**Hampshire Learning Disability Partnership**

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**Complex Needs Group**

Meeting Notes from 14th May 2024

**Attendees**

Everyone introduced themselves and the minutes of the last meeting were agreed.

Attendees were pleased to hear more about Hamberley and Parity are looking into possibilities to access their facilities in future, such as the neuro gym.

AB shared about great Changing Places Toilet in Northampton on the South side of the motorway at a service station. It had a hoist, adult changing bed, and a wash basin that could raise or lower.

The Complex Needs Consortium information was shared and AC has been in touch to find out more.

Some other links were also shared:

[VoiceAbility | Complex Needs Consortium](https://www.voiceability.org/about-us/what-we-think-influencing-policy/complex-needs-consortium-1)

[PMLD - Involve Me | Mencap](https://www.mencap.org.uk/learning-disability-explained/profound-and-multiple-learning-disabilities-pmld/pmld-involve-me)

[Appointments and Annual Health Checks - Dimensions (dimensions-uk.org)](https://dimensions-uk.org/dimensions-campaigns/mygpandme-campaign-health-inequalities/appointments-annual-health-checks/)

AB gave an update on meeting with first year nurses to talk about complex needs. She said people appreciated hearing from those with lived experience and they had already thought about reasonable adjustments, easy read and communication. AB feels these are very worthwhile sessions to do.

Parity is also working with the University of Winchester to look at third year nursing students undertaking clinical placements in their services.

**Barriers to Accessibility**

Cafes can be hard to access with minimal space between chairs and people don't always make an effort to make space, this means identifying the best places to go in advance.

For holidays, choosing suitable accommodation is important, such as wide doors and good shower facilities - wet rooms are best. BP spoke about a cruise that had worked very well but he had had to pay for a high level service.

BP managed to get an ultrasound for his daughter by speaking to the consultant rather than the normal breast screening procedure, he has received a letter one year later for another ultrasound appointment. This has been so much easier as it had taken ages to try and get an appropriate appointment and appropriate scan, this now seems to be in place annually.

CN said that having to prove disability to get discounts can be hard, for example if someone needs more than one carer; something purpose built costs more money and service users have to pay for extra care, having to prove things is hard work. AMC raised about hidden disabilities and problems such as parking in disabled spaces and having to prove entitlement.

Planning in advance is often needed. TW shared about a recent GP appointment where a GP expressed everyone is treated the same/ I wouldn't treat anyone differently, which isn't helpful when someone needs a personalised approach.

What happens if someone does not have advocates or they live alone, who follows up and chases about health appointments if someone doesn't attend, also people have to feel confident to ask the right questions. E-consult is not in easy read which is difficult for some.

CN: four bad appointments are more expensive than one great one that's been thought out and maybe takes a few minutes longer, how we can encourage health professionals to understand this? Also having the time to understand a situation and put in preventative measures will help save money later.

**PMLD and Exercise**

AC shared about the LD Physio (specialist physiotherapist) who presented at a Joanna Grace Conference and talked about accessible exercise. He commented that if you or I were to go to our GP and say we’re planning to sit on the sofa and not exercise for years, it would not be recommended; yet for people with complex disabilities the main input can be to provide a specialist wheelchair, then send people on their way with no further advice. https://theldphysio

People discussed their experience and examples.

AB encourages her daughter and support staff to get out of the wheelchair as much as possible. She uses a handling belt to prevent falls. When staff change they need to re-educate about exercise.

AB got a private physio to work with her daughter and the staff, to find a successful plan that worked well, to increase staff confidence. AB feels being able to weight bear and walk has kept her daughter more healthy and less prone to chest infections, but it takes time and effort. AB’s daughter has a special wheelchair to support correct posture.

Mental health is better with regular exercise. TW explained it does not need to be a set formal exercise plan, but simple things you can do to encourage movement every day; use what motivates people and use that as a simple way to exercise - this could be a favourite object or effect. Find ways to maximise opportunities, everyday things we use in the home don’t need to cost a lot. Link on research about the benefits of just 5 minutes in a green space: <https://www.sciencedaily.com/releases/2010/05/100502080414.htm> .

AB talked about the importance of encouragement and explaining things well if someone says no, to explain better the offer of going out and what might be enjoyable about it. AB mentioned Active Life in Basingstoke works well for her friend’s son.

BP said his daughter will use a treadmill in the home, she loves being in the sunshine. Alice Holt Cycling and Fareham Arts Centre were also mentioned. AC said Sailability has been a good option at Frensham Ponds for £6 a session.

CN shared that Saints football club is well set up and some clients have really enjoyed going there with additional staff support.

AMC mentioned some work is being looked at around exercising and nutrition at HCC as a healthy weight improves outcomes for people with a learning disability. The balance of educating on food and making healthy choices alongside people’s ability to choose what they want to eat was discussed.

AB shared about her friend’s son who is concerned that carers do not make the connection between food and health. Adults can make unwise choices, AB said this has felt like a taboo subject around having capacity and a choice and decision, versus the duty of care to help make a wise decision.

BP said the most worrying thing of his life to think about what will happen to his daughter in the future, thinking where they are and what they would be doing. BP gave an example of how his daughter had gone to respite care and sat alone and not engaged and he worries for her future.

**Future topics**

TS, HIOW ICB Learning Disabilities and Autism Transformation Manager, will be invited to speak about her role as she had been unable to attend today.

Moving on (Second Transition), healthy eating, transport.

For information on access to services for diet and exercise, TW suggested the community learning disability team would be able to attend, there are teams across the county who could attend.

Staff attitudes: Parents have found care staff can have fixed ideas and can be in opposition to certain possibilities. BP shared his experience of trying to support his daughter to stay in respite by purchasing a reclining chair, but even that was problematic, he found there were entrenched attitudes. More co-working with parents and families is important.

BP felt the respite facilities in Winchester and Alton were superior to those available in Basingstoke. AMC shared that she is due to have some conversations about provision in the Basingstoke area about day services and invited BP to e-mail his thoughts in to AL for them to be included in the conversation.

**Future Dates**

**Future meeting dates for 2024 were discussed and decided as**

16 July at 1.30pm

17 September at 1.30pm

5 November at 1.30pm

AC thanked all for attending and next meeting will be 16 July on Teams