

Wandsworth NHS CCG Engagement Insight Report

Purpose: To inform and test the Joint Wandsworth NHS CCG and Council Learning Disability Strategy 2020-2025 from the point of view of people who use and need Learning Disability services.

Dates workshops delivered: February 10th - 27th 2020



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Patient and Public Engagement Manager

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1. Project purpose

In February 2020 we worked with groups of people with a Learning Disability to inform and test the Joint Learning Disability Strategy prior to an engagement period to invite feedback.

The purpose of our engagement was to:

1. Raise awareness of the strategy in development;
2. Provide an opportunity for people with a Learning Disability to directly contribute to the strategy;
3. Find out what matters most to people in the borough;
4. Reflect on the involvement of people with lived experience of accessing Learning Disability Services in the borough so far and;
5. Ensure the direct voice of people with a Learning Disability runs through this strategy and shapes how it will be delivered going forward.

We wanted to know how we can continually improve how we engage with people so we can move towards a more meaningful model of cocreating good services. We know that we can be doing more to get this right.

2. Methods

The methods used to engage were:

- Focus groups – These were designed to meet the unique communication needs of the participants using:
 - ✓ Easy read meeting agendas
 - ✓ Easy read focus group session plan and questionnaire
 - ✓ Easy read visual speak-up poster board with visual prompts and visual feedback cards
 - ✓ Easy read versions of the Strategy
- Telephone interviews
- Face to face meetings

The visual materials that were used in the engagement sessions can be found in the appendix of this report.

3. Engagement Sessions

We carried out eight engagement sessions as follows:

1. NHS CCG Patient and Public Involvement Reference Group

2. Share Community
3. Generate
4. Baked Bean Charity
5. Wandsworth Care Alliance: Monthly Health Forum feeding into Clinical Reference Group
6. Clinical Reference Group member telephone interviews
7. Katherine Lowe Settlement: Independent Carers Group
8. Healthwatch Wandsworth

3.1 Patient and Public Involvement Reference Group

Date: Wednesday 19th Feb

Number of people present: 16

Chair: Carol Varlaam

Presenters: Juliana Braithwaite, Mark Robertson

Facilitators: Naomi Good

Organisations in attendance:

- Healthwatch Wandsworth
- Generate
- Wandsworth Care Alliance
- Wandle Locality Patient Group
- Katherine Lowe Settlement
- Wandsworth Voluntary Sector Coordination Service
- Putney mead GP Practice Patient Participation Group Chair
- Battersea Locality GP Patient Participation Commissioning Group
- Battersea GP Practice Chair of the GP Patient Participation Group
- West Wandsworth Locality GP Patient Participation Commissioning Group
- Wandsworth Carers
- NHS CCG PPI Reference Group Chair and PPI Lay member
- PPI Clinical Lead
- Wandsworth Borough Council
- Wandsworth NHS CCG

Record of session:

Language

- Need to revisit the language in the report around the vision consider 'leading ordinary lives' a very powerful statement. People want ordinary lives but need

extraordinary help to live in an ordinary way. Underneath the notion of 'ordinariness' there needs to be commitment to support of substance.

- Useful language as this 'means different things to different people' reflects unique needs of each person.
- Consider also 'Safe and worthwhile lives' and 'Reassured lives' - if things are going to change, they need assurance that they will also improve.
- 'Strengths based support' – include sentence to clarify what we mean – enabling people so they can do things for themselves and lead independent lives, ensuring a focus on what peoples strengths are – what they can do rather than what they can't, their support network and how we will provide help to strengthen this.

Definition of Learning Disability

- What part of the LD population does the strategy address? –This needs contextualising in terms of inclusion, exclusion criteria in the report.
- What is the definition of LD? – include what conditions this consists of.

Profile / demographic

- Clinical lead raised point on inaccuracy of the figures and the estimate of need.
- 62,000 people with a Learning Disability but policy only addresses circa 1000.
- Contained in an earlier iteration of the strategy so could be inserted from this

Clinical Reference Group

- Very good opportunity currently to refresh and strengthen the CRG and ensure clear shared purpose and commitment for both Council and CCG.
- Strategy will give the Joint CRG a clear purpose, programme of work and a workplan to monitor progress of strategy implementation and development.
- Need to build user groups and work together going forward with user's experience running through everything we do.
- 'Clinical' is perhaps now the wrong term, needs to be a 'stakeholder' group.

Definition of coproduction and our joint commitment to the approach

- Need to clarify our definition of and commitment to coproduction.
- People with a Learning Disability need to be involved in writing and helping to develop plans.
- Concern raised about the commitment to support involvement, to ensure the voice of the service users with a Learning Disability gets heard.
- Discussion regarding what we mean by representation needed.

Learning

- Strategy will benefit from including the learning from recent years of what works best for people with a Learning Disability
- Give a sense of progress, highlight the good practice and achievement and what will be strengthened with this strategy.

- 111 Clinical hub Integrated Urgent Care Service (Vocare and Seldoc) – how are we linking to this to ensure accessible and promoted to people with LD?
- People with Mental Health problems have Crisis Cafes how do these support people with LD? Is there a better model for LD Mental Health Crisis?

Mapping services currently provided

- e.g. MH and LD Team in Balham / Community LD Health Team.

Housing Support

- Housing is always on the agenda with service users.
- Must reflect the experiences of people with a Learning Disability in social housing.
- Reflect the learning that has happened over the last 10 years or so of the experience of people in supported housing which has been inadequate due to insufficient funding.

Carers

- Draw on learning from the Richmond Pilot programme – looking at the early stages and challenges and successes.
- Important to involve carers in focus groups.
- Carers group could possibly offer some shared thinking.

