Planning Together Meeting Wednesday 20th July 2022

- 1. Welcome and Introduction
- 2. Review of Actions from last meeting

Poppy gave an update. Please see information on the <u>Planning Together website</u>

ACTION: Synergy could write to Google and say what support or training people with LD want from them

3. CLDS Updates

Health Update

There is a concern that women with LD are not attending breast screenings. The screening team is going to meet with service providers to think how to help. Lynette will come back to Planning Together with a bigger presentation.

LD nurse Sarah Cope asked if we can look at hospital passports in Camden. There is a worry people have different passports and some are not correct.

Q: Ranna asked; will women receive appointments for breast screenings?
A: Lynette said that first they will check in with women in supported living have already been invited but not attended and encourage them to attend.

They will then look at everyone else who hasn't been invited or has not attended.

Q: Sandie asked; do men need a breast screen as well. The doctor can send you to the cancer hospital and it can be frightening.

A: The government screen is just for women but it is just as important for men to check too. There is a good video that they can show next time. Sandie could do the presentation with Lynette if he would like.

ACTION: Lynette to have a meeting including Jason and Synergy to think how to make hospital passports better and to think about better screening

ACTION Lynette to come back to Planning Together with a presentation on breast screening

Social Care Update

CLDS contacted people to check they were staying as cool as they can in the heatwave. We need to think how we can support people with LD with this type of weather event. It can be life threatening if you don't take action.

Camden have not done as well as other London boroughs supporting people into employment. They want to get better. Catherine is speaking to people about what we can do further. We want to make this a priority for CLDS and the whole Council.

4. Cost of Living crisis - Synergy

Synergy members spoke about how the cost of living crisis was affecting people:

- They visited the day centre. One person's sister looked after her money. They said their favourite game of bingo had gone up but other things haven't changed.
- They spoke to a Camden Irish charity. They said gas and electricity is going up and it's scary.
- People are not buying the same things they used to buy. They have to cut back on meat and fish, and go to cheap shops.

They asked about who to ask for help:

- One person would ask the work and pensions department
- You can save money on food bills by growing your own vegetables. Synergy
 members have an apple tree, make their own bread, biscuits and butter and save
 £100 a week on food doing this.
- 'Taking Charge' is a website where you can learn to cut down on bills and has an easy read guide. You can find the website Here

5. Welfare Benefits

Please see presentation from Melanie Black and Suzette Gregu on the <u>Planning</u> Together website

Q: Sandie stated; it is difficult that there is no paper form for Universal Credit. When you phone up it is sometimes difficult.

A: The advisors are not happy there are no paper forms, they like to sit and help. The Citizens Advice Bureau have a 'help to claim' service. It is helpful if you have someone with you, or someone able to use the internet.

Most people find it stressful when you first set up Universal Credit, and also having to wait for a payment. Once you have set up a claim you can get paper forms.

Q: Sandie said; when a form comes giving a time and you can't get an appointment you can panic.

A: If you can't go online, telephone is best. You can also go to your local job centre and talk to people there. If you can't meet the deadline, make sure you call the number and ask if you can have more time.

Q: Rory asked; When people first claim Universal Credit the housing benefit comes directly to them rather than the landlord. It is important to remind people this is for rent.

A: It can be really difficult when you get a large payment and need to budget for rent. The money for rent can be paid direct to the landlord but this will not happen without asking.

When you get Universal Credit you will be allocated a person to look after the claim. You can ask them about getting the rent portion paid to direct to your landlord, or your landlord can ask.

The DWP can decide to pay the housing element to your landlord if you owe rent, or find it hard to budget.

You MUST make a separate council tax claim and this is paid directly into your council tax account.

Budgeting help is also important

ACTION: Melanie Black to visit and talk with Synergy.

6. Paying towards your care and support

If you get Care and Support that is paid for by the Council, you will probably have to pay some money towards this. Please see presentation from David Kinloch on the Planning Together website

Q: Clare asked; do you have to pay for your care if your savings are over a certain amount?

