

# Planning Together Meeting

Wednesday 24 July 2024

## 1. Review and update on actions

Please see slides on the [Planning together website](#)

## 2. CLDS Updates

### Health Update



**Jasmin Oven** is the new **Health Facilitator for Cancer Screening** and works in both Camden and Islington aiming to increase the number of people with LD who go to screenings for cervical, bowel and breast cancer. Jasmin is working with different screening services to try and make things easier.



**Cara St John** is joining to offer health support for provider services teams that are part of the council e.g. Breakaway and the LD day service.



**Elyse Luxon**, Speech and Language Therapist, is going to be doing a similar role to Cara supporting the LD day service and Breakaway.



### Social Care Update

**Renee Theberge** is a new Social Worker



**Harbinder Ghir** is a new Lead Practitioner.

## 3. Mental Health

**Leah Jesnick** gave a presentation on mental health support for people with learning disabilities in Camden. Please see slides on the [Planning together website](#)

**Q:** What does **iCope** mean?

**A: iCope** is the main talking therapy service for everyone in the borough. If you see a GP and they think you need to see a psychologist or another therapist they will call iCope in Camden.

**Q:** What is the waiting list for things? iCope have a big waiting list

**A:** Leah explained that the waiting list for iCope is long for everyone. For CLDS psychology it is quite short as they only see people open to CLDS. They usually try to meet everyone who wants to see them in 2 weeks and talk about what is helpful. If it is agreed talking therapy is helpful the waiting list is about 1-2 months.

Andrew said there is no waiting list to see a psychiatrist but they won't always see everyone. They make a decision if it's the right thing.

**Q:** My daughter has profound and multiple LD. They know when something is up. Sometimes she needs drinks, cakes, or there are moments when she is very reserved and does not communicate or want to talk to anyone. She lives in LDN and they are all very busy. Do they offer training for staff about how to engage, pick up what is going on, and how to make things better?

**A:** Leah explained that they do work with people with a profound and multiple LD and they mainly work in a behavioural way. They look at behaviour and try to understand e.g. what someone usually might do, are they more quiet or not doing what they enjoy. They work with staff closely and ask them to note down things. They then look for patterns, try to understand what they mean. They do offer training for all the providers in Camden regarding behavioural support, and individual support to people where there are some concerns.

They have almost finished the new therapy room at 5 Pancras Square. This is one room and will only be used for CLDS and the children's service to see people for talking therapies. There are sofas, colours, plants. It is a lovely room and they hope to use it from September.

**Q:** It is great people with LD can go to their GP and iCope, but how good are those services at changing what they do? It is important that we find out and work with those services. Does anyone have experiences?

**A:** Leah explained that it is mixed. Some people tell them it is a good experience, sometimes not so much. They try and work with other services in Camden and Islington so they are joined up for mental health. When people have seen a GP who says talking therapy would be good they usually contact CLDS and meet. CLDS ask if people would rather see someone from CLDS psychology or go to the mainstream services. It is people's right to choose. Some people choose CLDS as it is quicker, others say mainstream and CLDS support that service as much as they can.

Ellis said that over the years they have done joint work. This is mainly about Reasonable Adjustments and for some people CLDS join the session every 3 or 4 times, and update and link to community work. They support iCope to be creative. The CLDS library has what Reasonable Adjustments are. There is some good pieces of work but ongoing areas for development.

**Q:** iCope is working but it needs more staff. There is a 3 month wait and bad things can happen.

**A:** Leah said they hear a lot from iCope and other mainstream services. They can't find enough staff and roles are not filled. Leah agreed it is really difficult.

#### 4. Universal Credit

Melanie Black gave a presentation about the plan to move people in Camden on to Universal Credit. Please see slides on the [Planning together website](#). Melanie answered the following questions:

**Q:** At the last Provider Forum they said there was a delay for people with LD switching to Universal Credit until 2028 / 29

**A:** Nothing has been confirmed. They get updates and the Housing Benefits team have a lot of information too. Initially they were thinking 2028, but they were told earlier this year it would be a window from September to December 2024. They will only know a few days or weeks before and when people start to receive migration letters. They were told that for people on ESA if it looks like they have not claimed the Department of Work and Pensions will attempt to make contact 3 times.

**Q:** Does it apply to all people? Is it for people in certain types of Supported Living?

**A:** Residents stay on Housing Benefit if they are in what is called **specified accommodation**. This is very specific types of accommodation. For money to live on they will still need to claim for Universal Credit. Housing Benefit know what type of accommodation people are living in.