Day Opportunities

- Important to look at day care provision again and how it can be delivered differently.
- Important for user involvement in this area and their carers.
- Promoting people's independence and looking at pathways for employment
- Concern that funding will be withdrawn.

Sexual Health

- Include sexual health development, both psychological and physical development workstream in this strategy.
- My body and Me and sexual awareness courses – Generate. All providers have brought up as an issue.
- Organisations already undertaking this work perhaps could be recruited to draw on insight and create a working group.
- Dr Sian Job to provide information from voluntary sector organisation that had previously undertaken a piece of work on teenagers with a Learning Disability and sexual health development.

Transition

- Need to explore with specific stakeholder reference group and their carers.
- Strengthen and support role of family and peer support - Work to support parents before they pass away.
- Transition social worker roles – where are these now?

- Parent /carers have been grateful for group work and peer support in the past.
- Need strength-based circles of support/friendship.
- Members of PPIRG can join in the working groups, looking at the priorities and assisting in the development of policies and strategy.
- Focus groups currently ongoing – need to look at status quo before launching into new things.

Financial choice / Personal Health Budgets – pooling budgets

- Direct payments - Need to explore with specific stakeholder reference group.
- Need to map National good practice examples and draw on the learning.
- Few opportunities for client group to get together to develop their thoughts.
- Need to think about how best to recruit to user groups.

Transforming Care Programmes

- Ensuring hospital stays are monitored effectively and people are not forgotten about.
- Making cost savings with more effective local care alternatives.

Out of area placements

- Placements down in the borough from 15 to around 6. Has been reduced after the last few years.
- New guidance from NHSE states placements need to be reviewed every 8 weeks for LD (6 weeks for mental health)

LeDeR / Health Services

- Learning from LeDeR reviews.
- Accessibility of services review.
- Health screening reasonable adjustments in GP practices – fast tracking LD Patients in, longer appt times.
- Specific support for obesity.
- Annual health checks.

3.2 Share Community Focus Group

Date: Tuesday 25th Feb

Number of people present: 13

Session facilitators: Naomi Good, Melanie Cressey

Group leaders: Julia Roxborough, Ashley Brown

Record of session:

At the Doctors

- Friendliness very important.
- It's good if they are always smiling.
- They do check's each month for my Blood Pressure.
- I need help for me to be (more.) brave.
- I need to go by myself but it's scary.
- I need to be more confident and ask the doctors to repeat things.
- The doctors need to take it more slowly.
- They give me an appointment only to meet my GP with my parents there.
- I used to be scared but not anymore, I got used to it.
- It's hard to get rid of cough had for a very long time.
- I am still waiting to see a GP, but the GP usually calls.
- I am due to have my toes done.
- I go with my sister, there are lots of questions that I do not know. When she isn't around, I don't go to the GP.
- I say to them that I stick to 3 meals a day.
- I was given a chart for my diet and my sister keeps it.
- I get help to quit smoking I can pop in any time help and advice is always there.
- I have a good doctor, but I haven't been well. [Al have a] terrible back. I mentioned it a lot and I need hospital.
- I have depression, it is very hard to get out of the house, I feel claustrophobic sometimes when sister is away for 6 weeks. I go every 6 weeks to collect my medication from the chemist. I have reviews of my medication with my chemist for my mental health. I talk to the nurse at the GP practice about my mental health.
- It is very hard on public transport travelling alone.
- I try to ring up for appointments but can't get through in time.
- My mum makes my appointments for me.
- At the GP it tells you the room number for the doctor, but I get lost as I can't read it.
- I refuse to go because I am scare. My doctor is nice and listens to me. He explains so I can understand what he means about the medicine for my sensitive skin.
- I am dyslexic and sometimes I am forgetful. I get confused why I am sitting in front of a doctor. I have a lot of conditions and I have lots of appointments. I wish this was joined-up, so I don't have so many trips for my health. I get very tired. I would like a plan, so I have it all together.
- I sometimes forget to take my tablets which isn't good, and I find diaries difficult. I don't know what the medicines are all for. I would like a visual plan with a flow chart and for the GP to send text messages, so I remember. I have lots of tests and never know any of the results.
- I am hard of hearing too and need to go for 3 monthly check-ups to check my hearing aid and make it louder. I have to go to a walk in for audiology at Charing Cross but often I go and there are too many people, so I don't get

seen and I miss work that day for nothing. I would like to have a set time and to go somewhere local.

- I am scared of the doctors, but I am more comfortable if it is a doctor, I know.
- I wish the doctors would call me on the phone to tell me when my appointment is for a check-up.

Flu Jab

- 5 out of 13 had a flu jab in the last year.
- I am very scared of needles so I used to never go to the doctors but now I have a ball to squeeze and let me lay down and I can have the flu jab and other needles.
- We'd like to have the flu jab together out in the community rather than having to go to the doctors.

Annual Health Checks

- 5/13 had an annual review with their doctor.
- I would like to be reminded by phone and by text.

Communication passport

4/13 have a hospital passport via the wellbeing day at Share.

Care Plan

- 2/13 have a care plan.

Mental Health Services

- 7/13 people had used mental health services.
- I don't have a health person I can feel I can speak to like a support worker in the home.
- Good I tell her. I want to feel healthy.
- I now do exercise walks and dance and feel I am improving.
- I want to join a gym.

Ideas for making things better

- I can be independent if things are close by. If I know I will get back ok, I will do things.

Housing

- I like the staff at my home they listen to me.
- I live with two other people but the people I live with really get on my nerves. I am unhappy. They argue and it makes me very unhappy. Wandsworth is a nice borough, but I do not feel comfortable staying there. I need a baked beans house somewhere quieter, so I don't feel so bad. I want to live alone I am 23 so I want to live someone in my age range. My doctor says my health is bad about this.

