

Planning Together Meeting

Wednesday 23 October 2024

1. Welcome and Introductions

A 'Moving on Marketplace' was held following Planning Together that everyone was welcome to attend. This was responding directly to feedback in previous meetings. There were information sharing stalls about the different choices for people with learning disabilities to be supported when family carers are thinking they may no longer be able to care.

2. Update CLDS Head of Service

Catherine said some people may be surprised not to see Andrew. He has been a huge part of the Camden learning disability community for 8 years and there was a lot of respect for him. Andrew has left CLDS for a new job. He did not have the chance to say goodbye in person because of calendars, but they would want to say thank you and are proud of the work done.

We have come a long way in the last 8 years with wellbeing, health, and people with learning disabilities leading better lives. They were sorry to see Andrew go. He is joining the British Association of Social Workers and will continue important work for better practice in social work. Andrew passed on thanks to everyone and goodbye.

Catherine and Lynette are going to cover the Head of Service role from 1 November 2024 for the next 6 months. There will be a job longer term but it is not advertised just yet. Catherine and Lynette will not do everything as they are still doing their other jobs. Lynette is still a Nurse, Catherine is still a Service Manager. Andrew left a long handover. They are confident to do the very best over the next 6 months and then they will see what's next for the Head of Service.

3. Review and update on actions

Please see slides on the [Planning together website](#). Meeting members discussed the action regarding Universal Credit and shared their experiences of migrating to Universal Credit:

- There was lots to do online and they had to go through page by page.
- There is a journal you have to keep going into.
- You put questions in the journal and there is an answer but there is not an allocated worker to work through things. It was incredibly frustrating.
- It involved taking lots of documents to the job centre. One person had difficulty getting the transitional money and had to keep making contact.
- Don't assume the worker has information about a person's health conditions.

There was a cross council meeting today to decide how to communicate, and agree what support is on offer. A letter in Easy Read is being prepared with some advice, and with a phone number to contact. They know people will need ongoing support with the system and want to stop a crisis.

There will be two new advisors starting. It is not yet agreed what support will look like and they need to look at the best options for people.

There are discussions about whether a drop in is needed.

Centre 404 are reaching out to everyone they work with and providing support. They asked every support worker to check if people have a letter. So far no one has a letter, but they are working with people get ID to prepare for when they get the letter.

It is stressful and complicated but it is good to hear everyone is working together. Camden will make sure what is sent out responds to what we are hearing.

ACTION: Universal Credit information to be sent to Planning Together attendees when ready. It will include a guide for people on what to do before and when they get the Universal Credit letter

4. CLDS Updates

Social Care Update

The biggest update is about the Head of Service roles. Catherine is now focussing on what are the important things to look at in the next 6 months.

Catherine is supporting the team with a CQC inspection happening the week of the 18 November 2024. Some service providers and people with learning disabilities known to the service will be contacted. There is a plan, lots of support around, and a lot of work to do to prepare. Lynette explained that the CQC inspection was not just learning disabilities but across the council. CLDS are just a small part of it.

Other important work is with carers and, as discussed, about Universal Credit. Everyone will be changing to Universal Credit so they will work with providers and across the council about what will happen.

They want someone to be part of a planning group with carers. This is to get thoughts, experiences and expert opinions. We know there needs to be better reach out, support, advice, and planning ahead for people being cared for. If anyone is interested please contact Catherine - catherine.schreiber@camden.gov.uk

Health Update

Lynette is now the Joint Interim Head of Service - Clinical Lead

Health Psychology in CLDS will be running a feelings group. They have already run one and will run it again. If you know anyone who is interested please contact the Psychology team on LD.Psychology@camden.gov.uk or phone CLDS on **020 79 74 37 37** and ask for Psychology.

Lynette explained that someone from NHS England has contacted CLDS. They have a new project where they want to bring everyone together about health plans. This will include the ambulance service, hospitals, GP's, CLDS. It is a big project and will be good for Camden. They want people with learning disabilities to be part of it.

Lynette is meeting a nurse called Gemma. They will be doing it with Islington as well, and they need people interested in joining a project group.

ACTION: Lynette will email more information about the Health Plan project with NHS England.

