



Carers And Parents of adults with learning disabilities in Enfield

Chair: Surojit Walawalkar
Vice-Chair / Secretary: Wendy Berry
Treasurer: John Berry
Administrator: Luan Malley

Community House
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Meeting: Monday 1st July 2019

At: Community House

Minutes

Chair: Surojit Walawalkar (SW), **Vice-chair:** Wendy Berry (WB), **Administrator:** Luan Malley - EDA (LM)

Members attended: 18

Guest Speakers: Geoff Lambrick: Head of Learning Disabilities Care Management
Charlotte Wilson: Learning Disabilities G.P. Liaison Nurse

Welcome: SW welcomed the members and guest speakers Geoff and Charlotte. After hearing from Geoff and Charlotte we will update members on the reports from the LDPB and Sub Committee meetings.

Welcome to our new members Roger and Victoria

Geoff Lambrick: Thanked the group for his invite. He informed the group he is retiring this Sept having working for 46 years in health and social care, which has been a great privilege and experience. He went on to explain his history starting his career in asylums to his role today. He explained the passion from the professionals he has worked with and how the service has gone from being ok ish to the best adult service in London. This has been measured by people living independently, being employed and reviews being carried out. One of his great pleasures was being able to meet family carers as previously this was not the case.

- It's been fantastic working together with CAPE. Responding to the feedback where issues were not great, from personal experience and trying to find ways to improve.
- Having worked with some of you closely on some challenging issues, there are still some unresolved e.g. NHS Continuing Health Care.
- The austerity that has been experienced over the last 7 – 8 years where LBE has lost 40% of government funding cut. To have managed to achieve what we have done as a service he feels proud to be a part of it.
- Interviews will be taking place next week. The new appointee will work with Geoff over the next three months mentoring, introducing to key people to try and minimise disruption of change.
- Geoff feels confident they have built up the service that is robust enough to cope with moving forward. The commitment to continue will be there.
- Geoff also informed the group Niel Niehorster is also retiring in November 2019. Vicky Main has been appointed. He updated the group on her background; she was previously Head of Older Peoples services in Enfield.

Geoff thanked CAPE for their contribution, which has enhanced his role and has been rewarding. Through the difficult financial times for the service, we have had our ups and downs which have been fine. He explained he has nothing but admiration for family carers, the dedication and commitment they give to family members is incredible, when considering lack of support trying to take on organisations and local authority.

SW: Praised the achievements Geoff and Niel have made while in post. They will be hard act to follow and hope the new appointees will be able to carry on the standards. How they have reached out to others and it's great the vision is still there. They have gained the Beacon award, and will hope the standards will be continued.

WB: Thanked Geoff and Niel as they have always being willing to communicate, listened and respecting our views. Having had access through the partnership board and sub-committee groups we have access to you which we would like to obtain.



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Question: Do you think the new appointee will be able to adapt, having come from a culture that used to be in Enfield, which is not the same now?

GL: Yes having worked with Vicky previously. In terms with working with staff she is very committed to being open and autocratic, and is committed to ensuring the services are the best they can be.

SW: Having built a strong foundation we as CAPE will try and make sure there is a smooth transition.

SW: Thanked Geoff and introduced Charlotte the LD GP Liaison Nurse, who oversees the implementation of the annual G.P. Health Checks for people with learning disabilities

Charlotte Wilson: Thanked the group for inviting her. She went on to explain that she went to university and qualified as a nurse, after service in the public sector, working with housing, street homeless and domestic violence. She has worked with clients with mental health, disabilities, alcohol and drug use. Her practice has always been not to argue, we work with respect and dignity. She has also taken her experience and gained more, not just working in the UK but internationally.

- Now liaising with GPs, which has been a challenge? It was assumed Charlotte was a medical rep so a lot of doors were closed. She did not give up, and then went to the PLT (Protected Learning Time for GPs) sessions to inform GPs. Initially they said they did not have time to do the annual LD Health Checks. Email then sent via CCG to acknowledge. Gradually practice managers and doctors came round to listening.
- The old Cardiff templates were being used along with another 2 page document. The national LD template should be used which is 4 pages long. This covers head to toe and should take around an hour to complete. Charlotte reiterated time needs to be made to complete these.
- Audits were completed and Charlotte offered support to get all registered LD clients health checks completed. Not all parents, carers are aware these are available and are completed on an annual basis.
- A health check is extremely thorough. Weight, height, blood pressure, eyes, teeth, hearing swallowing, cardio, urine system, bowels, feet then also check for screening, flu jabs. Any referral that needs to be made, the GP needs to do them straight away. Also there is a section on, sexual advice and end of life.
- Discussed with GP's their communication skills due to language being too high and is required to become softer. The index needs to be brought down. They need to engage with the client and minimise the time e.g. while taking blood pressure at the same time asking other questions.
- Charlotte supports GP's to encourage reasonable adjustments. If a person cannot go to the GP a home visit will be requested. CW will also attend to enable the form to be completed. The carer should be ready and prepare the person. She will take bloods with additional work like desensitisation and give the person the time. We do not want to traumatise the client as we need to achieve the outcome. Important to have a good experience.
- The assessments start from the age of 14.
- The GPs need to understand LD and listen to carers. CW working with GPs around this.