- It is important for me to be near public transport and shops. I want to live next to friends so I can go to see them. I need my social worker to help with housing at my next review.
- I'd like the staff in my house to talk to me.
- I'd like help with the stove and the oven the staff are meant to help but they don't.
- I want to be brave and use the oven, but I need help.
- I need help to cook healthily.
- I live with my mum and my brother but sometimes my brother doesn't come home. I enjoy living with my family, but I want to be independent I want to find a special home.
- I live in a 2 bed, but I need help as I have to live in the living room and sleep on the sofa as I have two children. As well as my learning disability I have fibromyalgia and I am dyslexic, and things are really hard. The man didn't call me back from the council when I went to explain. When you tell people, you are dyslexic they treat you wrong and think you'll forget but I can't forget living like this. Next time I won't tell them I am dyslexic or have a learning disability so they will listen to me.

Getting out and about

- I can use public transport, but I don't like it because people on the buses look at me funny as I was born with down syndrome. It's easier if I am with someone.

3.3 Generate

Date: Monday 17th Feb 11-1

Number of people: 8

Age ranges: 30-60

Facilitator: Naomi Good, Colm O' Flynn

Group lead: Amy Ferguson

Record of session:

At the Doctors

- My doctor always talks. [The] doctor needs to talk clearly; I ask for him to *please repeat that*. He sometimes talks too fast and I feel nervous and can't think what to say.
- The doctor needs to slow it down.
- I feel nervous sometimes going there.

- Some people have a panic attack as they are frightened of the doctor and in case the doctor does something wrong to them.
- My doctor asks lots of questions, so my dad says things to the doctor for me for the time.
- Listen more.
- Will they wait till I finish speaking?
- Helping me to understand I have a disability.
- Writes down appointment and help to add in my phone so I don't forget
- Last time I went, I had my blood test.
- My doctor talks to my carer sometimes hard to understand.
- I have to wait for ages.
- When I phone up, I speak with the receptionist.
- I have to wait all day there to see a doctor.
- My mum and dad book my appointments.
- They sometimes don't understand me.
- Waiting waiting, waiting, then they cancelled it when I was in the waiting room
- I know they are busy...
- My doctor asks lots of questions and it's hard for me to answer as I need time to say [answer] each one.
- I had a tube last time I was at the doctor. (Blood sugar test)
- Balham.
- My dog comes with me and its helpful to keep calm.
- [My] doctor is good I like them [they are] nice.
- Not sure if a GP can listen to you.

At the Hospital:

- At St Georges, the injection hurts.
- At Queen Marys, I [need to] go back. [There needs to be] better food as its awful.
- St Thomas Hospital [I went there as I had an] ear infection and a high temperature. [I] went by myself as they know me there, they've known me for a long time, so I always go there.
- It's a lot to take in.
- Explain in more depth so you can understand it.
- When my mum went to hospital spoke to doctors and they put her in a frame. (walking frame)
- More beds [needed] in the hospital.
- More staff.
- More nurses and choice of male or female nurse.
- [I] slept there, [I had] dizziness from crazy driving.
- Hospital food not good. [There is a] bad menu.
- Needs to be cleaner, not up to scratch.
- [I need] help with my ears, throat and chest.
- [My] social worker speaks to the doctors about my chest.

- [I think they are] charging patients in the operating theatre.
- I went to St Georges with an upset tummy.

How I stay healthy:

- Football tournament
- Exercise
- Losing weight
- Ride a bike
- Twice a week
- Line dancing
- Dance
- Football every day

Involvement / Coproduction (Conversation with Staff members x2)

- We would like to see more Co-development with people with a learning Disability.
- There is much more evidence of involvement with service providers than users.
- It feels much like just consultation rather than something created in a true partnership from the start and from the ground up.
- This means it will be too late to inform substantial change.
- Language used in the strategy needs to be more inclusive for example around strengths-based commissioning.
- Concerns raised that when strengths-based approaches are implemented in the community it is important that service users, their families and carers are fully informed to make clear that it is not an approach linked to cutting services.
- Concerned about how the strategy will be disseminated. How will it reach people?
- Confusion as to what will happen as a result of this strategy.
- Parents and carers don't know what will come out of it.
- The word Strategy means having services cut and visits from CCG and Council meaning an audit rather than help.

Clinical Reference Group feedback

- Not engaging.
- Feels uncomfortable.
- Agenda not clear or presented in an accessible way.
- Service users are not made aware what their power is to influence, and effect change so they don't contribute in a meaningful way.

Ideas for development of Coproduction model

- We have an opportunity to create something much more effective in the borough building on the CRG.
- CRG - Need to create this as a 'go to' place in the borough for influencing change.
- Recognise the different needs, skills and abilities and ensuring support is optimised.
- We need to look at good practice examples like the Mosaic Centre in Brixton and the Merton Forum chaired by people with a Learning Disability – much more inclusive and rewarding.
- Generate Voices is our proposed new programme where people with a Learning Disability will be trained and have specific interests in a health forum to enable them to bring relevant issues to the table and with support from peer advocates and who are identified as being passionate about making change.
- Books beyond words – use this approach to stimulate debate. This is service user led with group members trained to deliver and support debate.
- Role play – act out experiences together with professionals to develop understanding.
- Consider the meetings being co-chaired with someone with a LD.
- Implement traffic lights – a reasonable adjustment in the meeting.
- Workshops – 'my body and me' for sexual health.
- Train-the-trainer series of workshops on Coproduction.
- Start well, live well, age well is a good way to represent the plans
- How will the LD Strategy fit into the Local Health and Care plan implementation?
- We need to focus on how we'll make things better.
- Must highlight the positives.

