



West Sussex Learning Disability Partnership Board 12th May 2022, held in Horsham

Who came:


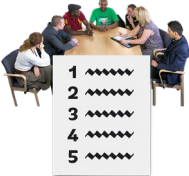

Amanda Jupp – Cabinet Member Adults Services (Co-Chair)
Mike Smith – WSCC Commissioning Officer (Co-Chair)
Heidi Vineall – Self Advocate, Voice
Daniel Arundey - Self Advocate, Voice
Richard Hamilton - Self Advocate, Voice
Wendy Byrne - Self Advocate, Speakup
Cathy Cassim - Self Advocate, People Come First
Zad Cassim - Self Advocate, People Come First
Steven Bensley - Self Advocate, People Come First
Sue Fuller – Parent Carer
Nikki Carter - Self Advocate, People Come First
Lisa Loveman – WSCC Commissioning Manager
Harriet Wilson – Team Leader, Impact Advocacy
Debbie Elleston – Impact Advocacy Supporter Speakabout
Liz Holmes – Impact Advocacy People Come First
Ron Little – Self Advocate, Speakup
Hollie Ferrie – BSL Interpreter
Sarah Maynard – BSL Interpreter
Corinne Nikolova – Health Facilitation Team
Faye Delaney - Impact Advocacy Supporter
Tim Claydon – DEA Lead Coastal, DWP
Fas Shamoom – Strawfords Day Service
Julia Pascoe – Workaid, Aldingbourne Trust
Edel Parsons – Sussex CCG, LEDER Programme Lead
Diana Bernhardt – WSCC Senior Commissioning Manager

Guests:

Jo Baldwin – WSCC Commissioning Officer
Johanna Kaminer – WSCC Public Health Team
Emma Gentle - Post Covid Assessment and Support Service
Jocelyn Collier - Post Covid Assessment and Support Service
LEDER Reviewer, Sussex CCG

Apologies:

Andrew Walker – Self Advocate Speakabout
Casper Beade Rioseco – Co-production Manager, Aldingbourne Trust
Helen Lambert – Community Learning Disability Health Team
Tracey Light – WSCC Communities Team
Sheryl Bunting – Carers Support West Sussex
Steve Roberts – WSCC Directly Provided services
Adrian Caines – WSCC Lifelong services, Service Manager
Amy Dissanayake – Sussex CCG Clinical Health Lead
Caroline Bannier – Community Learning Disability Health Team
Angie Hatcher – Sussex CCG LDA programme
Michelle Martin – WSCC Community Relationship Lead
Michelle Olden – WSCC Lifelong Services, Transitions Team Manager
Stacey Knight - Community Learning Disability Health Team
Boba Rangelov - Surrey and Sussex Cancer Alliance
Sheryl Bunting – Carers Support West Sussex

	<p>Minutes and Workplan</p> <p>A copy of the minutes and workplan will be posted on the council's webpage here.</p> <p>The workplan includes actions agreed in each meeting.</p>
	<p>Introduction</p> <p>The meeting theme was Covid Recovery, this is in the Boards workplan as a priority area.</p> <p>Everyone was sent information from the National covid learning disability study to look at before the meeting.</p>
	<p>Introduction</p> <p>Lisa Loveman presentation</p> <p>Many organisations have looked at covid recovery and have plans in place. This</p>



meeting focused on what people with a learning disability need to recover and for organisations to share plans to support this.

Good to 'look back' because:

- We can see if things have got better or worse.
- We can look to see if there are things we can learn.
- We can see where people have managed well and where people have struggled.
- We can recognise where people have worked hard and tried their best.

Good to look at 'what's ahead' because:

- Covid is here for the foreseeable future.
- We need to think about how people with a learning disability can get the support they need.
- To think about what is the best way to support people longer-term.

The covid study finished in August 2021 researchers interviewed 500 people with a learning disability and surveyed 300 carers and support workers.

We can use these findings and ask what's happening in West Sussex:

- People were worried about leaving the house and felt more anxious.
- Family carers and support workers felt stressed and tired.
- Fewer people had annual health check and more people waiting for planned medical procedure.



- People said they were getting less support from services. More people were getting support online.
- 3 in 10 people said their personal budget was being used for services they were not getting.
- 4 in 10 were paying for some services out of own money.
- 2 out of 10 people with profound or multiple learning disability still shielding.
- ¼ of all people do not feel safe enough to go back to all the places they used to.
- Less than 1 in 10 said their life had gone back to normal.
- Most people with a learning disability on GP register have had vaccination
- People followed the rules
- Being able to get online and connect with people
- Having more relaxed pace of life
- Spending more time with people close to them.

What we know in West Sussex:

- There are big staff recruitment and retention problems across all organisations.
- Annual Health Checks in West Sussex only had a small drop-off 68.2% were done last year (target 70%).
- Only a small number of people are unvaccinated - 88 out of 4807 on GP Learning Disability Register.
- Some services are not fully returned to pre-covid user numbers or ways of working. This includes day services and respite.



