



Carers And Parents of adults with learning disabilities in Enfield

Community House
311 Fore Street
Edmonton
N9 0PZ

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

Tel: 020 8373 6228
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Minutes

Meeting: Monday 10th February 2020, 10.00 a.m.
Location: Park Avenue Disability Resource Centre.
Present: Board members: Chair -Surojit Walawalkar (SW), Vice-Chair- Wendy Berry (WB), Jane Richards (JR), John Berry (JB) and Bernadette Reigar (BR). Minute Taker - Luan Malley (LM) from EDA.
Members attended: 31

AGENDA	
1	Welcome & Apologies
	<p>WB welcomed the members to the new venue, and said how nice it was to see so many carers attending. Apologies from Jackie, & Vic Moore and Roger Hill. LM informed the group of the house keeping. SW welcomed the new faces and spoke of the history of CAPE, what we do, how CAPE is involved in meetings with London Borough of Enfield and Health, plus how they have been successful with challenging recent charging and transport proposals. We invite members of the Local Authority (LA) and other organizations to speak at our meetings. CAPE board members represent carers on the Learning Disability (LD) Partnership Board and its sub groups. Minutes of these meetings are published on Enfield's my life website. CAPE is also represented in many other forums, and JR takes a leading role in events connected with transition and 'Moving On', via her Carer 2 Carer group.</p> <ul style="list-style-type: none"> • WB spoke to the group how CAPE has helped her, when she first joined the group nearly 20 years ago, and how members all support each other. • SW updated the group on the new website:www.cape-ld.org. • BR explained her story around CAPE. Informally there are people to discuss issues/ concerns around care planning, and charges etc. On the formal side, the group has a much respected role in committees at the Local Authority and in Health. CAPE has been influential in informing the LA on things related to those for whom we care, and to make positive changes. • WB informed the group that CAPE is now formally constituted as an independent organisation. We receive funding from Enfield Disability Action as part of their Enfield Advocacy Service, grant funded by the Local Authority to deliver advocacy services. CAPE is funded to deliver peer advocacy to L.D. carers. This funding pays for room rental, administration, reference materials, website set-up and maintenance, etc. All CAPE committee members work in a voluntary capacity and take no payment. CAPE is now a member of the Disability Rights UK; they produce a book entitled the Disability Rights Handbook, which contains masses of useful information, particularly about benefits. All committee members have a copy, so if you have any questions, please ask. • CAPE funding has also enabled us to purchase a book entitled Community Care and the Law. This has been written by Professor Luke Clements and is the definitive legal reference for all matters relating to Adult Social Care and the 2014 Care Act. This has helped us to challenge many issues. • WB informed the group than JR, BR and herself also sit (as carer representatives) on a group called the Charging Reference Group. This has been set up to meet regularly with officers and advice providers. It monitors Enfield's policies and processes for charging for Adult Social Care, and ensures that they are fair and lawful.





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2	Guest Speaker: Sarah Carney (SC) from Independence and Wellbeing Enfield (IWE)
	<ul style="list-style-type: none">• WB introduced Sarah Carney, who is Wellbeing Service Manager with IWE.• SC apologised for being a little late and thanked the group for the invitation.• IWE is a trading company which was set up 3 years ago by the LA. The aim was to develop new services and ensure that existing services would continue. This has been successful.• A recent cabinet ruling has now been passed which will bring the IWE services back in-house, and under the direct control of the LA. All staff will be TUPE'd across to the LA during April and May.• Nothing will change for the service users. The services will stay the same, along with the transport.• The IWE LD day services e.g. Community Link Edmonton & Enfield, New Options and Formont, will be part of this process.• Another part of IWE is their outreach service, which covers enablement. This will continue to be operated by the LA. This also includes services for those being discharged from hospital, and the provision of any equipment from beds to frames (via the hospital).• IWE operates Enfield's Shopmobility for services which enable disabled people to hire out a scooter for shopping.• IWE operate the Inclusive cycling scheme at Bush Hill Park. This must be pre-booked and it is very popular. It is closed during January and February.• Community Link (Edmonton) members have worked hard with colleges and are developing NVQ level 2 life skills courses.• Formont is aiming to extend the opening hours of the sensory pool (Sundays / evenings). They are currently advertising for a caretaker to cover these periods.• The Formont pool is not classified as a hydro pool. It's a sensory, heated pool. Information has been circulated to CAPE members about the pool, facilities and the benefits.• The Formont sensory room and wellbeing room can also be booked out. Park Avenue Hall is also available to hire.• Prices are on the website. Check for group bookings as this works out cheaper.• Payments: IWE accept cheques, cash and cards. Payments can be made on line.<ul style="list-style-type: none">○ It was discussed if Direct Payments can or cannot be used for IWE services once they have moved back in-house. IWE cannot confirm, and this will be addressed during the transition period.• If you wish to use any of the IWE services, you can make a case to the social worker to add it to the client's care & support plan, and included in the personal budget. For e.g. the use of the pool could enhance wellbeing by helping with pain management, obesity, muscle spasms and challenging behaviour.• It was discussed if service users could pay on a sessional basis just for the class they wish to do e.g. cooking, rather than having to pay for ½ a day or a whole day.<ul style="list-style-type: none">○ IWE will be looking into this, as parents and services are requesting this.○ JR explained personalization is to enable the individual to have choice and control over the way they want to live and use their personal budget.• Park Avenue is not counted as a day service it is a community resource centre and anyone with a disability can attend.