3.4 Baked Bean Charity

Date: 21st August 2019 / 27th February 2020

Facilitator: Naomi Good

Group leader: CEO Sarah Gentles

Number of people: 26

Age ranges: 18-55

Record of session:

At the Doctors

- Be more patient with us.
- Give more time and focus.

- Feeling very frustrated - I can hear everything but can't verbalise, so I need help to communicate with pictures (with help from support worker).
- Be more friendly.
- Add my preferred communication methods and adaptations needed to health care records.
- I see my GP once a month. I like my GP and I like my dentist
- Often, I have a 2 week wait to get a doctor's appointment for my husband sometimes longer.
- It's not possible for me to make my own appointment, my mum has to do it, but she gets very frustrated as there are no appointments available.

Transitions

More work needed with transitions: I need ongoing support to help me with 'moving on.' I still live at home at 30 and I want to be independent.

Mental Health

- I need Community Mental Health Team support to find appropriate accommodation and deal with separation from family. This is key to me building my confidence and independence.
- I felt really listened to at Family Action (now closed) I don't know what the alternative is now I feel lost since then.

Day opportunities

- Access to quality employment needs to improve.

At the hospital

- Hospital can be distressing.
- We tried the walk-in centre but never again as the wait is just too long and we get too restless to stay waiting for 4 hours.
- More patience and friendliness needed.
- 111 is a major obstacle for us. I can't speak on the phone. I can't follow all their questions. What can I do instead?

Carers

- Carer – With technology, I don't know what to do there are so many steps' Need for support with technological aids
- I need some respite, so I come here to learn about checking emails, create spreadsheets and learn how we can stay safe on the computer
- Foster carer – we have got good services; we have not needed input from social care

- Little was known by carers, volunteers and people with LD mental health needs re annual health checks and people's eligibility which has inevitable knock on effect for UC and ED later down the road.

Care plans

- Use simple language and better communication.
- I have a 'wiki' – my own personalised website you can look at to see my preferred communication methods.

Involvement / Coproduction (Conversation with Staff)

The Baked Bean company use numerous methods to involve people which could be helpfully adopted to support coproduction. Baked Bean uses improvisation and verbatim theatre methods. They devise methods to make their voices heard and regularly work with universities, NHS trusts and local councils to deliver workshops, performances and training as follows:

In Conversation

In Conversation gives the audience a unique insight into what it is like to navigate life and have a learning disability through sharing their life stories. This could be stories of healthcare and of trying to coproduce good health and social care. This is done through a relaxed interview style and you get the opportunity to hear our performers talk candidly about their personal journey's.

Simulated Patient

Our actors regularly work with local universities and NHS trusts to deliver simulated patient training for medical students. We have been working with healthcare trusts for over 12 years and are booked on their training programmes regularly every year, these include: St. George's Hospital, Great Ormond Street Hospital, Kingston University, Maudsley Hospital, Greenwich Hospital and Lambeth.

Health Bites

A series of short scenes set in various health service locations. Health Bites delivers a serious message in a light-hearted way. Each of the scenes presented in 'Health Bites' are based on real-life experiences of the actors and their peers. Health Bites is used as a training tool for healthcare professionals using forum theatre.

<https://www.youtube.com/watch?v=Wwfs1L4TrGI&feature=youtu.be>

Sunshine Support – Focus on the CQC and Residential living

What's it like living at the Sunshine Support residential home? This play tells the story of a group of residents, who along with help from the Care Quality Commission, turn their residential house into the home they were promised!

I Want It All - Focus on transition

This method explores choices and how people with Learning Disabilities can make sure they get the best service. This provides a glimpse of what it's like to transition from school to adult services and explores the different options and pathways.

3.5 Wandsworth Care Alliance: Learning Disabilities Health Network

Date: Monday 24th Feb

Number of people: 6 People

Age range: 30 – 70

Facilitator: Naomi Good

Group Leader: Lukasz Birycki

Focus Group

We want to be the '*Make things better*' group!

Record of session:

Experiences of the GP

- I last went to see my GP a week ago as I can't sleep, I have insomnia. If I don't sleep again, he said he would give me sleeping pills.
- We need more GPs more nurses and more X ray photos.
- I need to ask the GP to slow down.
- Sometimes I understand sometimes I ask my GP to repeat himself.
- When the GP speaks to me, I like the support worker to explain what he was on about otherwise I don't know. If I am there on my own, I am no better off than when I leave.

- Some doctors speak too fast... the men. The women doctor I see speaks ok. I can't remember what they say.
- When I have said I am not well every time I go there, they think I am not saying things right. But I am feeling uptight and then they ask are you taking medication every day. I do I have a calendar with each day on it. I am uptight and shout at people in my home, but I don't really mean it I am just uptight. I wanted money for myself I get £3 per day but I can't go to the cinema with this or take my friend for a meal. This is not enough so I can't do anything. I am really uptight and swear but don't mean it.
- I am confident but I am not going to be rude. They can tell you things about how to eat healthy.
- You can't tell a GP what to do, they want it their way.
- It is to do with the receptionist at the GP there was a problem the other week as they wouldn't tell me about my daughter, but I am her main carer. They think people with a LD can't care for people so they don't tell me anything but they have the permission and so the practice manager came out and eventually helped me about medicines for my daughter.

Communication passport

- 1/6 has one. 2 people asked what this was.

Mental Health

- My psychiatrist is fine. I have medicine and I don't really mean it when I swear. I see a psychiatrist at Springfield. I have a new one last week, but I can't remember everything. I get into moods and need emotional support. My psychiatrist advises me what to do. I used to bang doors and call people names, but I have got a lot better and I take medication.

