

Welcome and Introductions

Review of Actions

Updates on actions can be found on [The Planning Together](#) website

CLDS and CYPDS updates

Andrew speaking on behalf of Lynette (CLDS Health):

Reminded people of the need to be asking people with LD (as well as their family members/carers) whether have had a flu jab and also getting their Covid boosters. This is the single most important thing you can do to keep people well and out of hospital this winter.

Emma Winn, the Lead Speech and Language Therapist at CLDS will be retiring at Christmas. He thanked her for her years of dedicated service and commitment. We have interviewed 5 people to replace Emma. 3 of them were excellent, and we have offered the post to Rene Relph, a senior Speech and Language Therapist in CLDS.

Andrew speaking on behalf Catherine (CLDS Social Work)

London Borough of Camden have funding for extra social worker capacity to support those people with LD placed out of the borough. This should open up more capacity within CLDS.

Rebecca Coleman, from CYPDS:

The first face to face event for family and carers on pathways into adulthood. Will be at the Greenwood Centre on 11/11/22 at 10am. The flyer will be circulated directly after the meeting. See [Planning Together](#) website

Cost of Living and Winter Fuel Costs

Synergy presented a video on winter costs. See [Planning Together](#) website

Their opinions and conclusions were:

- It was difficult to understand the information.
- Cost of living was so difficult to bear.
- There were numerous challenges and concerns including if there was a cut off for electricity in the evenings.
- Suggestion that people should prepare a survival box: food, torch, wired up radio, sleeping bag, hot water bottle in case of power cuts.

The whole meeting congratulated and thanked Synergy for there really powerful video which really communicated the sense of confusion and anxiety people are feeling.

Welfare Benefits

Melanie Black and Suzette Gregu from the Welfare Rights service presented their cost-of-living slides. See [Planning Together website](#).

Main elements:

- Everyone is entitled to some help with their energy bills this winter.

- People on certain means tested or disability benefits are entitled to even more help.
- If you have a key meter, look out for your voucher that has been sent to you by post. You will need to take it to where you charge your key so it can be added to your meter.

Sources of help

- ✓ Centre 404 will help with the forms as well at their Wednesday morning drop-in sessions. See [Planning Together - Camden Council](#) website and attached.
- ✓ The council have also created a directory of Warm Welcome Spaces for people to go to during the day. [Warm spaces in Camden - Camden Council](#)
- ✓ Food Banks are also available to support with local needs.
- ✓ Please see presentation from Catherine Schreiber on the [Planning Together - Camden Council](#) website.
- ✓ The main place to get help if you are in crisis is the Camden Advice Network. [Adviceline - Citizens Advice Camden \(camdencabservice.org.uk\)](#)

Simon:

Said there are delays of an extra 2 months to get support for people on Working Tax Credit and/or Child Tax Credit.

Rethink Advocacy: Introduction

Sian Phillips from Rethink presented slides. See [Planning Together](#) website.

Camden and Islington Councils have joined together on a new advocacy service. Rethink won the contract.

Jackie asked what support could be provided to family carers to better advocate for their loved ones.

Sian said that Rethink can train people to be advocates for each other. Please contact Sian if interested. Sian.Phillips@rethink.org

Action: Synergy asked Sian to contact them and arrange to run an advocacy workshop for them.

Feedback from Camden Carers Family Members Reference Group

Katy Anderson from Camden Carers informed the meeting of groups that had attended and their meetings:

- Synergy on the work they do and the volunteering opportunities they have.

- Unity Works on the catering group they run at Greenwood – LD communities have felt the loss of Flapjack. Brendan came to the meeting as well. 5 other cafes available for work experience including placements and paid opportunities. One possibly with Centre 404.
- Greenwood has a range of new social activities, clubs, and groups which people can go to with their support workers. Brendan will return to update.
- Elfrida Rathbone on a new education project officer to develop life skills.
- Leon, Mental Health Service Manager at Greenwood on the Wikipage 'Things to do in Camden', a directory of social and recreational activities with pictures and audio. [All our Wikis - Camden - Wiki \(rixwiki.org\)](#)
- Challenging Behaviour Foundation offering direct support to carers through workshops.
- North Central London Integrated Care Board (NHS) on how positive behaviour therapy is being rolled out across service and the framework for support.

Future meetings: Cost of Living: services and groups that are available to support.

Invite Martin from Breakaway.

Possibly Amanda and Poppy attending to do a presentation.

Wider discussion:

What is a Wiki?

A Wiki is a simplified, easy to access website, usually best viewed on a tablet such as an iPad or other touch screen.