A: There are two limits. Your savings under £13,250 are not counted. If you have more than £23,250 in savings you have to pay all of your care costs from your own money. If you savings are less that £23,250 what you pay is linked to your income and outgoings.

Q: Mary asked; how can they help people with learning disabilities who do not have someone to look into all their contributions and expenses?

A: They can arrange for someone from the Council team to come and see people and help get it right.

If someone is getting care and support in Camden there will be someone supporting them when they first arrange services. They can arrange to go around.

At the annual review they can check the figures, and review any expenses.

Q: Ranna asked; can they automatically reduce costs for all clients as the cost of living has gone up?

A: It is not possible to automatically reduce costs. It is a government policy on how much they charge. There is an annual review of what people have to pay.

Q: Andrew asked; are there systems to pick it up if people stop paying, or is it only at the annual review?

A: There is a Credit Control team who deal with debt to the council. If someone stops paying they come back to CLDS to see if they need to arrange to see them.

Q: Rory asked; is there anything else that decides if people need to pay care charges?

A: Nobody should be asked to pay more than they can afford. £120 of your income is not looked at. The Government says this is enough for people to live on.

ACTION: If people want to make suggestions on changes to the rules on how much people are asked to pay for their care and support, they can contact Councillor Anna Wright (who has taken over Pat Callaghan) - anna.wright@camden.gov.uk

7. Food poverty

Please see presentation from Catherine Schreiber on the <u>Planning Together</u> website

The main place to get help if you are in crisis is the <u>Camden Advice Network</u>. They have a straightforward referral and offer all sorts of help

They are helping people to think about 'cash first'. If you are in crisis it is about getting enough money rather than needing to use a foodbank.

Camden also offer help in a financial emergency for extreme hardship eg. you do not have enough money for food and there is an effect on health.

There is more information <u>here</u> on the Camden Advice Network or make a **free** call to **0808 278 7835**.

Q: Sandie said; he did a course years ago on budgeting called Quids In. Can anyone help people budget day to day?

A: Centre 404 Floating Support help people in support sessions.

Centre 404 are also thinking of doing a workshop if people want this.

The Camden Society also offer budgeting as part of their support.

Unity Works still run Quid's In. This is free for people aged 19+ with a learning disability or autism. They will be teaching again from September. Please contact jesamine.murray@unityworks.org.uk or email acl-courses@unityworks.org.uk to join the mailing list to get an update when courses are open for bookings.

ACTION: Rory to look at doing a budgeting workshop at the Centre 404 drop in.

Small Group Discussion

Group members shared thoughts and ideas about the cost of living crisis:

- It can be a barrier if you have problems getting online or don't know how to make contact. The right phone numbers need to be clear. (The number to call is 0.808
 278 7835. It is free from any phone.)
- Some payments are made to people out of the blue eg. for heating. People might be nervous asking DWP what it is for.
- Camden Advice Network can help. It is made up of lots of different organisations and they contact the right one.
- It would help if the letters about arrears are easy read to start off. If people are in arrears they should be told sooner rather than later.
- Could there be a 'vulnerable list' including people with LD so they can get help sooner

ACTION: Louise to put Synergy in touch with those changing the way Contact Camden is working to help make it better.

8. Hospital appointments

Please see presentation from Ruth Wetherall, the Learning Disability Liaison Nurse at the Whittington Hospital, on the <u>Planning Together website</u>

Q: Sandie asked; how would a person with LD contact Ruth if they didn't have the number?

A: There is often a 'flag' on the computer if the person is known and Ruth gets an email. Doctors and nurses can also contact Ruth. Ruth can meet people at the emergency department or appointments.

If you can't remember Ruth's name ask for the LD liaison nurse.

Q: Jason asked; how can people get a hospital passport?

A: You can 'Google' hospital passport, there is a link to the community team and you can get a copy.

Some people have slightly different hospital passports. Clare can share the one they use in Supported Living with Jason.