- The number of people with a learning disability in paid work is lower than pre-covid.



Self-Advocates

The Board watched 2 short films; the [first film](#) was made by self-advocates. This film focussed on the impact of covid on people's lives and services that are not fully open.



The second film was from a family carer on the national study. This film was about people with complex health needs who have spent much of the past 2+ years shielding. The carer talks about life now.

[Coronavirus and people with learning disabilities research: Sarah Walker - YouTube](#)



Key messages from the films:

Spring 2022 - some people are not back at their day services or not going out as much as they used to. People do not know what is happening to their old support plan.



People living on their own feel isolated and lonely. Things they want to do haven't started up again.

Carers of people with complex health needs are feeling left out of guidance around end to covid rules.



Discussion

How can we help fill some of the gaps left by Covid?

Important to have evidence so we can understand the picture clearly.

Some of the gaps are because of staff vacancies and growing workloads. Organisations should let people who use services know what's happening and how long things might take.

Families caring for people who have complex health needs lack guidance about what's safe to get back to doing. Is there any psychological support available? Who is responsible for doing risk assessments for people living with their families?

Can we get data on the 32% who didn't have an annual health check to find out why? Are people offered a home visit when they have been shielding?

Wellbeing Hubs – making sure these hubs are accessible especially for people who live independently with no or little support.

Increasing use of agency staff increasing covid risks.

Mental health needs have increased, has there been any additional investment in learning disability mental health support?

People find it hard to get a doctor or dentist appointment. Some people haven't seen GP or dentist. How is this being addressed.

Not all My Network Hubs have gone back to drop-in's and people must make



appointments. When will the service be back to normal?

Ways of working differently were brought in because of covid. Is there any that we think are positive and want to build upon?

Its good people are offered a choice between online and face to face. Some people need ongoing support to go online.

During Covid the welfare checks worked well, and people felt they were not forgotten.

Community Volunteer Response – positive during covid, how can this be a legacy for people with a learning disability?

Online and contactless increasing and people need easy read guidance and training about keeping safe.

Do Social Prescribers and Wellbeing Hubs staff have learning disability awareness training?

Residential services seem to be more risk adverse than other types of services but infection rates just as high.

What are the important things to think about for people who are stuck inside or worried about going out and trying new things?

Making sure this group are not forgotten.

Asking carers what would help them.



Outcomes	
1 <input checked="" type="checkbox"/>	6 <input checked="" type="checkbox"/>
2 <input checked="" type="checkbox"/>	7 <input checked="" type="checkbox"/>
3 <input checked="" type="checkbox"/>	8 <input checked="" type="checkbox"/>
4 <input checked="" type="checkbox"/>	9 <input checked="" type="checkbox"/>
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People who are in the complex health group can access anti-viral treatments. How do they find out about this?

Could more 'quiet' sessions be set-up and promoted to help people feel less scared.

Need clearer information about 'real risks' there is a lot of mis-information.

Map what is available in the community and what places are supportive to people who are shielding, for example, masks are being worn.

Bringing it together

Isolation, loneliness, lack of information and restrictions lead to poor outcomes for people with a learning disability.

What if anything can the Partnership Board do or ask other people to do about these things?

1. Actions for health and social care commissioners:

Set-up an open-ended survey so that people can leave their feedback on how covid is impacting their lives and ideas on what would help.

Check services set-up specifically to support post covid are accessible to people with a learning disability and staff have had training.

2. Actions for Providers of services:



All Service Providers to give regular updates to service users.

Day services and My Network Hubs to update people waiting to return to in-person support.

3. Actions for Health

Share information about the NHS website to register anyone waiting for NHS care and treatment.

Get more information on why people did not have their annual health check and if home visits can be offered as a reasonable adjustment.

Share information about access to anti-viral treatments.

Report back on what is planned to increase take-up of GP and Dentist appointments where people have not been attending.

Share information on what mental health support is available.

4. Actions for carers support

Targeted piece of work with families that were shielding.

All to share '[Carers Response Line](#)' Tel: 0300 028 8888 open six days a week.

Share information on places carers can go that are safe for people who continue to shield.

5. Actions for Public Health



Wellbeing Hubs and Social Prescribers to check accessibility and training of staff.

Community volunteers and Covid Community Hub have a local role to continue to offer support as people are still being impacted.



Post Covid Assessment and Support service (PCASS)

[Emma and Jocelyn's presentation.](#)

PCASS is a health team that helps people with long-covid.

1 in every 10 people suffer from long-covid.

GP's can refer people to PCASS.

PCASS can offer a range of clinical help. This starts with an assessment and then 3 and 6 month follow-up calls to see how you are doing.

Patients can contact PCASS at any time.

Link to [PCASS referral form.](#)



Next meeting:

14th July 2022

Venue: TBC

Theme: Having enough money to live the life you want.