5. Community support

Anjalene Whittier and Sal Bryant from the commissioning team spoke about learning disability community support service. Please see slides on the [Planning together website](#). It is time to buy more support – this is called a re-tender and Anjalene and Sal would like to hear from people about how the service will look. Meeting members discussed this in small groups and shared some ideas:

- People would like to learn new things. They might be able to do something but might need help doing it in a different situation e.g. travelling to a new activity.
- It would be helpful to know where local toilets are especially [Changing Places Toilets](#)
- There are already a lot of things to do in Camden. Providers do a number of things. There are challenges advertising these so people know what is happening and come. Is there a map of what's out there to connect people?
- There are already lots of activities, but it is still very solitary and restricted. It was hoped when Greenwood opened there would be more variety, they need that. There is a social café going every Wednesday where people drop in make coffee and socialise.
- Some people prefer one to one, some prefer group activities together. It is good to have variety of both, everyone is different.
- Sometimes people don't turn up but there is a reason behind it. A lot of services are not accessible for a range of things.
- It's about talking to people in an easy way. Some people are scared to go in a room of people they don't know and won't talk, some people will. There could be an Open Day or something to try different things.
- The main thing is the importance of trust and friendship with the support worker. It needs good communication e.g. if they are going to be late let people know.

6. Future Planning

A slot was planned with Katy Anderson from Camden Carers to hear feedback from carers about future planning. Unfortunately Katy could not attend the meeting.

ACTION: Camden Carers slides to be shared after the meeting and will be added to the [Planning together website](#)

Carers in the meeting were asked if they had any feedback and shared the following:

- One carer has been involved in Camden Carers a long time and is now a trustee. They managed to get carers coming to meetings and talking about issues, there are always burning issues for everyone.
- What happens when carers are no longer there? E.g. due to old age, becoming seriously ill and passing away. One occupational therapist said the saddest thing was to visit someone in domiciliary care who was used to having their mum or

dad around and having to explain. It is a bit of a taboo subject but things need to be put in place so it is not quite so bad.

- It links to friendship groups and social life.
- There are more young adult carers around and are we doing enough for them?
- In other families a lot of things are found out about community things 'at the school gates'. That does not happen for family carers. Without Camden Carers there is no way they can all talk to each other.
- One carer was trying to sort out Supported Living for their son who is 19 and has Autism and LD. This is a lot younger than they thought but it was brought forward quickly due to ill health. They started the search 2 years ago for supported living. Connections out of the family are really important, or a work placement so people have what they need every day to live their best life. One supported living place fell through and it was a year process. They learnt lessons as parents and are now going to try again and know what not to do, but don't want it to happen to other parents.
- Could there be a supported living hub where parents can share what they have gone through? good or bad experiences. When children are younger there is a lot of work preparing for adulthood, but then when they are adults they need more guidance on the options. It would be good to have a chance to talk to people who went through processes.
- Supported Living is good if the right care package is given and it does what it says, and you think about the groups of people living together and their needs.
- One carer had a terrible experience at an early stage because they missed out on important planning. Carers have raised people from being a baby and understand better rather than just 'ticking boxes'.

Catherine explained there are booklets online where you can start planning for the future. These are from Together Matters and the Foundation for People with LD. They include a thinking ahead planning guide for families, and guidance on finances, what to do in an emergency, taking a break, and how to ask for help. Here is the link for the [Together Matters website](#) – you do need a computer but CLDS can work out how to get a copy if you don't have a computer.

CLDS are also looking at a Carers Planning Group. Carers can also contact social workers and ask for a carers conversation to start a plan. Conversations can be sensitive, painful, and difficult to address but there is support. We are listening to all feedback and working on that in a monthly meeting planning accommodation.

Lynette explained for supported accommodation it often takes 3-4 years. They don't talk about that in preparing for adulthood. They start talking when someone is 16 not because people are ready, but they need to start talking a lot earlier. It does take a long time, they can't change that but they can talk about it.

There is a need for more accommodation that is suitable and accessible.

Clare from LDN recommended a series of books by <https://booksbeyondwords.co.uk/>. These are excellent books around people dying and having support.

7. Moving On

Synergy members gave a presentation on peoples experiences of Moving On. Please see slides on the [Planning together website](#)

CLDS need a bit more detail about the individual experiences shared e.g. one person had said they did not have help for their mental health or with moving. Did they ask for support and not get any? People don't just work with CLDS but also other people e.g. the GP and mental health teams so it would help to know where they reported difficulties to understand and support people.