Hospital experiences

- At St Georges I needed a support worker. I needed a helmet on my head to have a scan because I am not steady on my legs. The bed was raised up and I just wanted to get down. With a bit of help I might have been able to do it, but I was frightened. I have a phobia of closed spaces and just could not do it and there was no help. I need to wait now for another letter to come but I need someone to help me calm down to have (it) [the scan].
- At the hospital I needed help and I was given an injection and a picture an x-ray they drew the curtains and then I fell asleep then I woke up. The food wasn't nice so I could not eat at all. When I woke up, I felt dizzy and there was no water, so I was told to buy some water from the shop after an operation on my chest. This was in 2017-2018. I don't like hospital and I had to stay overnight and wear their clothes which I don't like as I can't be me. I don't know when I am scared. The nurse wasn't helping, telling me to eat food. I said it is nasty. The pasta and the chicken was cold, but I only eat these warm. The microwave wasn't working.

- In hospital. I was there as my legs were swollen and I had bad pneumonia. I was rushed into the hospital as I was very ill, and they thought I was going to die. My legs were in bandages and so I couldn't get out of bed, so I had an accident I needed to be washed clean but had to wait a long time. My ex-boyfriend came but he used to beat me up and so then the police came. After that I went to court for him nearly killing me and he was charged. I am not in touch now. I spoke to my support workers about this. I get medication to help. I don't speak to anyone else about it.

Health checks

- GP reception sent letter to remind. Was good.
- Asked me if I am alright monthly to review me.
- Not happy with my GP because he never answers my questions.
- I was sent home with diarrhoea and pneumonia, but I didn't know.
- I had antibiotics at the hospital they listened to my chest and I had phlegm but I wasn't sent to hospital after the GP I was taken to hospital and rushed with support worker as I had got worse and they rang an ambulance the GP why didn't she know she didn't answer my question don't like to go to the GP as I am frightened why did they miss it (pneumonia)
- My check was sent in the post my GP was taking over though and talking too fast.
- I said can you slow down please – it's more rewarding.
- My GP was saying you are not eating but I am, and I had a blood pressure test. I think I am ok at eating just there are things I like more which are healthy like fruit.
- I had a recent check-up and was told to drink plenty water I felt listened to the home books the appointments for me.
- LD people don't count.
- All of us are not listened to – It's about time we are told what is happening
- They are patronising
- They need to get their act together.
- Worried about support worker who left and the new one.
- Epilepsy - I have worries how to manage in the community.
- Would like peer training for my friends on my fits.
- Problems with going to the dentist and having new teeth as they hurt, and wont were them if they cause pain.

Involvement / Coproduction

- I have attended all of the CRG meetings this last year.
- I forget what they were about now. They don't send me minutes.

Information in advance of the meeting

- We have to do [planning] in the morning to the café to talk so we can look at the agenda before the meeting.
- No, I need information about the meetings. They get cancelled a lot.

Feeling listened to

- There was no time for me to speak.
- Not much time for us.
- They don't seem to listen.
- Don't understand.
- They made it difficult.
- Made out they didn't understand what I was saying.
- I did say things, but I didn't get any response.
- I could see they were listening; they wrote down what I said.
- They don't know and don't like to go against their colleagues.
- There was no answer to things.
- I'd like to know the answers to what we talk about.
- No rules for the meeting.

Feeling you influenced and made a difference

- They don't explain what was done. - When you leave, you are no better off.
- Not really listening.
- Alright, I am hard of hearing so I have to lip read but they all sit away so I can't see.
- What is the use if we are not getting feedback?

Meeting room

- I'd rather the meeting was somewhere local.
- No space to move.

Ideas for improvement – what would you change what are your ideas?

- Listen!
- Explain what you are going to do.
- Explain what has changed.
- Have meeting rules.
- Support for you to have a say.
- Use pictures and images not words all the time.
- I need something to remind what we are on about [prompts, subject triggers].
- Give us information about the meetings before we come.

Do you want to continue?

- I enjoyed going to the meetings but would be better if they tell you what has happened.
- Yes, I want to go back

- When all different professionals hear me, it makes me feel alright.
- I want to help.

Feedback on the focus group

- I like this place.
- Good talking about the hospitals.
- I enjoyed it.
- All the meeting went well.
- I'd like us to have more pictures.

3.6 Telephone interviews with CRG members

Date: Thursday 27th Feb

Number of people: 2 Clinical Reference Group members

Age ranges: 50-65

Interviewer: Naomi Good

Record of session:

Involvement / Coproduction

What works well

- I get a lot of good experience.
- We talk about getting checked out by the GP.
- It is important. We can test things out and tell the group next time.
- We were given badges to try out with 'please can you give me a seat' on.
Good for us to test out. Some [other passengers] help you and some won't.
They pretend they don't see the badge. Some stare at you.
- I tell my friends about it.
- Talking about different things and helping.
- Monthly discussion group helps to think about what to say.

Ideas for improvement

- Once they explain things, it's ok.
- Prefer when it was at the Town Hall, it was easier to get to.
- When things are put into pictures, I feel more in control.
- Not good to have the reference group meeting so far away - easier to get to if in Wandsworth I have to get 2 buses – no 270 then another no 156.
- Venue is too squashed. Too many people together makes me feel anxious.
- I couldn't see in the room - I couldn't see the tv properly so I didn't know what to say.
- Not enough information before the group.
- When we said our bit, they were being difficult.

- Not enough time to say anything.
- Need minutes to help to write down thoughts to take to meeting.
- No feedback on what has changed.
- Would like training.
- Would like support to chair a meeting.

