



## **West Sussex Learning Disability Partnership Board 29<sup>th</sup> September 2022, held in Horsham**




### **Who came:**

Amanda Jupp – Cabinet Member Adults (Co-Chair)  
Nicola Smith - Self Advocate, Voice (Co Chair)  
Mike Smith – WSCC Commissioning Officer  
Andrew Walker – Self Advocate, Speakabout  
Casper Beade Rioseco – Co-production Manager, Aldingbourne Trust  
Dale Bacon – Self Advocate, Access All Areas  
Jackie Gibson – Self Advocate, Access All Areas  
Brian Huburn – Self Advocate, Access All Areas  
Katie Green – Self Advocate, Access All Areas  
Sarey England - Self Advocate, Speakabout  
Richard Hamilton - Self Advocate, Voice  
Wendy Byrne - Self Advocate, Speakup  
Lisa Loveman – WSCC Commissioning Manager  
Harriet Wilson – Team Leader, Impact Advocacy  
Debbie Elleston – Impact Advocacy Supporter  
Paul – Self Advocate, VOICE  
Ron Little – Self Advocate, Speakup  
Philip Turner - Self Advocate, Speakup  
Michael - Self Advocate, People Come First  
Mary - Self Advocate, People Come First  
Steven Bensley - Self Advocate, People Come First  
Liz Holmes - - Impact Advocacy Supporter  
Sue Fuller – Parent Carer  
Hollie Ferrie – BSL Interpreter  
Sarah Maynard – BSL Interpreter  
Corinne Nikolova – Health Facilitation Team  
Laura – Health Facilitation Team  
Layla – Health Facilitation Team  
Michael – Health Facilitation Team  
Faye Delaney - Impact Advocacy Supporter  
Tim Claydon – DEA Lead Coastal, DWP  
Sheryl Bunting – Carers Support West Sussex  
Helen Gledhill – Team Manager, CLDT, SPFT

David, Belinda, Maureen, David, Michael, Mark and Darren – Strawfords Day Service Self Advocacy Group  
 Ellesha and Fas – Strawfords Support Staff, WSCC  
 Sophie Storer – Issue Based Advocate, Impact  
 Tess – Horsham wellbeing Hub  
 Abby Lonsdale - LEDER Programme, NHS Sussex

**Guest:**

Tamsin Cornwall – Public Health Lead, WSCC

	<p><b>Minutes and Workplan</b></p> <p>A copy of the minutes and workplan will be posted on the council’s webpage <a href="#">here</a>.</p> <p>The workplan includes actions agreed in each meeting.</p>
	<p><b>Introduction</b></p> <p><u>Theme:</u> ‘How well are we doing on health?’</p> <p>Every year the Board has a focussed meeting on health. Key information from today’s meeting will be shared with the <a href="#">West Sussex Health and Wellbeing Board</a>. This is a multi-agency meeting chaired by the Chairman of the County Council.</p> <p>Everyone was sent the latest easy read <a href="#">LEDER Report</a> to look at before the meeting.</p>
	<p><b>Self-Advocates Presentation</b></p> <p>Nicola, Ron, and Wendy fed back from 4 independent groups.</p> <p><a href="#">Presentation Slides</a></p> <p><a href="#">Self-advocates personal story</a></p>



### What works well:

- Longer appointments
- Seeing the same GP who knows you
- Taking masks off
- Writing things down in simple terms
- Easy read letters
- Talking directly to you in simple words
- Involving a Supporter or Health Facilitation Team to help with difficult instructions
- Face to Face appointments
- Quieter waiting room
- GP understands learning disability

### What could be better:

Systems for making appointments including:

- Calling at 8.30am to get same day
- Waiting for call to be answered
- Choosing a switchboard option
- Online services – most people find these too difficult
- Not being rushed
- Letters not in easy read



### Wellbeing Programme

Tamsin Cornwall from Public Health gave a [presentation](#) about Wellbeing.

The Wellbeing Programme is about helping you to stay healthy or get a bit healthier. There are Wellbeing Hubs in each District and Borough. Each Hub has trained advisers who can give you support.

This is a free service. Up to 3 sessions one-to-one, group sessions and online appointments are available.