There is support to help move belongings and with mental health. CLDS make those arrangements all the time so it was sad to hear about one person who said they didn't get this help. They would like to understand why that happened.

Synergy members noted that the people they spoke to were speaking about their own experiences.

Meeting members discussed about how people may have different experiences if they live inside or outside London because of the different types of properties that are available.

ACTION: Synergy to share their key messages in good time so CLDS can look into any issues and take actions if people need support about their individual experiences.

8. Group discussion and feedback

Meeting members discussed ideas in small groups on what does and doesn't work when making changes, and what could be done differently:

- It doesn't work if people do not know the right information at the right time.
- Admissions to hospital are not working for a lot of people
- Work with Annual Health Checks is much better
- It helps to visit properties before you move
- They could work differently with LD liaison nurses going into hospital
- It's important to understand that change takes time and you have to work together better.
- With moving from Supported Living into your own flat you need to listen to people about what hasn't worked and what they want done differently. Some people might need the same amount of support even if they are independent
- Staff need to turn up when planned
- Change ideally should be gradual. Sometimes life throws you when something is difficult. If someone passes away it helps to have familiar things around you e.g. people, groups, activities.
- Personal growth for people being supported is very important. They need to do this with staff, and have the right tools for staff
- There is a lot of staff turnover, that can take its toll on managers and they need to make handovers more robust with newcomers and agency / bank staff.
- Significant 7 and One Page profiles work brilliantly but there is a bigger situation about staff morale, culture and coming together
- Maybe they need to look into what can be done better for staff morale and culture so people feel appreciated and there is personal growth

- There are better outcomes if they are more joined up as a support network, with the right structure and care packages.
- Teams feel they need to focus on people not papers
- It is really important for people moving to get information and are told what they are doing, understand what is communicated to them, and what is going on
- People need to understand wait times and housing is short, and make sure people have resources when they are waiting. There are places people can be signposted to go to while they wait so they are still receiving the support that they need.
- It is important when people are moving to maintain a sense of routine e.g. keeping the same decorations from the place before

Together with the carer feedback earlier in the meeting it is clear that it is the people there that really make a difference.

9. Topic for the next meeting

Group members discussed possible topics for the next meeting. The agenda planning group / previous Planning Together meetings have suggested the following themes:

- **Health** - there is a focus group looking at Annual Health Checks that would like to join the meeting, Camden Carers are doing work about hospital discharge, there could be a presentation from the Rapid Access Service, and Synergy can get peoples views.
- **Family planning, death and bereavement** including looking at a video from the Victoria and Stuart project about the way for a good death / what can be learnt from other areas of the country

New ideas raised in the meeting were:

- **LeDeR report** – this is a project in England that looks at every death of a person with a LD. It's important to talk about that report and the learning. They did not get to talk about the last one, but are due a new report. This links to health checks.
- **Universal Credit** – bring this back, there is a lot more to do.
- **Conversation with carers** – bring this back. There can be a few parts of the meeting to keep updating people if there are things that are really important to all of us
- **Big Plan** – this needs a review. What is important to us all and how are we going to get there
- **Hospital update** - Courtney asked if they can talk about what the University College London Hospital is doing and if it is helping. Richard is helping with patient leaflets to make them easier to understand. They are keen to hear from carers and people with LD about what they would like to see at the hospital.

10. Any Other Business

Booking blood tests

Courtney shared information on booking blood tests. Bookings are done online now. GP's don't give a form they send it electronically and you have to log in. The patient

experience team would like to hear what family carers and people with LD think if they have tried to book a blood test. They can bring what people say back to a future meeting.

Q: Are people allowed to phone?

A: Courtney said it is all online. If you are sent to UCLH for a blood test you have to log in.

There is a theme about access to health services, and a lot being online. All agreed to bring this back. Lynette said they are doing work in Islington. Some people don't like vaccinations and blood tests if they are too scared of needles. It is important to get feedback to see if we can do something that helps people be less scared.

Health Bus

Jasmin updated that the Health Bus is coming to the front of Greenwood on Friday 8 November. No appointment is necessary, just drop in for a flu jab, covid, health advice. Jasmin will be there to talk about cancer screening. It is the same bus that was at Health Fest.