3.7 Katherine Low Settlement: Independent Carers Focus Group

Date: Tuesday 25th Feb

Number of people: 2 Carers

Facilitator: Naomi Good

Record of session:

GP Practices

- Support from GP practices in Wandsworth needed to work with Carers.
- Need to do it together with peers.
- Need to be more routinely given BMI advice.
- There is a real problem with the GP changing all the time, so rapport doesn't develop. A GP can't know their patient and understand what makes them nervous, what makes them more cheerful and more likely to accept treatment.
- Is it clear on the patient notes that a person has LD?
- Can there be a named doctor like the policy if you are over 70? Can there be special times when the person can be seen by the named LD GP?
- What support is offered if the patient is non-verbal?
- Could we have a look at the data from the GP surgeries in Wandsworth? It would be good to know where the super practices are for LD i.e. those that are close by specialist LD housing schemes and have a high no of people with a LD people registered at the practice. Can we share good practice and the learning?
- Do we know how many GP's have an LD special interest in the borough and what practices they are based in?
- Is there a way to do something more for people with a LD through the seldom heard GP Practice visits?

Carers Health at the GP

- Often, if at all, it is just mum who gets the double carer appointment with the GP. It still seen as Mothers business. Why is this and why are the Dad carers not automatically offered double appointments too? This needs to be encouraged and be an expectation of GPs.

- There needs to be a triangle of care: Important that the named GP is given to the whole family, so the care is joined up.

Involvement / Coproduction

- More meaningful involvement is urgently needed – we need to be co-creating plans routinely.
- There are diminishing opportunities for LD people to speak out. By not making a noise they are becoming a more at-risk group.
- There used to be a borough wide GP forum at St Georges. Could people with LD not create something to take to this or the current version of this forum?
- Professor / Baroness of Wimbledon, Sheila Hollins at St Georges set up a family, carers and people with LD training programme for the medical school. Medical staff spent a weekend to see first-hand what it was like living with LD. What can be learnt from this? Can some of this be done to more meaningfully involve people with LD now with the CCG and Council? Learning from <https://booksbeyondwords.co.uk/> should be used.
- Can people with LD create a training programme for how to properly involve in commissioning?

Advanced Care planning

- Are Advanced Care Plans promoted with families who care for people with LD?
- Carers used to carry a card to say they were an LD carer and so that if they took ill services would be alerted that there was someone else to think about that their loved one with LD would be cared for and not forgotten. This helps carers have some piece of mind. For example, there may be advanced permission for a neighbour to come in and look after the person whilst they are in hospital.

Social workers

- There needs to be more clarification on decision making and capacity for carers.
- Who has the legal entitlement to make a decision on behalf of a person with LD?
- How do carers or support workers access guidance / training on this?

Hospitals

- How many specialist LD adult nurses are there at St Georges?
- How are people given an attachment to a specialist LD worker if they are admitted?
- My son won't tell you if he is in pain. He may have broken something, but he doesn't communicate it so medical profession and people supporting people with LD in the community need to know about this and take subtle non-verbal signs of distress very seriously. How are the staff trained to deal with this? How is the family history taken into consideration? Like heart conditions etc?

Sexual Health

- We need a model where social workers are linked into healthcare more.
- How many people with a LD have their smears compared to the general population? Often, they are missed as consent is difficult to get. But then is this in the best interests if or example the person has cancer and dies early?
- There seems to be a general assumption: *people with a LD are not sexually active or if they are, they shouldn't be*, as if they aren't human.
- There is general avoidance of treating people with a LD the same as the general population in relation to sexual health treatment.
- Family planning is an issue - there are so many babies born of people with a LD who are taken into care. Do we know the numbers? Is this increasing / decreasing? Are people supported to talk about it, so they have access to the morning after pill / contraceptive injections? Access to condoms in their housing and community centres?

Day opportunities

- Do people with a LD have any entitlements like access to a free gym pass?
- How are the new social prescribers helping people with LD? Are social prescribers able to help people with personal budgets to access opportunities?
- Can people with a LD become expert patients?
- The best thing for my son is the Dolphins group it is run by families but is struggling financially now. Can this be strengthened? as it is a very worthwhile resource good value for money and has run for years now.
- Do the Tooting Tryers still exist? Mencap parents used to run it and it included a lot of sports and was very successful.
- People with a LD need support to create friendships to enable a normal life. We need to do abnormal things to put these things in place for people to reduce the gap for people living with Learning Disabilities.
- Used to be Connect a family – helped to link people to the best support in the borough. Does this still exist? What is the alternative?

Transitions

- What exists for the young person with a LD to go into housing with a record of and continuity in the knowledge built about them as a person – their likes, dislikes, triggers, things that make up their identity? How does this knowledge travel with them?

Respite Care

- What provisions are out there and how do carers get to know about them?
- It is so valuable for the person with a LD to experience a holiday and experience being away from home.

- Is there a book of their likes and dislikes, what makes them cheerful and anxious created that goes with them?

3.8 Healthwatch Wandsworth

Date: Monday 24th Feb

Record of session:

Involvement / Coproduction

- Concern that people may be excluded if engagement is only via online forms.
- What adjustments will be made to be more inclusive to people who do not have a computer?
- How will the strategy will be disseminated?
- Would like to have capacity to collect views from Healthwatch perspective on this
- Highlighted example of Healthwatch in Redbridge that conducts enter and views with people with a Learning Disability.
<http://healthwatchredbridge.co.uk/news/involving-people-learning-disability-work>

4. Summary

A total of 78 people took part in the engagement activity which tested the Learning Disability Strategy 2020-2025+.

55 people were engaged between February 10th to 27th 2020. This included 32 people with a Learning Disability who access health and social care services, 16 attendees of the NHS Wandsworth CCG PPI Reference Group, 2 carers and 5 members of staff. 26 people took part in a session in August 2019.

The ages of those involved ranged from 18-75 however most of the participants were over 35 which highlights a need to revisit the engagement plan and deliver a specific session to reach young people going through the transition to adulthood and move to independence. We also spoke with a limited number of Carers so a session will be organised during the engagement period to ensure they are informed and included in this process.

