



## Lancashire Learning Disability Partnership Board Agenda for the Profound Intellectual and Multiple Disability Sub Group



Meeting held on Thursday 27<sup>th</sup>  
October 2016 Room A08, County Hall,  
Preston 10.00 am



David welcomed everyone and everyone introduced themselves

Opening Round was:  
What activities do you like to do at weekends?

David Grundy, Chair, family carer  
Chris Robinson, Lancaster and Morecambe Day Services  
Holly, Children's Learning Disability Complex Needs Practitioner, LCFT  
Mark Hampson, React  
Julie Ray, Area Manager, West Lancashire, Chorley, Leyland, Fylde and Wyre for Domiciliary and Short Breaks  
James Hughes, React  
Lisa, React  
Lisa Fitzsimmons, Dalesview Partnership  
Pete Crane, family carer, Expert by Experience (CTRs)  
Reeny, Learning Disability student nurse  
David Wood, React  
Richard Woods, React, Autism Champion

Richard likes relaxing and going out into town.  
David likes relaxing at the weekend and day trips.  
David likes cycling and woodturning  
Chris likes music weekends, next month it's Madness!  
Holly has started Lindy Hop!  
Mark likes having a long rest!  
Julie likes walking her dogs and seeing family and friends.  
James does Park Runs!  
Lisa works at the PDSA.

Pete travels in his classic car and races Scalextric.  
Reeny likes going out to the pub.  
Amanda likes socialising with friends or watching a film or going for a walk or swim.



## Apologies

People who could not come to the meeting:

Anne Wallis  
Mark O'Farrell  
Lynette A  
Natalie Vranjes  
Beth Leech  
Dave Barton



**Notes and actions from the last meeting held on 15/09/2016**

### **Outstanding Action:**

**Dave B will ask at UCLAN about our training for PIMD being included on the courses there.**

**Scilla Reed unfortunately cannot help us at present.**

**David and Amanda to speak to Charlotte Hammond and arrange a new date for the PIMD Training for social workers.**

**Information Task Group to arrange to meet again and includes Rosie, Chris Robinson, Lynette, Beth and possibly Chris Benson. Monday or Friday would be good for Beth.**

## Updates

Beth, David, Rosie and Scilla met to talk about communication and people with complex needs and designing a leaflet.

They thought James and Mark might be interested in designing it.

Amanda sent a leaflet from Mencap about Communication but the team thought it was too long.

The group wanted to call it a 'guide' and to circulate it in GPs, hospital waiting rooms, dentists, etc.

There should be a key learning disability speech and language therapist team contact for each area eg. Rosie for Lancaster.

The group want to include methods of communication, objects of reference, signing, etc.

There is a publication about communication with people with intensive needs. 5 Ways of Communication.

The Central Communication Group developed a Communication Checklist. It has been sent to the providers and partnership board. This could be included in the guide and possibly updated if appropriate.

Pete said it would be good for new family carers to receive the Communication Checklist.

Pete said that people who have been in long stay hospitals or assessment and treatment units, their family carers often do not have good support. Pete thinks these families will benefit from the Communication Checklist.

The Transforming Care Health and Social Care leads could be informed about the Checklist so that we make sure they can pass the information on.

**Action: Amanda can ask Glenn Mather how we can make sure this happens and if he can take it to the steering group.**

**This is the information we think will work well in a Communication Guide:**

- I pads can have Dynavox technology now.

They rely on wifi.

- Communication Passports
- Talking Mats
- Intensive Interaction
- Social stories
- Picture Exchange Communication System
- Sensory Diets
- Makaton
- Signalong
- Behaviour that challenges
- Positive Behaviour Support and Positive Behaviour Support Plans
- Where to get support
- Challenging Behaviour Foundation website
- Total Communication environments
- Assistive Technology: switches, etc
- A key contact for each area from SALT and CLDT eg. Rosie for Lancaster. Include children's services
- Eye gaze
- Objects of Reference
- Lancashire Learning Disability Partnership Board website with Communication Checklist signposted.

David had a team meeting with Comensus. They had a meeting with dentists. They can check if people have diabetes by looking at their teeth. This could help some people.

James told us about the laboratory in a box. With one pin prick they can test your blood for several conditions.

**Action: Amanda to ask Bill to put on the Lancashire Learning Disability Partnership Board website.**

**Action: Amanda to ask Bill to develop PIMD page on the Learning Disability Partnership Board website.**

**Action: Lisa to ask Beth to set up another task**

**group meeting and work on a leaflet. Beth to include Chris Robinson in this group.**

**Action: James to ask Easy Read for All to develop the easy read version of the leaflet with symbols and pictures.**



## **Feedback from task groups developing a new PIMD Lancashire Action Plan**



### **1. Training**

David and Lynette are now being paid as casual tutors when they do training at Lancaster University.

Pete works for Lancaster University as a casual tutor training social work students and clinical psychologists in complex needs. Pete has been doing this for ten years.

