Planning Together Meeting Wednesday 3 May 2023

1. Review and update on actions

Please see slides on the Planning Together website

2. CLDS Updates

Social Care

CLDS are expecting inspectors from the Care Quality Commission (CQC) for the first time since 2010. They are really interested in areas of focus and will want to look at these, and hear experiences. This includes good points and where we need to improve.

There will be a new additional lead practitioner coming to help. This is a good opportunity. Some areas of focus include:

- 'Transitions' when people move between services. This links to the Children and Young Peoples Team.
- The importance of relationships and the 'named worker' model. CLDS listened when people said they did not want to repeat stories or have too much change. They will look at how that is working and if there is anything better they can do.
- They will look at the First Contact duty system to see if people are happy when they make contact the first time.

There is a lot to do, and they will keep everyone up to date.

Another priority is employment. There are going to be some new workers in place to support more people with LD into work. Please see more notes under the Any Other Business section.

They are also developing a small care home in Camden for when people need an emergency placement if things break down. The main reason is because Breakaway has a lot of people going there for a short term placement as there is nowhere else. This means people who need a carers break have not been able to get it.

Health Update

There has been important progress with Annual Health Checks. Last year 61% of people with an LD (registered with a GP) had an Annual Health Check. In the last year up until March 2023 94% of people with an LD had an Annual Health Check. This is a huge improvement, mostly due to the work of Courtney Francis, Health Facilitator.

Courtney's priority next year is to check everyone has proper Health Action Plans.

The Annual Report will be shared at Planning Together in July. The priorities agreed by the LD Executive Board this year include:

- Making sure we deal with the impact of poverty and that people are aware where they can get help.
- To continue with Annual Health Checks and make sure people have good Health Action Plans.
- To find out more about whether people are more or less likely to get a good service depending on where they are from. For example do black people have a worse service than white people.

3. The Three Pillars model

Please see presentation and the Three Pillars model leaflet on the <u>Planning Together website</u>

They have developed a leaflet. Everyone was asked to have a look, say what they think about it, and make suggestions.

A model is a way of thinking about working with people and it is recommended to others eg. support workers or carers, people with LD themselves. They recommend using the Three Pillars model to feel happy, stable, and supported

Q: Is the leaflet for carers or the person being cared for?

A: It is a bit of both. They have made it Easy Read as much as possible. The example leaflet shown is for carers and parents for people with LD, and they can also think who else they can adapt it for.

People might not know this way of thinking. It helps to remind people not to change too many familiar things at one time. It could be useful to support workers in day centres or supported living.

Feedback given that the picture of the stool on the first page made it very clear. A couple of people found the leaflet difficult to read. There is a support group for parents with an LD who have children with disabilities and this information would be useful to them.

ACTION: Hannah Deakin will come and see Synergy and discuss making the leaflet easier to read. They can also look at making a video with the help of Richard Lohan.

4. Hospital Passports

Lynette Kennedy gave a presentation. Please see it on the <u>Planning Together</u> website

The video can be found online on the <u>CLDS website</u> and also on <u>YouTube</u>

You can download the hospital passport <u>here</u>. It is important to make sure everyone uses the same form.

Q It is difficult when you don't have access to technology. Can GP's help complete it?

A: GP's know about it but they can't guarantee that they are going to do it for you. There is a list of people who can support in the presentation on the Planning Together website. It is important have it done and keep it updated.

Q: In the NHS and other boroughs there are different ones

A: There is a bit of work to do. They only do this passport in Camden but they are hoping to work with NHS England on a national one.

Q: There are lots of papers to hand out

A: This is why we did the hospital passport. UCLH, Royal Free and Whittington felt there were lots of bits of paper that didn't get used, so they did this work together.

Q: How often do they recommend updating it?

A: It should be updated if you go to the GP and things change. It is different to the Health Action Plan. The passport is for when you go into hospital so they know how best to support you. If anyone needs support Courtney can come and do group sessions for those who haven't got one.

Q: Do you have to have one?

A: They are voluntary, but they are very helpful for when you go into hospital.

Q: How many pages are there once it is downloaded? If there are more than 2 pages it can be heavy to carry about.

A: There are about 9 pages. They know this is a lot but they agreed to keep it at 9 pages at the most. The pictures make it bigger. If you print it on both sides that is only 4 and a bit pages.