Next Steps

The insights gathered in this report will be used to inform the 5-year Strategy and its delivery. A full analysis of the themes contained in the report and the actions we can take will be undertaken during the engagement period. A *you said, we did* document will be created to feedback to all the people who took part in this engagement so they can find out how their experiences are informing the work of the NHS CCG and

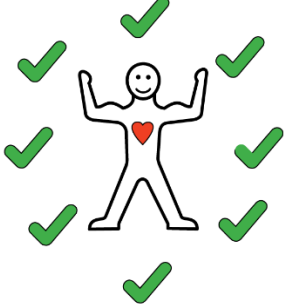

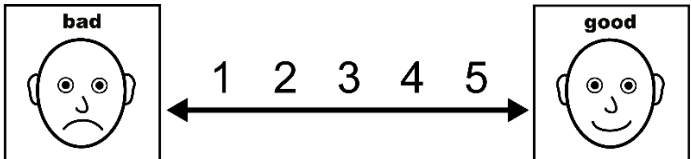
Council. This document will be published by July 2020 and will be shared with each of the groups that took part in this project. People who took part will also be invited to join the Strategy working groups which will monitor how the strategy is put into action and monitored.

<https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-meetings-accessible/#meeting-learning-disabilities>

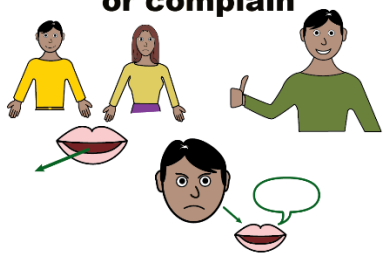
Appendix: Visual Questionnaires

1. LD Strategy Questionnaire

2. LD Involvement Questionnaire

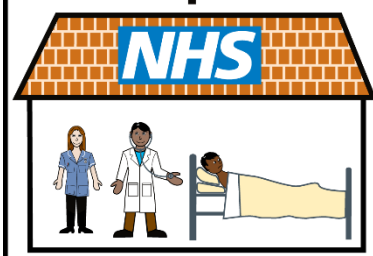
<p>good health</p> 	<p>Keeping People Well: Improving Health Services.</p> <p>We want to make sure that there are services which help people with a learning disability have good health and stay well.</p>
<p>GP practice</p> 	<p>Have you recently visited a doctor or nurse?</p> <p>Yes / No</p> <p>How was it?</p> <div data-bbox="651 1641 1394 1841"><p>bad</p><p>good</p></div>

**comment compliment
or complain**



Tell us what was good or bad:

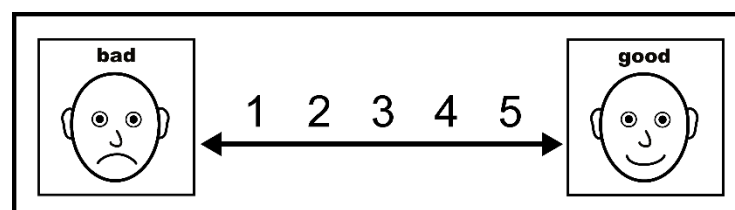
hospital



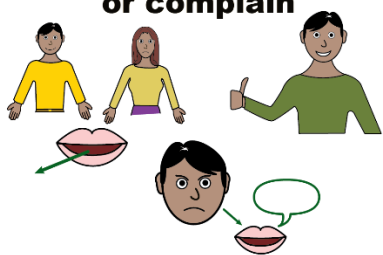
Have you recently visited a hospital?

Yes / No

How was it?

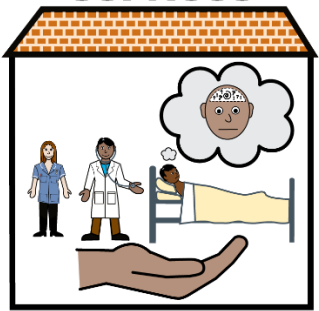





**comment compliment
or complain**



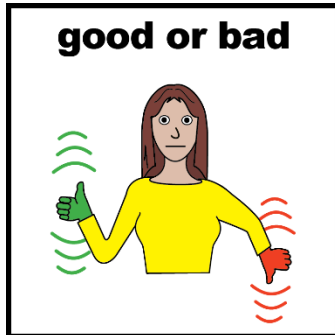
Tell us what was good or bad:

<p>health checks</p> 	<p>Have you ever been to the doctor for an annual health check?</p> <p>Yes / No</p>
<p>comment compliment or complain</p> 	<p>Tell us what was good or bad:</p>
<p>hear my voice</p> 	<p>Do the doctors and nurses you see talk in a way you can understand?</p>
<p>listen to me</p> 	<p>Did you feel listened to?</p>

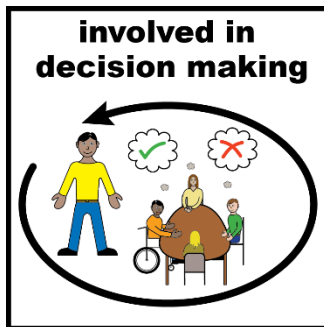
<p>mental health services</p> 	<p>Have you ever used mental health services?</p> <p>Yes / No</p> <p>How was it?</p> <div data-bbox="651 504 1390 712"> <div data-bbox="676 528 834 689"> <p>bad</p>  </div> <div data-bbox="839 584 1203 651"> <p>1 2 3 4 5</p>  </div> <div data-bbox="1208 528 1366 689"> <p>good</p>  </div> </div>
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What is bad?



What works for you?



Do you feel involved in your health care?

