Hampshire Carers Partnership & Learning Disability Partnership

Carers LD Working Group Meeting

Date: 23rd July 2024

Time: 2.00 – 4.00pm

Method: Zoom

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| **Attendees** | 10 |
| **Visitor** | |
|  | 1 |
| **Apologies** | |
|  | 8 |

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| **1.0** | **Welcome/Apologies/Introductions**  Introductions were made.  **Conflicts of Interest** – none declared.  There was a suggestion that an ICB rep be invited to these meetings  Action 1.1: Jo and AL to liaise on a rep and contact details | JH/AL |
| **2.0** | **AHC Update - JN** – see Appendix 1    *Available on request for members* |  |
| **3.0** | **Actions and Feedback from last meeting –** If no update, action has been achieved. See summary of actions on page 5.   * DH has asked for comms about Linden Farm Model/HALO to be copied into JH. * Re CASCAIDr - No new barrister reports yet, but CASCAIDr has been relaunched as a CIC [New life for CASCAIDr | Industry News | Independent Living](https://www.independentliving.co.uk/industry-news/new-life-for-cascaidr/) * AL will obtain more information about how members can be involved in consultations and pilots – AL has been in touch with AG [Health Facilitation :: Southern Health NHS Foundation Trust](https://www.southernhealth.nhs.uk/our-services/learning-disability-services/381/health-facilitation) * AL has provided links to Complex Needs Meeting notes: [Complex Needs Minutes - Hampshire Learning Disability Partnership (hldp.org.uk)](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fhldp.org.uk%2Fworking-groups%2Fcomplex-needs%2Fminutes%2F&data=05%7C02%7Cjo.hooper%40carerstogether.org.uk%7C1d5ba14d4f084a7c306308dcaff32cc8%7C602eec4992fa44fab8ae7f2e5ab763bb%7C0%7C0%7C638578706159273516%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=h9lXzu%2Fn6O9p5QYzsZYKYt20F1qR7CGe%2BP5O5mYFzyo%3D&reserved=0)   She has also provided this additional links:  [Carers Group (HLDP) Minutes - Hampshire Learning Disability Partnership](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fhldp.org.uk%2Fworking-groups%2Fcarers-ld%2Fminutes%2F&data=05%7C02%7Cjo.hooper%40carerstogether.org.uk%7C1d5ba14d4f084a7c306308dcaff32cc8%7C602eec4992fa44fab8ae7f2e5ab763bb%7C0%7C0%7C638578706159284008%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=huU5UrqIAWnpdM6iTt2smPIyN5JAw5ZM3zZwsPD%2Fg58%3D&reserved=0) These are also on the LDP website.   * The last LDPB meeting was cancelled. The next one is 25th September, at 10.00-12.30, on Teams. DH is unable to attend, but if any carers would like to attend in his place, let DH know.     Following this item JN was thanked and he left the meeting. |  |
| **4.0** | **Carers’ Views/Co-Production:**   * *What you feel the impact that the carers subgroup and working groups have on services that are delivered in Hampshire for unpaid carers* * *Your experience of working with Hampshire Adult services in this role*   JH gave some context – these are questions are posed by AHC, and carers’ responses can contribute to AHC’s CQC evidence of co-production. These questions have previously been circulated to carers, but to date, no responses have been received.  DH commented that this is a good co-production framework, in terms of the existing groups and information passed to carers, he feels it gives carers a voice and an opinion, his concern is he is not sure the views are impactful.  SE agreed. She feels there is a lack of continuity for carers as staff change so often and it feels like they sometimes keep reinventing the wheel. She acknowledged that the resources are extremely limited; respite has been an issue which is being raised many times**,** but nothing seems to change. MW also agreed and feels the same about the Hampshire Autism Board. She is concerned that staff who can provide a corporate memory are being lost to the organisation, and this, and the lack of money could make things deteriorate.  JL feels very positive about being in the group but asked if the reach is wide enough. The group definitely gives potential to influence but we don't know how many carers there are**,** and this is a small group; it would be good to get as many views as possible. Some carers are still mourning the loss of the LIGs.  There was an acknowledgement that despite this being a small group the groups that SE, AM and others have with carers is extensive. DH felt this was a good point but added that although the carer groups are great, they seem to have similar membership. The HALO group which DH attends is bigger but members can't attend other meetings as it interferes with their working day. DH shares the frustration around the provision of respite services.  AL reported that all the minutes to these meetings will be uploaded to the Learning Disability Partnership website in August. She would welcome any suggestions or ideas to add to the website and any that can be shared on Facebook.  There was a general acknowledgement that carers at this meeting do a lot to promote these meetings but new people don't seem to be willing to attend.  JL suggested maybe collecting evidence about the things that carers have raised and how these have been addressed, i.e**.** “you said, we did....”  MW reflected that in some instances it appears that senior managers are realising that views of carers are relevant and make sense, and this is what co-production is all about. She added that JB, when he previously worked for HCC, did listen to people about autism.  PH has recently been working with BS, and his experience of co-production in the social work training has been very positive. Social workers when working with anonymised case studies, have been creative and PH has received some very positive comments back. He has also seen the recent email on safeguarding and seeking carers views with lived experience.  Action 4.1: JH to summarise carers thoughts and send a response to JW | JH |
| **5.0** | **Updates:**  **Complex Needs Group** -TS Transition Manager for the ICB, talked about her role to increase annual health checks for people with learning disabilities. Also, the programme providing communication boxes in GP surgeries; 95% of surgeries have these boxes which are there to help those with autism and those with learning disabilities. Some members have already seen these boxes. TS also wants to get them into acute hospital wards.  Action 5.1: AL to share a slide on what is in the box.    There was feedback around two areas of concern: constipation and dental health checks. There are also concerns about the big increase in upfront cost of Motability cars.  Action 5.2: AL will share the Respect forms (see below) so that carers can see what they look like and the difference between these and DNRs (Do Not Resuscitate.)  The Respect Form (Hampshire Hospitals):  [ReSPECT :: Hampshire Hospitals](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.hampshirehospitals.nhs.uk%2Fpatients-visitors%2Frespect%23%3A~%3Atext%3DIt%2520is%2520recorded%2520in%2520brief%2Cthat%2520they%2520would%2520not%2520want.&data=05%7C02%7Cjo.hooper%40carerstogether.org.uk%7C1d5ba14d4f084a7c306308dcaff32cc8%7C602eec4992fa44fab8ae7f2e5ab763bb%7C0%7C0%7C638578706159291464%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=pnuigagRvmt3uZ88A2xDpF0HO1PmtSZB%2B9KtaR4DcpI%3D&reserved=0)  And Frimley for the North of the County:  [ReSPECT | Frimley Health and Care](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Ffrimleyhealthandcare.org.uk%2Fprofessional-resources%2Frespect%2F&data=05%7C02%7Cjo.hooper%40carerstogether.org.uk%7C1d5ba14d4f084a7c306308dcaff32cc8%7C602eec4992fa44fab8ae7f2e5ab763bb%7C0%7C0%7C638578706159298282%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=s2fQQcfKdyRjfDVZdyuEdkuMYr%2FFVQSPNQgUCgiXbfA%3D&reserved=0)  **Communications group** - AL talked about co-production. She has worked with three self-advocates to put together a video to talk about co-production and the new front door CART team, which includes a new message being developed for when people ring into CART, this will be a much shorter message and helps to get people into the right queue quickly. Safeguarding will be first option in the message. AL offered self-advocates could attend a future meeting if this is something that members would like.  Action 5.3: JH resend the email re care needs checker to all members. | *Achieved*  *Achieved*  JH |
| **6.0** | **New Information:**   * **Accessibility:** DH is working together with the organisers of the Victorious Festival in Portsmouth (this is in his paid role, as CEO of Shaping Portsmouth.) He is focusing on accessibility and use of the Access card. Accessibility is usually largely geared towards use of wheelchairs and physical disability access but DH is helping them to consider a carer's perspective of a person with the learning disability, and a family perspective, suggesting social stories.   DH gave some examples of the types of things that they are focusing on improving including disabled parking, adults changing facilities and a chillout area. The festival will honour the Access card for a person with two carers. Fareham Live also honour Access cards for more than one carer.  Action 6.1: DH asked that if anyone is going to attend the festival, please let him know.  JS has previously used the Access card for entrance to Legoland, Chessington and with the Merlin card you can queue jump. DH has also had positive experiences of using the Access card.  PH talked about a very positive experience had by his son, who has a learning disability, and his very pregnant daughter who went together to see Take That at St Mary's Stadium, Southampton, recently. They had a fantastic experience and were treated very well. DH added that he took his son to the O2 arena for a concert**,** and they couldn't do enough for them. DH, PH and JS have also been to the Abba experience which they said was also fantastic.   * **Fab and financial assessments**. JL reported that she could find very little information about financial assessments and contributions on the HCC website, DH agreed. DH talked about the financial assessment online portal**,** which is proving to be very challenging for carers: they don't know what information is coming up next and what they will be asked for, and it is not clear where they record the relevant information, this means often people are coming out with very high contributions. Members felt that older adults and people with a learning disability should be treated differently, for financial assessments. * **Blue Badge application:** JS talked about her new application for a Blue Badge: she had a 50-minute Zoom meeting with them to talk about the PIP section on the application form, to make the application easier, whilst still reducing fraud. * **PHBs:** The ICB are now paying personal health budgets every month not every four weeks**,** but they forgot to tell people! | All |
|  | **AOB:** None |  |
|  | **Date of next Meeting:** Tuesday 3rd September, 2.00 – 4.00pm |  |

