



Lancashire Learning Disability Partnership Board



Notes from the Profound Intellectual and Multiple Disability Meeting

**Thursday 15th December 2016
10am-1pm
County Hall, Pitt Street,
Preston in Room B02**

| | What we talked about |
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|  | <p>David welcomed members to the meeting and a round of introductions was made.</p> <p>Natalie took the minutes. Thank you everyone for a really great and productive meeting.</p> <p>An opening round question was asked:</p> <p>What do you like from Santa & why?</p> <p>Richard Woods David Wood James Hughes Amanda Topps David Grundy Sharon Whitecross Holly Phillips Lisa Fitzsimmons Mark Hampson Chris Robinson Natalie Vranjes</p> |



Apologies

David Barton
Anne Wallis
Julie Ray
Lynette A
Pete Crane



Notes and Actions from the Last Meeting held on 27/10/2016

Lisa told us that Beth has been busy but will set up a meeting for the Information Task Group in January.

Amanda and David need to ask Charlotte H when they can go to County Hall to train the social work staff in PIMD.

Glenn Harrison is no longer involved in Transforming Care a lady called Joanne Greenwood has taken over so Amanda can share the Communication Checklist with her, Sally Nightingale and Maria Howard.

We have had one family carer interested in supporting the group with the PIMD training. A woman called Margaret who has a brother who uses services and Margaret used to work in health services herself.

Lisa is also interested in helping the PIMD Training. Having a provider angle will be really helpful because doctors and nurses have to work with support workers and providers all the time.

Action: Amanda to ask all family carers in the network if they want to join in supporting roll out



the training across Lancashire and further.

Action: Lisa to send evaluation form which the team and James can use to ask for feedback about their courses.

This is important because it will then give us feedback we can use to get funding or to persuade medical establishments that they need our training.



Bill has been asked to do a PIMD page on the Partnership Board website.

Lisa found out from some self-advocates who have used the Advocacy service that Advocacy Focus have been providing non-instructed advocacy.

We will send some questions to Kieran Curran who reviews the advocacy services contract.

We want to know if the Advocacy Service has an easy read leaflet which mentions how to access non-instructed advocacy.

We want to know who advocacy services refer people to if they cannot provide a service themselves. For example, do they refer to Citizens Advice?

Julie had provided some information from a colleague about how people can get support to pay their Personal Assistant's their pension.

See document attached to the minutes.

Who is checking that people with PIMD are being offered Care Act Advocacy? This is advocacy the Care Act says you can get when you have a social

care assessment.

We need to ask Kieran Curran and or Charlotte Hammond.

Action: Lisa to find out who advocacy services refer people to if they are turning them down for their own service.

The group wanted to make sure people are being signposted for support.

The question about are people expected to fund pension payments out of their existing budget or Direct Payment has not been answered. We need to find out who to ask this question.

A member of the group had contacted someone at LCC and provided this information about budgets.

The action was to find out who may be able to get this information for the group and for the public.



Are people expected to fund the payment for the pension out of the existing direct payment or are Lancashire County Council going to add the extra funding needed to the direct payment?

"On the letters their employers have received from the Pensions Regulator there will be specified a staging date and this is the date they need to give to Cheshire Centre For Independent Living as they provide the payroll service and will make sure that pension deductions are entered onto payslips.

We also have Lancashire Centre for Independent Living who provide employment advice and they are really helpful. So if anyone has any queries they can be contacted on 01772 558863. They will give the

advice about what Pension companies can be used and options if anyone wants to opt out. Really I would advise that the employer makes contact with them and obtains the advice for the Personal Assistants (PAs).

If anyone wants to take out a pension the contributions will be debited out of their wages the same way as tax and NI contribution are paid.

The PA's will make a decision if they want to contribute towards a pension or opt out, if they decide to take out a pension they will contribute out of their wages and contributions will be deducted from gross pay. The carers will just need to ensure they are paying the net amount on the payslip.