Wellbeing Hubs think they could get better at helping people with a learning disability. Most



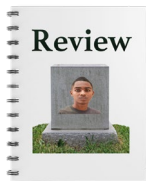
Board Members had heard about the Hubs but only a few people had used the service.

The Hubs would like to check how accessible they are. This includes checking the information and advice they give out, times of sessions and how easy it is for people to visit.

### **Discussion:**

Impact will share the Quality Check they did on the healthy eating programme and the resources that were developed by the Mid-Sussex Hub.

Self-advocates offered to visit the Hubs to look at what's on offer and share their ideas.



### **LeDeR**

Abby Lonsdale from NHS Sussex gave a [presentation](#) about 2021/22 LeDeR Findings.

LeDeR stands for Learning from Lives and Deaths of People with a Learning Disability and Autistic people.

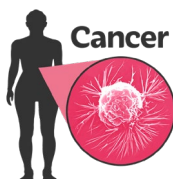
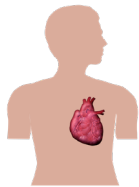
The aim of the NHS LeDeR programme is to make things better for people with a learning disability. To stop people dying too soon and to make health services more equal.

Sussex LeDeR have a self-advocacy group called 'Staying alive and well' who help to coproduce the programme. People who work on the programme also come to Partnership Boards to get feedback.

Abby showed a clip from a [film](#) called 'See me – Andrews Story' by disabled acting group Mixit.



**58 years old**



Andrew was a man with Downs Syndrome who died after his 2 broken hips were missed. His behaviour was put down to his learning disability and dementia. It was a hard-hitting film, and some self-advocates were upset by Andrew's story.

Abby said the LeDeR programme in Sussex found the average age of death of people with a learning disability is 58 years. For other people this average age is 82 years. 49% of people had an avoidable death.

The top causes of death were circulation (heart and blood), Blood pressure and heart disease.

The LeDeR Reviewers look at what happened before someone's death. What was going well and anything that could have been done better.

They share the learning from this review with people who should be able to make a difference to other people.

Some of the things the programme says will help are:

- Stop, Look, Care – [booklet](#) for support staff. Includes what to do when things start to go wrong.
- [Annual Health Checks](#) – your chance to get a full M.O.T.
- Cancer Screening Programmes including films such as [PooBusters](#)
- [STOMP](#) – reviewing medication and checking that you are not on too much.



## Table Discussion

1. What helps people stay healthy and well?
2. What makes it easier to use health services?
3. What should be done about heart disease?
4. What needs to get better?

Ideas from our table discussions can be downloaded [here](#)



## Bringing it all together

Good consistent support from carers is very important. With recruitment challenges and use of agency staff this is at risk. Using up-to-date health passports which are easily transported will help.



Important to have GP staff who know you well. Being able to see the same person consistently and face to face appointments helps reduce risk of things being missed and adjustments not being made.



Its not always easy to act on health messages. Low income, transport, unemployment, poor housing, social isolation all impact on your health. The cost of living crisis will impact on health inequalities.



People in funded services should have health outcomes included in Support Plans.



Top priority is for everyone to have an Annual Health Check and a good quality Health Action Plan. Somethings like blood pressure need checking often not just annually.





Health professionals agreed the following actions:

**Community Learning Disability Health Service:**

Always thinking about 'overshadowing'. This is when symptoms of physical illness are wrongly thought to be because someone has challenging behaviour or learning disability. The team will make sure all the physical health checks have been done – Helen Gledhill



**Health Facilitation Service:**

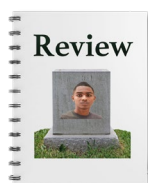
Will work with the Wellbeing Hubs. The service can help with easy information and the Wellbeing service can offer sessions to people with a learning disability - Laura



Share positive stories about the great relationship people have with their GP and how important this is - Laura

**Wellbeing Programme:**

To take Self Advocates up on their offer to visit the Hubs and give their ideas on how to make hubs more accessible – Tamsin Cornwall



**LeDeR:**

To review the presentation and talk to self-advocates about best ways to get these important messages out to people with a learning disability without causing distress – Abby Lonsdale.

	<p><b>Next meeting:</b></p>
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8<sup>th</sup> December 2022

Venue: County Hall North, Horsham