**Q:** A lot of people have financial appointees. Is the appointee responsible?

**A:** It will be the appointee. They were told the migration letters were going to residents rather than the appointee, but the letter should go to the appointee. If a letter shows up at Supported Living let the appointees know.

**Q:** The person I care for got the letter a year ago. He was on Working Tax Credits. There were several points he and I found it hard:

- We started filling in forms early but were going to hold off to the deadline as we were sure he would get less under Universal Credit than Working Tax Credits. It then said if you don't submit now you will have to start all over again so we then submitted earlier.
- He has savings and every month they take off money based on savings. It took 6 months before he got anything at all. They had to keep chasing. They got it wrong and then apologised and reassessed.
- You get a journal and it is all online. He had no idea how they were working out how much he was getting paid. Eventually they explained it was on a tab on the journal and I could understand the calculations.
- I think you never get less on Universal Credit than before. I think this is called 'transitional protection'

**A:** When there is a change of circumstances entitlement can and will change. It is handy to access the journal to try and work it out, this is a big move from paper

based. Transitional Protection means you enter Universal Credit on the amount you are getting now, but it does not mean it won't go down over time. You should not have less money. It is different when earning amounts go up and down.

**Q:** If someone is on ESA and doing supported permitted work it is not taken off the benefit. How will this effect the new benefit?

**A:** There are different earning rules with Universal Credit

**ACTION: Melanie to get the details of earning rules on Universal Credit and send them across**

**Q:** It was mentioned that there is a window from September 2024 to December 2025. Once someone gets the letter do they have 3 months to look? What will happen if they have not responded?

**A:** If they don't look then the first thing they will notice is that in December or January their ESA will stop all of a sudden. They will get a letter off the rent officer saying their rent has stopped. Some action must be taken. The person will need to let Universal Credit know they need extra time, but people will not be able to stay on or go back to ESA.

The Department of Work and Pensions have promised to make 3 attempts at contact. They will say did you get the letter, and do you need help. They also promise home visits in exceptional cases, but Melanie can't answer for them. Please do raise concerns all the time and they will feed them back.

**Q:** What is the journal? Is there a code for the journal?

**A:** The journal is a webpage the government uses instead of letters. You get a special code to use to put into the website and can look at your benefit claim. It will tell you what you are going to get paid, and how much they will pay your landlord.

There is a chat part where you can put a message for your work coach, that is the person at the job centre. Don't worry that they are called job coach, if you are on ESA there will not be any more contact with the job centre. When you set up your claim they will ask you for a username and password. Every time they want you to look at the journal they will send you a text.

**Q:** We had many conversations with people in Belfast about my sons claim. They also needed to take documents to the Job Centre but it was nowhere near

**A:** The main thing to remember is that you have the ability to put down what you need to say. Keep saying the message and if there is an appeal you can show the panel what action you took. If there is a work capability assessment you won't need anything to do with the work coach.

**Q:** When you do it on a computer if you try to go on the phone it does not recognise you

**A:** There are lots of glitches and they are coming across new ones. They always try and find a way to get through it. This is not about what you are entitled to, it is about administration and getting used to new ways of doing things.

**Q:** What face to face support will people in this community be offered on a more regular basis e.g. it can be scary when you get told there is a message on the journal.

**A:** Melanie explained they don't know how many people will be coming forward and how much space there is for help. If it is a case of logging on and looking at the journal Citizens Advice Bureau can provide support from the migration notice to first payment, beyond that it is wherever people can get help.

Chris explained they can hear there is a lot they don't know e.g. timings, the number of people it may effect and how. One thing they have talked about is getting more people to help for a short period of time and making sure there are the right amount of people. They are doing that very soon. It is important to feel confident that if there is a question there is someone there to answer.

Andrew explained it will still be difficult and is very confusing but there is help. The main thing is **don't ignore the letter** and ask for help from the **Citizens Advice Bureau on 0800 028 3146** or **CLDS on 020 7974 3737**

## 5. Cancer screening

**Vanessa Nzekwu** from the Bowel Cancer Screening service and **Keziah Hards** and **Kumbi Shire** from the Breast Cancer screening service gave presentations. Please see slides on the [Planning together website](#)

**Q:** A problem I have and many people might have, is collection of the poo. I know they send a stick but it is hard to go through. Can Jasmin support people with LD and their families. I don't think easy read will help people with the collection of the poo, can they try to help the community?

**A:** Vanessa said she understands the barriers. They try to speak to keyworkers who look after people with LD and take time to show them. People with LD will be teaching those with LD how to complete, and people will come with them to events. It is about watching how it is done, and showing carers and families.