The best place to discuss this is with Lancashire Centre for Independent Living, called LILS for short!

If there are any employers liabilities LILS will advise, but all carers should have a "buffer" of funds but LILS have a calculator they use and this calculates they will have sufficient to cover all costs, holiday pay, expenses, NI contributions, so they could always ask for a visit for LILS to go through everything.

Members of the group observed that this had not totally answered the question about extra monies going into direct payments to cover the extra cost.

Action: To find out who can answer this question at LCC. Could be Tony Pounder or County Councillor Tony Martin?



Holly said that there is now an LD Liaison Nurse at the Royal Lancaster Infirmary (RLI). Morecambe Bay have also recruited one LD nurse on the surgical ward in Barrow and one at the RLI in Lancaster.

Action: Amanda to find out who this person is. Holly will ask too.



We discussed that GPs also need equipment so that people can access check-ups, be comfortable during physical examinations and get their weight checked etc.

We would like some good practice examples to share with GPs and other health professionals.

Holly had a good example about the dentist.

Lisa had a good example too.

Action: Holly and Lisa to ask for permission to share stories and write them up as a good practice story with details about why it was a good appointment before the next meeting.

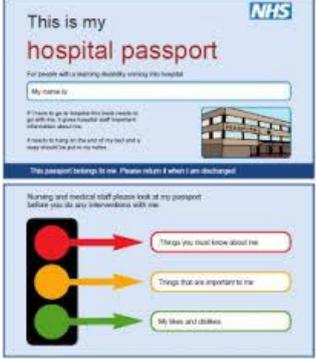
We can then include these stories in our PIMD Training too when we share about reasonable adjustments.

We talked about needing a 'baseline' for people with PIMD. This is so that people supporting someone can know when their health is not right. For example around blood pressure or special feeding regimes.

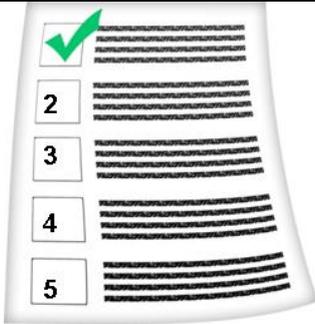
Lisa highlighted that she thinks that some practice around medical interventions for people with PIMD does not suit their needs and needs to be more

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| | <p>flexible.</p> <p>Holly said we could do a campaign around this. To do this we will need more stories about health care practices which we think do not fully support someone's health or recovery.</p> <p>We started talking about doctors who do home visits. This can make the check up so much easier for everyone and more comfortable and dignified for the person with PIMD.</p> <p>More information can be shared because it is to hand at the person's house so the support or parent can check.</p> <p>Everyone is less stressed and more comfortable.</p> <p>Someone asked if we could get involved with CQC by our family members being Experts by Experience.</p> |
|  | <p>Lancashire PIMD Proposed Action Plan 2016 – 2020</p> <p>(i) Discuss Proposed Plan We looked at the Health and Education sections of the plan.</p> <p>(ii) Make amendments, agree plan We added some sections to the plan. See attached.</p> <p>(iii) Set target dates and people responsible for actions We agreed some actions and timescales.</p> <p>(iv) Agree presentation team to take plan to the</p> |

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| | <p>Lancashire LDPB</p> <p>To be done when the plan is finished. We need to continue to check the plan at the next meeting.</p> |
|  | <p>We talked about Education. Lancashire Adult Learning has changed and is not offering many courses at all for people with PIMD.</p> <p>Amanda said the WEA had approached her to see if we need any courses in Lancashire. They can provide the tutor and we can support finding a local venue. They would need 10-12 people minimum to take part for the funding requirements.</p> <p>We can help by giving them information about accessible venues. We said it would be ideal if we can offer venues with Changing Places and parking.</p> <p>We discussed what we need in Lancashire.</p> <p>This was our list of ideas. The top two ideas we want to pursue as a pilot with WEA to see if it will work:</p> |
|  | <p>An interactive music art and drama sensory session involving installation art and a sensory environment called 'Involve Me 2'.</p> <p>This was our favourite idea. We would like it to be a year long course and involve technology.</p> |

