnerable people, in other types of care and support accommodation, do not miss out on health support.*

### **Example 3 - Spotting the early signs that someone is becoming unwell.**

The Learning Disability Partnership Board heard that everyone needs to be able to beware of:

- Diagnostic overshadowing - this is when a change in someone is put down to their disability or mental health without looking into other things like their physical health.
- Be aware of atypical presentations to pain, illness, or discomfort – this is when a person doesn't have the usual signs of being ill.
- [Hospital Passports](#) – a passport is important for helping hospital staff see important information about you quickly to care for you well.
- Listening to carers and families who will know the person well.

Adapt communication - simple clear language and pictures.

- Making reasonable adjustments.

*The Health and Wellbeing Board could look at what training people who deliver care and support are given to be able to spot the early signs of ill health.*

## Making sure people with a learning disability are not left behind in a digital world



This is the NHS calling to make a Covid-19 vaccine appointment

This report looks at best ways to support digital inclusion:

Guide to [digital inclusion](#) published in December 2020.



We are living in a digital world where lots of things online including:

- Universal Credit
- Electricity and other bills
- Contacting your GP
- Online Annual Health Checks
- Being in touch with family and friends

During the Lockdown many services moved to online appointments, support and activities.

For example:

- Day Services were closed, and they did online classes via Zoom.
- There were no Gigs, so [Gig Buddies](#) put on a weekly online music festival that was featured on Radio 1.
- Self-advocacy groups started meeting online.

Joining online Zoom meetings has been important for some people. Self-advocates said they felt less lonely and happy to see people's faces.

Not everyone can access Zoom.

There are services providing help, for example:





- The Aldingbourne Trust has Lottery Funding to employ someone to remotely support service users with online issues.
- Stay Up Late have teamed up with Brighton Digital Inclusion to fund SMART phones and internet connections.
- Impact Advocacy have charitable funding to buy and lend out devices to Self-Advocates.

But many people with a learning disability do not have equipment, a broadband connection or the knowhow to do things online.

To support people to connect to their families. the NHS have given Care Homes free iPads and found internet connection deals. This offer did not extend to all types of services.

*The Health and Wellbeing Board could consider:*

- *If new Assessments should look at what support a person needs to be able to use online services in their daily life and the cost of doing this.*
- *Who can help people with a learning disability develop their digital skills and what support is needed.*
- *In delivery of services - is face-to-face still available when online isn't an option.*
- *Do digital inclusion programmes include people with a learning disability.*