Question: Do the GPs get additional funding for these assessments and is the screening carried out straight away?

Answer: Yes £140-150 per check. These need to be completed correctly. Screening when entitled, they will receive a letter (not easy read) another area we are working on. Appointment will be made.

Some cases discussed: CW to meet with professional to discuss the best interests. Vaccinations (cervical cancer) discussed this has not been offered at this point. This will be up for discussion through the CCG.

- The form does not save. CW advised bloods to be taken two weeks prior to the appointment. The two different forms were explained both 2 and 4 page. GPs have been using the incorrect forms.
- A parent has been waiting 1 ½ years for an RA appointment with the ENT dept, being pushed down the list due to the appointment requiring more time, and concerned for future referral that require an RA appointment. CW advised to let her know to enable her to liaise with the hospital



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- GP should be writing to invite the client for the medical assessment. They have designed an easy read letter for GPs to send out. When you receive the letter then you need to collect a blood form. Contact GP liaison nurse to discuss. Home visits can be arranged under RA and the procedure explained.

SW: Explained the reason we invited CW was to explain and update us. She is trying to improve on the horror stories you have mentioned. There is another aspect some GPs are better with LD than others. A list is available, CAPE will try and get this as NHS cannot recommend.

Feedback from the group: Vouch for CW provides the best experience and her son is always asking for her. Can the form be sent to the group for a better understanding and ensure things are being skipped? CW said she will forward it. GPs can do it on line. Do neighbouring boroughs have the same service? CW advised to contact the Cumberland Road in Haringey to ask for the GP liaison office in the safe guarding team.

- We have monitored the assessments over the last year and there has been an increase. 1st Quarter, 65; second Quarter, 125; third quarter, 149; fourth quarter, not yet known.
- GP same day appointments. If none need to go to a hub (but no Reasonable Adjustments taken into consideration) and asked has this been raised? CW to raise.

Break

Learning Disabilities Partnership Board (LDPB) - SW: The last LDPB meeting was held on the 20th May. The main concerns are the changes that are happening at a senior level, with both Geoff Lambrick and Niel Niehorster retiring in the next few months. We wanted reassurance from LBE it would not upset the delicate balance of what we have achieved. The director of Adult Social Care, Bindi Nagra attended the LDPB. He gave us a warm assurance all that has been set up will continue. The work that CAPE has completed will be honored. We will engage with the new appointees asap, as we do not want to lose the traction we have achieved after 12 years. There is a lack of L.A. councillors involved in the board, but we are hopeful that new members will be attending future meetings. Alev Cazimoglu, the Enfield Cabinet member for ASC, is still continuing to monitor the board.

Healthwatch held a consultation and event to understand any issues with the NHS Continuing Health Care (CHC) service. This is on CAPE's radar, as a number of people with L.D. are affected by this.

ASC Learning Disabilities Service (ILDS) Finance: Last year there was a deficit in the budget by £720, 000 against a 5 million budget.

Health Sub Group: Soobhash Ramphul, Enfield's L.D. Community Nurse Team Leader, sadly passed away, he will be greatly missed. Priscilla Surfraz has taken over.

Disability Related Expenses (DRE) Group and Charging Reference Group (CRG)- WB: A few weeks ago you will have received the contribution letter from the financial assessment team. The DRE group has been working on this (18 months prior) to try to improve the process and make it fairer. The new letters have the breakdown enclosed, new DRE guidance and application form. The allowance levels were explained along with receipts. The bad news is that the charging department does not appear to have fully taken these changes on board. We are hearing from CAB and EDA that expenditure amounts are being knocked back, so there are still issues for us to address. The local authority tried to stop the DRE group, due to its work in this area being completed. Group members, particularly carers and voluntary sector reps, want to carry on and broaden the remit. Therefore, we are no longer called the DRE Group. We are now called Charging Reference Group (CRG). This broadens the charging issues we can raise. We will wait six months from the last DRE meeting to feedback on if the new assessments and DRE were working. First meeting of the CRG is on the 25th July. Fay Hammond, Enfield's Executive Director of Resources, who reports directly to Enfield's Chief Executive, will



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chair the initial meeting of this group. We are going to ensure the agenda addresses our issues. Any problems with financial assessments let Bernadette, Jane or Wendy (or EDA, CAB, Enfield Carers Centre or Enfield Connections) know, to enable them to feedback.

Also DWP have made an error nationally, by assessing people for the wrong type of ESA. Therefore, people did not receive the Enhanced Disability Premium, and also lost entitlement to a number of other things (free dental care, etc.). People are being reimbursed for the loss of the ESA payments, some going back many years. This may affect the social charging. This is now being looked into. We shall keep you informed.

Next meeting: Monday 12th August 2019, 7pm-9pm., Community House, Edmonton.
Guest Speaker: Niel Niehorster

If you have questions please contact Luan Malley at EDA on 020 8373 6228 or CAPE@e-d-a.org.uk