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|  | <p>Intensive Interaction</p> <p>We think this course could run over 6-8 sessions for a maximum of 2 hours each session. It should involve support workers and the person they are supporting.</p> |
|  | <p>Communication Passports</p> <p>We think this could last one to two terms and run over 12-15 weeks. It should include a review of the communication passport in a later session.</p> |
|  | <p>Basic Cooking – a cook and eat sensory session</p> |
|  | <p>Drama including bag books and stories</p> |
|  | <p>Hospital and Health Passport</p> <p>8-16 weeks course with equipment so people can see what is involved in hospital visits. Use YouTube clips to help familiarisation when going to doctors or dentist. Think about graded exposure, which means taking time to visit the surgery, find out which room the appointment will be in. Look at the equipment used, etc.</p> |

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|  | <p>Makaton</p> |
|  | <p>Hair and Beauty Therapy</p> |
|  | <p>Animal Care</p> |
|  | <p>We came up with ideas for education course venues:</p> <p>Clayton Green Sport Centre</p> <p>Morecambe Disability Day Service</p> <p>Evergreen Children's Day Service</p> <p>Cornerstones in Lancaster</p> <p>Wyre Disability Day Service</p> <p>Fylde Disability Day Service – the training rooms cost £12 per session.</p> <p>White Cross Mill 14 owned by LCC</p> <p>Plungington Centre</p> |



Action: Lisa and her colleague will put together a proposal for the training.

Action: Amanda to find out what outcomes does the funding measure? Is there a limit to the length of a course?

Can we use the model of family carer or paid supporter and self-advocate attending the training together?

Action: Amanda to send to LD Health Teams for ideas and to ask who would be interested.

We thought it would be good to share positive health stories in the GP newsletters so we need to get stories together with good and bad experiences.

Amanda said Healthwatch have published their Specialist Dentist Report.

Action: Amanda to forward the report to the group.



We said that for some people support staff, family carers and medical staff need a baseline. This means we know what people are like when they are well so we can tell when their health is starting to deteriorate but they cannot tell us.

It would be like a list of things to look out for and should be in the health action plan or the person's health or hospital passport.

It could include person centred information like blood pressure and feeding regimes, dietician's advice, etc.

We wanted to find out how family carers can get

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| | <p>involved in improving GP and hospital services.</p> <p>Currently, they can get involved in the surgeries in Patient Participation Group, with the CCB Listening groups and with PALS in the hospitals or equivalent.</p> <p>We need to have good relationships with the LD Liaison Nurses in all the hospitals.</p> <p>Julie Clift works in the East Lancashire hospital trust.</p> <p>Stephanie Iaconianni works in the Lancashire Teaching Hospitals Trust.</p> <p>We think there should be a flag on hospital computer systems to show someone has PIMD.</p> |
|  | <p>Health – let's talk about health priorities for the Health sub group</p> <p>We decided we would use the priorities on the action plan.</p> <p>We added some extra ideas and actions.</p> <p>We want group members to think about this before the next meeting and bring any more ideas to the meeting.</p> |
|  | <p>Any Other Business</p> |

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|  | <p>Closing Round People enjoyed the meeting and thought a lot of good work had been done.</p> <p>We think we have some good actions and a good approach to help improve health services using the PIMD training and getting more family carers involved.</p> |
|  | <p>Date of next meeting</p> <p>Thursday 2 February 10-1 in room B02 County Hall, Pitt Street, Preston</p> |
|  | <p>Meetings for 2017</p> <p>Themed Meetings in line with PIMD Plan</p> <p>All on Thursdays from 10-1 in A06 at County Hall in Preston on:</p> <p>30 March</p> <p>25 May</p> <p>20 July</p> <p>14 September</p> <p>9 November</p> |



Partnership Board website:

www.ldpb.org