Q: Can this be used for emergency use?

A: Yes. It can be used every time you go to planned hospital outpatient appointments, or if you don't feel very well and go to the emergency department. You can print it out or have it on your phone, or the support worker can have it on their phone. You can also send it to the liaison nurses. They can put it on files so if you do forget they will have a copy. Here are their contact details:

Royal Free: Sarah Lally - Acute Liaison Nurse - Learning Disabilities (due to go on

maternity leave)

Tel: 0207 794 0500 Ext 39517 / Mobile: 07903 225052

Email: s.lally@nhs.net

UCLH: Sarah Cope - Learning Disabilities & Autism Nurse specialist

Tel: 02034478238 / Mobile: 07984288589

Email: sarah.cope5@nhs.net

Whittington Ruth Wetherall - Acute Liaison Nurse - Learning Disabilities

Tel: 02072885358 / Mobile: 07876145298

Email: ruth.wetherall@nhs.net

Q: When people go into hospital there is a lot to think about and sometimes staff might not read the hospital passport

A: If you don't think staff are reading the passport then the advice would be to speak to the liaison nurse or safeguarding lead if the liaison nurse is not there.

Q: With how chaotic things are how can they ensure things are agreed in the handover?

A: In hospital there is now a daisy symbol that can be put on a headboard so staff know there is additional information to read. All these little things together with support workers can remind people to read the hospital passport.

Q: Some places in the country use maternity passports, are there different types of passport?

A: the next project will be the Health Action Plan so everyone has the same one form that they all agree to use. There are lots of different passports including medication, maternity, paediatric for children, but it may be too much to carry. They are trying to stick to two: Hospital Passport and Health Action Plan.

Q: Do children and Young People use the same passport?

A: Yes, they can be used from age 14. Lynette went to the Special Parent's Forum. It would be good to attend again to remind people and the school nurses.

5. Included and not included groups

Family Members Reference Group

Katy from Camden Carers runs the Family Members Reference Group. This is a group of carers for people with LD and autism. Please see updates below:

- They looked at underrepresented groups.
- Jill came and let them know about 'our group your group'. This is the group for parents with a LD and includes new parents and offers peer to peer support eg. help to attend GP's or advice and information regarding what help there is.
- They are now looking at campaigning and how to improve services, and working with social workers
- Melissa Shaw came to give a talk on the leadership programme at CDA. This is giving young disabled people leadership training to get jobs and find work. One big thing they are doing is looking at Greenwood and how to creatively use the different spaces eg. rooftop, music studio, IT space, conference rooms.
- Gillian came to speak about Making Carers Count and shared an accessible leaflet. They are working to make sure the information they are making is easy to understand, open and welcoming.
- They are looking more generally at Camden Carers and the information they are putting out to make sure it is easy to understand

Making Carers Count

Anna Campbell is a Community Engagement Project Manager at Camden Carers and gave a presentation on Making Carers Count. Please see presentation on the Planning Together website

Synergy Role play

Synergy performed a role play. Jill explained that the reason why they did that role play was that when some people put up posters at Greenwood there are lots of colours and white writing and people with LD can't read this.

Q: The presentations were great. The Making Carers Count presentation mentioned certain communities they were researching (Bengali, Somali, Chinese). Are they making sure they are inclusive in the research? Eg. different countries in Africa, the Black Carers Collective. If not the same people will attend and they will miss out on other carers.

A: The reason they picked those groups was based on looking at carers currently using the service and the data on the population of Camden. Those 3 groups have a high population in Camden but low use of the services so that is where they can see most immediate need. This is not to say they are the only groups they are trying to engage with. They are also working with Emoja (previously known as the African Health Forum) and Henna South Asian Women's group and it is hoped there will be benefits for a number of ethnic communities.

Q: Do they do things in Greenwood or online?

A: They do things at Greenwood and online, and additionally they deliver activities across the borough in locations where community groups are already working. There is better engagement if they go to places people are used to.

Q Is there an online page or leaflet for the parents group?

A: Gill said there is a leaflet but it is not printed out yet, they can send it online. Katy said there is also an online video they made.

Small group discussion

Everyone shared ideas on the following questions: how to make sure information is accessible? How do we make sure we are more effective at working with diverse groups, and what we are doing across the LD system is relevant and open to people from minority groups?