A Wiki can be either:

- a public website that provides a range of useful videos to support service users and carers including carer organisations.
- a private digital 'About Me' website where you can save videos or documents about your likes, your dislikes, how to support you or anything that is important to you.

Action: Poppy will send a link to the wiki webpages after the meeting.

[My Camden Disability Action Leadership Project: A Train to use Zoom Project](#)

Fatima Begum presented her slides on the project. See [Planning Together - Camden Council](#) website.

Fatima spoke about her experiences with Zoom including the challenges; the training and support she had developed; promoting her training packs and workshops for other disabled people.

The support is based at Greenwood at the moment. Fatima has plans to maybe go into schools and colleges in the future. Possibly link up to Alexander Centre in the future.

Fatima's presentation and work was warmly received by attendees.

[CLDS Annual Report](#)

Andrew presented the video version of the annual report from CLDS – it is based on the period 1st April 2021 to 31st March 2022 and it summarises

- What went well
- What did not go well and needs to improve
- Our priorities for this year (2022/23).

Video presented was a summary of the Report. See [Planning Together - Camden Council](#) website. Full Report available.

Vicky complimented the work of CLDS nurse- 'very grateful to the health team at CLDS particularly the nurses for their support with the vaccination take-up. Really caring and engaging.'

Jill: Does CLDS support cover council housing?

Andrew: yes it does. Some people were left behind during Covid as they were not eligible for care packages, and we focused our support there.

Social workers are under pressure and 2 new workers joining the team will add capacity. There is also funding for 100 simple annual review through an outside Social Work agency.

Do enough people get their annual health checks?

Andrew: People on the LD Register are automatically contacted to have an Annual Health Check.

Courtney, our Health Facilitator is supporting us with this work by working with GPs. We are looking to apply for a 2-year extension

Jide: 'How do people get Personal Assistants?'

Andrew: Personal Assistants are paid through direct payments. If you do not have someone to help you to recruit and support, you will be unlikely to get direct payments for a personal assistant.

Sian at Rethink: Our advocate are not able to support with accessing personal assistants.

Andrew: We have a new Direct Payments support service provided by People Plus: [peopleplus](#)

Sandy asked how people can be better supported when they have to go to hospital

Andrew: All our hospitals have LD liaison nurses.

Attach their contact details

The report mentioned the number of people who died falling. Why is that?

Andrew: In a typical year 6 people die that are known to CLDS.

In 2020-21 at the height of the pandemic 10 people dies but it decreased to 6 in 2021-22.

All deaths are reviewed by the NHS as part of LeDeR, a system to review all deaths of people with learning disabilities to consider whether we could have done more, and the lessons learned.

Sandy: The process of grieving is made much harder by the difficulties in registering a death and the costs. No one is at the Crowndale Centre to support with this.

Sian at Rethink: We can help but we are not an emergency service. Will take 2-3 days to get an advocate.

Action: Andrew to look at how we can arrange for Camden Council front of house staff to receive training on LD awareness and how to make reasonable adjustments

Action: Rethink to look into setting up monthly drop-in sessions at the Greenwood Centre

Synergy Conference

Jason: Synergy facilitator.

Synergy want to lead, plan, and manage an event. Idea suggested by LDN. Provisionally set for LD Awareness week, after Healthfest in summer 2023. 6 people are part of the planning group. It will be face to face with an option to participate online via Zoom. Volunteers will also be involved on the day.

Looking to invite Jobcentres, Sainsbury's, Google, BBC, Arsenal FC. Will be sending out Easy Read material for organisations to promote so people can sign up.

Theme is yet to be decided by the planning group but possibly related to employment or entertainment. Will leave it to Synergy members to decide. Please contact Jason or a Synergy member to discuss how you might support or be involved.

Jason: Concerns about CIL and Synergy's ability to input into groups and meetings.

Action: Poppy to liaise with Synergy and the responsible commissioner to see how best the issues can be fed back and resolved.

Topic for Next Meeting

- Film about hospital passports: Musa at Synergy is working on. Possibly invite Sara Pope from UCL who helped to create.
- Power cuts.
- Camden Housing Repairs Service: Synergy to contact them.
- Benefits for people with LD: Fear that some people with LD are being left behind as they are just outside the benefits system.
- Synergy and Camden Carers Family Reference Group: joint presentation?
- PBS Framework: subgroups – making them work again (Poppy).

List to go to Agenda Planning Group in 2 weeks' time.

A.O.B

Katy Anderson asked: 'is there a regular respite service separate to Breakaway?'

Andrew replied 'It's mainly Breakaway and we are privileged to have them. When we do look to see if we can find another provider who can offer regular short breaks, we have not been able to find one.'