Lisa suggested we talk to Pathways Associates for family carers to work at UCLAN.

**Action: Lisa F will contact Pathways to ask their network of family carers.**

**Action: Amanda to email the Family Carer network.**

**Action: James and Richard to ask Wendy if she would be interested in joining the team.**

3 a year at University of Cumbria and 4 Lancaster University hour and a half sessions.

**Action: Amanda to contact Donna at UCLAN to see how we can get family carers to train social work students, nurses, pharmacy, paramedics**

**and possibly other courses.**

Note that Comensus currently do training at UCLAN who are experts by experience. They don't get paid.

At Preston College and Blackpool and Fylde College we think there may be social care courses.



## **2. Family Carers**

Pete, Lynette and David emailed each other to talk about what family carers need to know.

What is Lancashire County Council doing about the Independent Living Fund?

Pete's family has used Independent Living Fund. Their Circle Facilitator wrote the LCC for a formal response about ILF.

Having evidence relating to the support plan showed the assessor that the money was needed in the Direct Payment.

The evidence came from his Circle meetings.

The evidence also came from the need to fulfil the law around mental capacity.

Family carers need to know how to manage the social care system.

Information will help people retain the funding they need.

Paperwork and keeping records helps.

Maybe family carers would benefit from a peer support network.

Pete mentioned the Reaching Communities funding stream which could be used to support family carers and Circles. Could someone apply for this money? 'Someone in the front room' who has good links with the council and can work with the family.

Amanda mentioned the Wellbeing Service and how family carers could get six sessions of support to support their wellbeing and help family carers with issues.

Advocacy services need to do non-instructed advocacy. Progress with this needs checking at the contract review. Advocacy services to make clear in their literature and information that they provide non instructed advocacy.

**Action: Amanda to check who is now reviewing the generic advocacy contract for Lancashire County Council.**

Family carers need to know what they can ask for, ie a menu of options.

We may need a communication strategy to say who gets the information, when and what.

Information about Rights, the Law, Direct Payments – what they are and what they can be used for.

Lisa is aware of some people who have been refused personal budgets.

Family carers need to work with the social workers to discover a way forward fitting with the rules and regulations.

Pete said that their Circle Facilitator wrote to the social worker to explain the needs and situation.

Pathways have hosted two events about HOLD about shared ownership of a house. People can then own their own house with a Housing Association.

Pete talked about supporting family carers to not have to fight for care packages and support.

David thinks the Council also needs to be sharing information about Direct Payment and how it can be

used.

The new Pension law is effecting care packages because people may need to afford this out of their direct payment. No one has received a letter from Lancashire County Council about how direct payments will support this change in the law.

**Action: Julie will find out who may be able to get this information for the group and for the public. Are people expected to fund the payment the pension out of the existing direct payment or are Lancashire County Council going to add the extra funding needed to the direct payment?**

Chris said that a redundancy protection could be included in the package of care. Fish insurance do a higher rate insurance policy. There are two rates. There is a higher rate policy which is more expensive. It is specifically for people on direct payments.

Family carers and people supporting Direct Payments for service users need to know about:  
Employment Law, Pension Law and Direct Payments.

**Does LCC have a duty of care to provide the finance for this change in the law about pensions?**

Cheshire Centre for Independent Living sent a letter to a family carer. The letter invited all the Personal Assistants if they wanted to join the pension scheme. All the staff wanted to join the scheme. The family carer did not receive extra funding to pay for this out of the Direct Payment.

Pete asked what about families with a Direct Payment who have not received these letters from CCIL because they control their payroll and Direct Payment themselves.

Money needs to be put aside to afford the pension. Where will this money come from?



**DAVID TO ADD NOTES HERE.**

Mental Capacity Act and Deprivation of Liberty Safeguards.

Families need to know about Continuing Health Care funding.

Information about Housing – the right home.

We need to be aware of what the Mansell Report says about the challenges family carers face.

For example, key facts about family carers and their caring role needs sharing.

Lancaster University hold an International Disability Conference for students and the UK appears to be at the forefront of social care for people with disabilities. Lancashire as an authority is also seen to have some exceptional practise regarding adult social care.

Co-production event for people with PIMD their families and supporters (including professionals).

Link to the Transforming Care agenda

We could ask:

What's working well?

Issues that need some work.

We can share knowledge, the sort of things we talked about today in the meeting that family carers need.

Information marketplace

Activities for people with PIMD – providers who are good at supporting social activities and daytime activities could showcase their activities and work.

Technology providers could bring eye gaze and ipad technology.

Day services could provide some sessions for people.



## **PIMD Action Plan**

**Action: David and Amanda will review and tidy up this document ready for the next meeting.**



### **Any other business**

There was no any other business.

### **Dates & Time of the next meeting**

15<sup>th</sup> December 2016 10-1pm

County Hall, Preston in room B02.