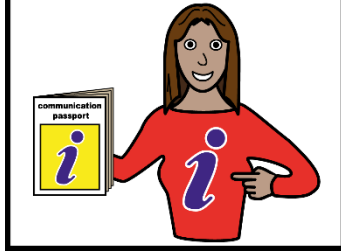
Yes / No



Do you have a health plan?

Yes / No

**communication
passport**



Do you have a communication passport?

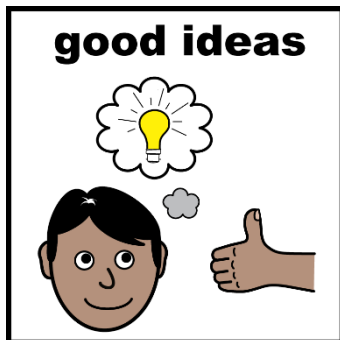
Yes / No / I don't know what this is

happy



Are you supported to live a healthy happy life?

good ideas



Tell us your ideas for making things better

care at home



Where you Live:

Housing and Support.

We want to make sure we have the right services in Wandsworth for everyone with a learning disability. This includes where people live.

independent living

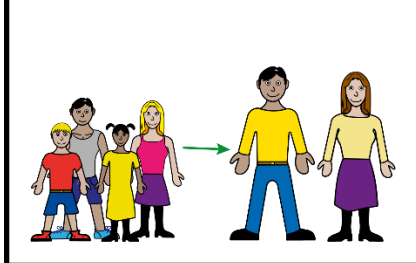


What you do:

Employment and Day Opportunities.

We want to help all people with a learning disability to be as independent as possible. This could include learning new skills or getting a job.

transition



Moving to Adulthood:


Transitions.


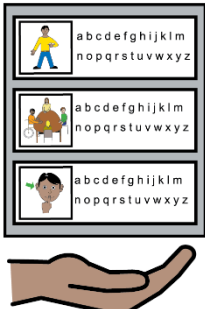
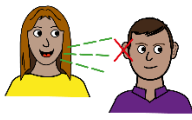
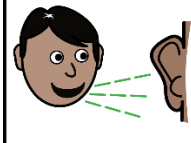
We want to help young people with a learning disability who are leaving school to plan for the future.

<p>direct payment</p> 	<p>Increasing Life Opportunities: Financial Choice.</p> <p>We want to help people with a learning disability to make choices about how they spend the money that they need.</p> <p>Do you have a health budget / direct payment?</p>

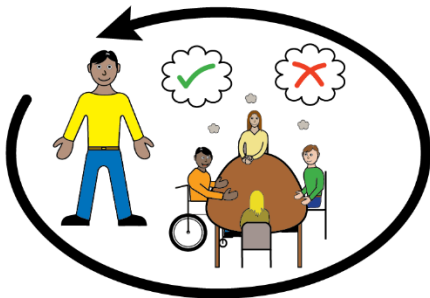
Involvement Questions

- We are reviewing / looking at how we involve patients in our work.
- We'd like your views on how the NHS and the Council in Wandsworth have involved you.

<p>group meeting</p> 	<p>How many meetings have you attended?</p> <p>Do you know what these were about?</p>
---	--

<div data-bbox="225 194 576 539"> <p>good information</p>  </div> <div data-bbox="225 546 576 974"> <p>document support</p>  </div>	<p>Were you given information in advance of the meeting?</p> <p>Was this accessible? Could you read and understand it?</p>
<div data-bbox="209 987 416 1189"> <p>not listening</p>  </div> <div data-bbox="416 987 628 1189"> <p>hear my voice</p>  </div>	<p>Did you feel you were listened to?</p>
	<p>Do you feel you influenced (made a change to) health and social care services?</p>

involved in decision making



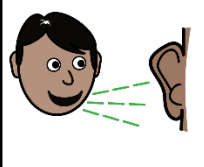
better care



achieve goals



hear my voice



important to me



Did you feel valued?

Please tell us what was good or bad:

meeting room



How was the meeting room?

Was it easy to find?
Did you like the space?
Did you feel comfortable?

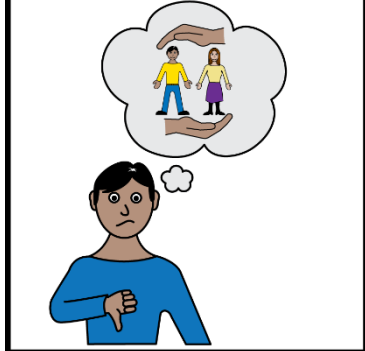
<div data-bbox="256 262 625 678" data-label="Image"> </div>	<p>How was the facilitation</p> <p>Did you have time to share your view?</p> <p>Do you have Terms of Reference (rules for the group)?</p>
<div data-bbox="247 1093 620 1464" data-label="Image"> </div>	<p>Was the meeting easy to follow / understand?</p>

get it right



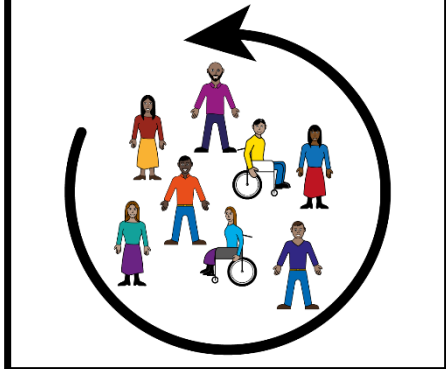
What worked well?

get it wrong




What did not work well?

involvement



How do you feel about your involvement?

<p>ideas</p> 	<p>What would you change? What are your ideas?</p>
<p>comment compliment or complain</p> 	<p>What else can we do to better support you to have a say?</p>
	<p>Do you understand what coproduction /codesign is?</p>
<p>training</p> 	<p>Were you given any training?</p>