- They can use things like Google and they can use the microphone or speaker and speak for you.
- Sometimes there are two versions of a form one for LD and one for everyone else. This does not seem necessary. Information should be shared in the most simple easy to understand way so it is clear for people with LD and English as a second language.
- Wall posters should be clear.
- Online information links in posters and QR codes can be challenging. They should use videos instead of leaflets where possible.
- There could be a focus group or panel of people with LD or autism that review posters or leaflets before they go out.
- With the focus group they should think of what incentive there is for taking part. This is not just about vouchers, it could be training etc.
- Communication needs to work for everyone. The hub should be accessible to all and then they should look at internal council buildings and champion things internally.
- The Accessible Information Service can help and is free to anyone who works in the council. They offer cheaper rates to anyone who is in North Central London.

6. Topic for the next meeting

- Disability Oversight Panel
- Trauma Informed Care
- Employment
- CLDS annual report
- Transport (future meeting). This should also include buses and safety. When buses stop in the middle of the pavement or cycle lane and people in wheelchairs find it difficult to come off the bus.
- Repairs (future meeting). Andrew will meet with the person who oversees the system.

Repairs should include the Enhanced List as this is not working well for people. The system for choosing who gets seen first now is anyone over 55. There are a lot of people over 55 anyway. This needs to change and they need to look at how to do prioritisation better.

ACTION: Jide to be invited to the next Disability Oversight Panel.

7. Any Other Business

Employment

They are trying to work hard to target barriers to accessing employment and there will be two new posts (Work Ready Coach and LD Job Advisor). These will just be for people with LD who are known to the service and will support people to develop skills, confidence to work towards their goals and dreams, and for employers to make the adjustments needed.

The new Work Ready Coach, Rachael, starts on the 15 May 2023. Rachael will sit with CLDS and the Job Hub. They will start off looking at the Living a Good Life group and people who they know are interested and want to work.

The Work Ready Coach will start getting to know people, understand their strengths and what difficulties they have had in accessing work. They will then build a programme to work on those eg. people skills, socialising, crowds. Once ready people will be referred to the LD job advisor who will find work and training for people.

Trauma informed care

Anwar Kabir, Psychologist in CLDS spoke about work they are doing on an approach called Trauma Informed Care. Anwar shared a leaflet on what trauma is.

Anwar explained it is something we may experience eg. a big thing, an accident, abuse. It could sometimes happen lots of times eg. being bullied. If you experience trauma it can effect the way you feel in your mental health and how you work with other people.

It is important to understand if you have had a bad experience how to make things better, and how we can make services we offer to you better so you don't experience bad things with us.

Anwar will come to the next meeting and talk a bit more and ask for help. It would help for people to share their experiences and think what we need to do as a service.

Q: The leaflet needs to be in Easy Read

A: The leaflet was borrowed from another area in the country to give a bit of information when talking about trauma and what it is.

ACTION: Anwar to think about whether to develop a different leaflet on trauma in Easy Read

Disability Oversight Panel

Councillor Larraine Revah from Gospel Oak spoke about the Disability Oversight Panel. Larraine chairs this meeting and Councillor Kemi Atolagbe is Vice Chair.

They are trying to make Camden a more disabled friendly borough starting with 4 wards. There are regular meetings and 6 champions in the councillors who the

Leader of the Council chose. They go out to talk to all organisations and try and meet service users and have a conversation.

A lot of organisations come to Larraine to look at things they are finding difficult and how to help make things better.

The meetings happen 3 x a year. There are themed meetings. There was one last night which Synergy attended and they spoke about transport. There were 60 people including TFL and their own in-house service.

They set up the group to be a voice for people with all different kinds of ailment whether in childhood or adulthood. They are working hard to hear from anyone with any ailment. They would like to hear from groups, organisations or service users

On the third Tuesday of the month Larraine holds a special surgery at Greenwood from 1-3pm where anyone with an ailment or their carer can phone up and make an appointment and attend.

Larraine will come back next time with Kemi and talk more about the Disability Oversight Panel. Please get in touch if you have any difficulties or know people you think need to get in touch. It doesn't matter what ward people live in they can come and they hope to help.

Active for All

The Active for All event is taking place at Talacre on 27 May 2023.

Healthfest

Healthfest is taking place on Friday 16th June 2023