See below for Action Summary

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| **No.** | **Ref** | **Actions from previous meeting** |  |
| 1 |  | *JL to send a copy of the Dimensions Induction Plan for circulation* – JN to follow up. | JN |
| 2 |  | The last LDPB meeting was cancelled. The next one is 25th September, at 10.00-12.30, on Teams. DH is unable to attend, but if any carers would like to attend in his place, let DH know. | All |
| 3 |  | AL will ask AC if there could be more preparation time, so that members can see what is being reported to the LDPB, in advance of the meeting. | AL |
| 4 |  | JH to invite Mandy to a future meeting to talk about Shared Lives review. | *Achieved* |
|  |  | **Updates/Actions from 23rd July 2024** |  |
| 5 | 1.1 | JH and AL to liaise on an ICB rep and contact details | AL/  JH |
| 6 | 2.1 | JH to invite JN Brandon to a future meeting. | JH |
| 7 | 2.2 | JN to feedback any further information on Purple Oaks at future meetings. | JN |
| 8 | 2.3 | SE and JS have recently been to a party with their son/daughter, where they observed some very concerning behaviour by paid carers with service users.  JS and SE to put their concerns in an email and send to JN. | SE/  JS |
| 9 | 4.1 | JH to summarise carers thoughts on co-production and send a response to JW | JH |
| 10 | 5.1 | AL to share a slide on what is in the boxes in GP Practices (see above). | *Achieved* |
| 11 | 5.2 | AL will share the Respect forms (see above) so that carers can see what they look like and the difference between these and DNRs (Do Not Resuscitate.) | *Achieved* |
| 12 | 5.3 | JH resend the email re care needs checker to all members. | JH |
| 13 | 6.1 | DH asked that if anyone is going to attend the Victorious Festival, please let him know. | All |