Q: Clare asked; are there days and times Ruth works? Does the Whittington use the red bag scheme for people coming into hospital?

A: Ruth works Monday to Friday 8.30am-4.30pm. Most hospitals have LD Liaison nurses with similar hours. They don't use the red bag scheme but Ruth is happy to talk and put it in place.

Q: Mary said; there are not enough LD Liaison nurses. Can they have the numbers of the other nurses at other hospitals eg. UCLH, Royal Free?

A: The contact number for Ruth and UCLH can be found in the presentation on the Planning Together website

The contact number for **Royal Free** is:

Sarah Lally

Acute Liaison Nurse - Learning Disabilities

Tel: 0207 794 0500 Ext 39517

Mobile: 07903 225052 Email: s.lally@nhs.net

www.royalfree.nhs.uk/learningdisability

Q: Sandie said; Synergy did videos for the NHS about the hospital passport on the YouTube channel.

A: There is a link to the UCLH video <u>Here</u>. The Whittington are currently making one and hopefully it will be ready in the next couple of months.

9. Topic for the next meeting

Group members suggested topics for the next meeting:

- Presentation on the CDA Leadership programme by Fatima
- Presentation on the PBS framework
- CLDS annual report (including the video version)
- Employment: more people with good jobs!
- Video on breast examination
- Making things happene: can we make subgroups work? Some items can be looked at as a sub group and report back.
- Proposal for a Synergy Learning Disability conference
- Supporting people with the winter energy costs eg. using less or help to pay.
- The 'LeDer report' has numbers of people dying. They want to make sure people get the best healthcare and learn from this group. Could this be a sub-group?
- There are problems with repairs in Camden.

ACTION: Someone from Repairs is coming to speak to Synergy. Jason to arrange a meeting.

ACTION: Agenda planning group to decide topics for the next meeting.

10. Any Other Business

Substance Misuse retender

Please see information from Lisa Luhman on the Planning Together website

Lisa manages contracts for drug and alcohol services in Camden.

They are changing in April 2023. At the moment there are 4 separate services. They will bring them all together in one service to make it easier for people to get help.

Lisa and the team will work with CLDS to make sure the new service is able support people with LD with drug and alcohol problems.

They really want feedback on what is good, and what can be improved.

When the new service starts someone will come back to Planning Together to update on opportunities to get involved.

A service user group has been set up called Moving Forward, there are chances for people to join that group.

You can contact Lisa here: lisa.luhman@islington.gov.uk

Q: Jason asked; do many people with LD have drug and alcohol problems?

A: It is a small amount but there is probably a bigger need they are not meeting so the new service needs to be really accessible.

Lynette said that we know that people with a more mild LD living independently are more likely to smoke and drink than the general population.

It is easier for people to get cheap and strong alcohol without understanding what might go wrong.

Q: Ranna asked; what is the address of the site where they can refer?

A: The new service is not up and running yet but Lisa can send the details of the current services.

Please see below for details of current drug and alcohol services

Camden Community Drug Treatment Service (Change, Grow, Live)

Camden-referrals@cgl.org.uk or 020 7485 2722

https://www.changegrowlive.org/community-drug-service-camden/info

This service is for people using any type of drug including over the counter, prescription medications, and street drugs. Those who would prefer to be seen at one of our GP satellites have this option.

Integrated Camden Alcohol Service (ICAS) (Change, Grow, Live)

Camden-referrals@cgl.org.uk or 020 3227 4950

https://www.changegrowlive.org/camden-alcohol-service-icas/info

This service open is available for individuals who are experiencing difficulty with alcohol use or who are affected by alcohol use issues.

Camden Recovery Service (Single Homeless Project)

camdenrecoveryservice@shp.org.uk or 020 7520 8682

This service is for people who are stable or in recovery from substance use and want help getting back into education, training or employment.

HealthFest

Lynette thanked everyone for the parts they all played in making Healthfest such a success, it was great and we hope you all enjoyed it.