**Q:** What about people with higher support needs and how to provide samples. It was said that poo should not be in contact with toilet water, but some people they support wear pads and need support to change. Is it ok to take the sample if the poo is on the pad?

**A:** Vanessa said I think it should be ok. They test a tiny amount and if it is watery it is still acceptable.

**Q:** Another thing is embarrassment. Can people with LD get support to overcome embarrassment?

**A:** Vanessa explained that lives are saved by screening. Bowel cancer is a quiet killer as there are no symptoms. It may be embarrassing but it could save your life

**Q:** What is a mammogram?

**A:** A mammogram is an Xray of the breast to see if there are any tiny cancers you can't see

One meeting member explained they got the mammogram letter but didn't bother. It's not great fun, you can't do it in your own home, and you have to put your breast in a big clamp, but they found out a year ago because of that test they had breast cancer. They have now had treatment. Please do go and have the test.

More information can be found at [CLDS info](#) including the following:

- [A Family carer guide to supporting cancer screening for people with LD](#)
- Barnet Mencap have this [video](#) about screening made by people with LD.
- There are also these easy read guides:
  - [Bowel Cancer Screening](#)
  - [Breast Cancer Screening](#)
  - [Cervical Cancer screening - having a smear test](#)

## 6. Feedback for the council

Synergy, Camden Carers and LD support providers gave feedback to the council on the 3 questions below.

- what is working well in Camden?
- what is your main challenge?
- what one change would you make in Camden if you had a magic wand?

Cllr Anna Wright and Chris Lehmann, Director in ASC attended to hear feedback. Please see slides on the [Planning together website](#).

Cllr Anna Wright will be asking for copies of all the information and said it sounded like it was a useful process gathering feedback. Cllr Wright has been listening and working with Camden communities for a few years and there has actually been some progress.

Some things that weren't working well are getting better. One thing that is getting a lot better and they are more serious about is co-production and working with people who draw on care and support so services are organised and designed in ways that work for people. They are so much better at that in Camden and there is a real commitment.

For example on Monday night they launched the new [Carers Action Plan](#) at a full council meeting. This was a result of real co-production. If you are worried about how input is not used this was developed with a wide group of carers, and carers are leading to make sure Camden deliver and do the things promised in the plan.

They are also a lot better at different types of activities and services, and also Reasonable Adjustments and things in Easy Read.

They should not have to use a magic wand for things they want and need like buses not being so packed, good social housing, or to go to a nightclub but some things in the world today do need a magic wand. Cllr Wright wishes everyone can have a good proper home on social rent. That is not the world they are in but in Camden they can do good things with the smaller more achievable stuff.

**ACTION: Planning Together to invite Cllr Wright and Chris Lehmann back when they have thought some more about the feedback.**

## 7. Topic for the next meeting

The next agenda planning group will discuss the following topic ideas:

- **Options for moving on.** This could include information on moving out of the family home, shared lives, supported living, someone from the Social Work team about the support offer for your own tenancy / flat, hearing from Synergy / people with LD about their own experiences of moving on, and also from Camden Carers. They could also book the hall for longer and have a chance to speak to providers

- **Family planning, bereavement and grief** - If they are talking about bereavement planning they could watch a video from the Victoria and Stuart project about the way for a good death.
- **Day opportunities review**
- **Recommissioning Floating Support**
- **PIP consultation** - The government were doing a consultation about changes to PIP that closed on Monday, Camden Carers sent in an answer. As far as is known CDA didn't. It was a really worrying consultation, and they were quite open they want to save money on PIP and talked about things like using vouchers, or having to provide receipts.

## 8. Any Other Business

### CLDS online Health Library

Eilis shared information on the [CLDS online health library](#). This has lots of information. They encourage all GP's to use this library for easy read. It includes information on the LD register, Annual Health Checks, how to live and eat well, and about different health conditions.

Eilis explained that the Annual Health Check is recorded on file. A doctor will see you have had the check. There is a group working together and they hope to join Planning Together in the future.

### Healthfest

Thank you everyone who attended Healthfest, it was an amazing success. It keeps getting bigger and better, and there was a big effort from everyone.

### CLDS carers support

**Genevieve Somorin-Adebiyi** is working within CLDS and is focused on the support they provide for carers. Genevieve will be working on ensuring that they follow up on Carers Conversations. This is an opportunity to speak about the needs of carers and how to provide better support. They will also work with the Carers Centre with any follow up and sharing information.