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	<ul style="list-style-type: none"> • On a Thursday evening (7pm -9pm, 50p entrance) There is an adults LD club, at Park Avenue which was taken over from Mencap. It is run by volunteers. • Parents and carers can contact Sarah her email address is sarah.carney@iwenfield.gov.uk or contact her directly. Sarah has broken down the costs for services for personal budgets and Direct Payments. • JR advised to get as much detail as possible in the care & support plan, about the services you wish to purchase with a Direct Payment. • SW thanked Sarah for attending.
	<p>Meetings</p>
	<ul style="list-style-type: none"> • SW informed the group Niel Niehorster and Geoff Lambrick have retired. Vicky Main has taken Niel's role as head of the Integrated Learning Disabilities Service (ILDS). She will be attending the next meeting and SW urged people to attend. Trevor Uys has taken over from Geoff Lambrick. • WB asked if members had received a letter from the LA regarding a possible refund of social care charges. This applies to some people who were switched from Incapacity Benefit to Employment Support Allowance (around 2012). Thousands of people were put onto the wrong level of benefit, and missed out on the premiums to which they were entitled. In 2018, the DWP admitted their mistake and have been making back payments of around £5,000 - £7,000 to service users who were affected. If you have received a refund from the DWP, you may have been overcharged for your social care. You need to inform the LA they will apply a refund if applicable. WB urged all who received the LAs letter to respond, if they also received a refund from the DWP. • Blue Badges <ul style="list-style-type: none"> ○ Qualification is automatic when in receipt of higher rate mobility component of DLA. ○ If you receive PIP, you will NOT automatically qualify if in receipt of the higher rate mobility component. <ul style="list-style-type: none"> ▪ You will now require 8 points or more in "physical being able to move around" category. ○ You may also qualify under Hidden Disabilities criteria. This has to be handled through LA's Concessionary Travel team (CT). We have worked hard with them to try to explain what hidden disabilities, LD and challenging behaviours are. ○ CT has said they will link in with ILDS and the social workers. ○ You may have to get social workers to help with contacting CT. ○ Disability Rights Handbook confirmed the qualification for a Blue Badge. • Disability Freedom Pass <ul style="list-style-type: none"> ○ Similar issues to the above ○ If your family member is known to ILDS team they will qualify. ○ JR is meeting with David Wearing from CT, and ILDS management next week. • NHS Continuing Health Care (CHC) <ul style="list-style-type: none"> ○ Both Health and the LA are trying to save money. People are being passed from Adult Social Care to NHS CHC, and then possibly back again! ○ Service users may be asked to have an assessment to transfer over to CHC funding. This can be a lengthy and complex process. CAPE members have a lot of experience in this.





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	<ul style="list-style-type: none"> • DAZU <ul style="list-style-type: none"> ○ A service mainly used by children and also used for transition age ○ The group was informed this service has been suspended due to ongoing investigation.
4	AOB
	<ul style="list-style-type: none"> • SW updated the group on the website, and links to Facebook and Twitter. We would like the group to give feedback etc. We would like to use the website as live communication. • Some members had had difficulty opening the CAPE agenda document. LM agreed to investigate and send out as a Word Document. • WB advised the people who would like to make a case to add something to their Personal Budget e.g. swimming, - point the social worker to the Care Act assessment criteria (there are 10). One of these states 'making use of necessary facilities or services in the local community including transport and recreational facilities'. This would not only apply to day services, it should also include evening and weekend activities, if desired. • JR explained to the group that any agencies or domiciliary care services, purchased using a Direct Payment must be CQC registered. CQC registration is a legal requirement for these services. Also, any independent PAs must be employed by the service user or their appointee – they cannot just be paid a cash amount. DPs MUST be used to purchase services in a LAWFUL manner! If carers are in any doubt as to the way that can use a DP, they must check with ILDS. A Direct Payments Guide is available, which lists everything you need to know – please ask for a copy. • We should like to discuss housing in a future meeting. BR and JR have been invited to go and view new LD housing developments, as CAPE is concerned that some of these are looking more like care homes or institutions. We should be grateful for any members' feedback on housing issues. We can then take these forward.
5	Date of next meeting
	<p>Our next meeting is Monday 20th April 10am to 12pm At Park Avenue Disability Resource Centre. Our Guest Speaker will be Vicky Main, Head of the Integrated Learning Disabilities Service (ILDS).</p> <p>Please join us – we shall now be meeting in the Main Hall – so there should be more room!</p>