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| MEETING NOTES: | Autism Partnership Board |
| DATE: | 20 th June 2019 |
| LOCATION: | Wesley Halls, Wesley Street, Redruth, TR15 2EG |

ATTENDANCE

| Name | Position | Organisation |
|------------------------|---|-------------------------|
| Nuala Kiely (NK) | Partnership Boards Officer | Healthwatch Cornwall |
| Sophie Smith | Data Officer | Healthwatch Cornwall |
| Andrew Gray | Trustee | Cornwall People First |
| Nory Menneer | Clinical Lead and Programme Manager for Learning Disabilities | KCCG |
| Rachel Brown (RB) | Clinical Psychologist | Spectrum |
| David Allkins (DA) | Revenue and Benefits Admin Assistant | Cornwall Council |
| Shelagh Mitchell (SM) | Liaison Lead for Learning Disabilities/Autism, CHAMPs and Safe Places Manager | Cornwall Council |
| Heather Davison (HD) | Self-advocate and Parent Carer | |
| Amy Claridge (AC) | Commissioning Manager | Cornwall Council |
| Julie Jamaa Ben M'Hand | Diverse Communities Team | Devon & Cornwall Police |
| Anna Passmore | Patient Experience Lead | CPFT |
| Kelvin Yates | Commissioning Manager - Carers Lead | Cornwall Council |
| Dina Holder | Community Engagement Manager | The Women's Centre |
| Stephanie Shard | DIVA | The Women's Centre |
| Derek Hoddinott | Direct Payments Reviewer | Cornwall Council |
| Heather Davison | Self-advocate | |
| Ebony Thomas | Self-advocate | CHAMPs |
| Nicola Hancox | Assistant Psychologist | Outlook South West |
| Gemma Dyson | Clinical Psychologist | Outlook South West |

APOLOGIES

| Name | Organisation |
|--------------------|------------------------------------|
| Caroline Finlayson | CPFT |
| Julie Attwell-Cook | Cornwall Council |
| Lorna Brydon | Mencap |
| Martin de St Aubin | Mencap |
| Jane Rees | RCHT |
| Jacquie Gammon | Cornwall Council |
| Ben Law | CHAMPs |
| Adrian Quest | RCHT |
| Alison Stephens | Outlook South West |
| Sarah Thorneycroft | Cornwall Council |
| Paula Volkner | KCCG |
| Rose Taylor | Volunteer Cornwall |
| Steven Ford | Volunteer Cornwall |
| Ellen Hearn | CPFT |
| Gill Pipkin | Citizens Advice Bureau |
| Helen Childs | KCCG |
| Tracey Chater | United Response |
| Kerry Crawley | Cornwall Council |
| Rebecca Jelbert | Outlook South West |
| Jack Whitfield | Autism Assemble |
| Tasha Milton | DWP |
| Michelle Lobb | Parent Carer Council |
| Suzanne Wixey | Cornwall Council |
| Tim Francis | KCCG |
| Jonathan Price | Cornwall Council |
| Keith Coleman | Cornwall Council |
| Katy Neve | Cornwall Council |
| Colin Blandford | Cornwall Council |
| Susie Seviour | National Autistic Society Cornwall |
| Emma Corlett | KCCG |
| Glen Beale | Cornwall Fire & Rescue Service |
| Jamie Hanson | Cornwall Council |
| Kay Henry | Parent Carers Cornwall |
| Katy Gilbert | Cornwall Council |
| Leona Thorpe | Cornwall Council |
| Mike Date | Mencap |
| Rob Rotchell | Cornwall Council |
| Rozanne Sutherland | Cornwall People First |
| Ruth Wellings | KCCG |
| Sam Edwards | KCCG |
| Stuart Cohen | KCCG |
| Suzanne Leggett | Cornwall People First |
| Zoe Cooper | RCHT |
| Abigail McCormack | Outlook South West |
| Anna Hudson | Cornwall Council |
| Emma Rowe | Cornwall Council |
| Gemma Johns | Outlook South West |
| Lerryn Hogg | RCHT |
| Richard Sharpe | Cornwall Council |
| Sue Bartlett | United Response |
| Kelvin Yates | Cornwall Council |
| Amy Claridge | Cornwall Council |

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| Ginette Trewren | Cornwall Council |
| John Groom | KCCG |
| Christine Bateman | Cornwall Advocacy |

ACTION LOG

| DATE | ACTION | RESPONSIBLE | STATUS |
|-------------|--|--------------------|--|
| 19/03/2019 | 1 - Shelagh Mitchell to speak to Elizabeth Campling to get a review of scripts available for Council staff to use when speaking to someone with autism. | SM | SM to bring correct scripts with correct phone options to next meeting. |
| 19/03/2019 | 2 - Board to create a pathway through services for someone with autism. NK will ask Rebecca Jelbert from Outlook South West, Dr Rohit Shankar at CFT, Liz Cahill at NHS Kernow to help | NK/NM | Ongoing. |
| 19/03/2019 | 3 - Sophie Smith to create a standing item on the agenda for the Council's Day Services consultation and project | SS | Completed. |
| 19/03/2019 | 4 - Hugh Evans to find out from Jill Gilbert at the Council what happens to minibuses at the end of their lease for day services and why they aren't being replaced | HE | To be completed. |
| 19/03/2019 | 5 - SS to create a standing item on the agenda for updating the autism strategy | SS | Completed. |
| 19/03/2019 | 6 - NK/KY to liaise with Board members about possibility of event with professionals and service users to look at autism strategy and create workable action points for push forwards | NK/KY | Ongoing. NK to meet up with KY after KY meets with key KCCG members about integrating the autism strategy with children's services |
| 19/03/2019 | 7 - KY to link KN with DWP contact for possible further funding for Pentreath's Living Well to Work project | KY | Completed. |
| 19/03/2019 | 8 - All- circulate the govt.'s consultation documents on LD/autism training for medical professionals | All | Completed. The consultation is now closed. |
| 19/03/2019 | 9 - RB to send invitation to Spectrum's event at Underground House for NK to circulate | RB | Completed. The event was very well attended. |

| | <u>ACTION</u> | <u>RESPONSIBLE</u> | <u>COMPLETED</u> |
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| 1 | All - Please send any views about how the non-emergency police number should be set up to improve accessibility for people with autism to Julie Jamaa Ben M'Hand. Contact details circulated by email. | All | |
| 2 | JJBM - Present at the next Board meeting about Devon & Cornwall Police's consultation on improving accessibility of 101 number for people with autism | JJBM | |
| 3 | KY to organise meeting with NK after meeting with KCCG commissioners on integrating the autism strategy across children and adults' services | KY | |
| 4 | KY to liaise with Amy Claridge to see what the answer was to day centre minibus fuel allowance being so low | KY | |
| 5 | All to contact NK if you are interested in recreating Pentreath's "Living Well to Work" programme or have any ideas for funding streams | All | |
| 6 | Venues for drop-in engagement sessions for proposed day service changes will be circulated when ready. | NK | |
| 7 | Contact details, website and phonenumber for day service engagement project will be circulated when ready. | NK | |

| Item | What was discussed? | Action |
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| 1 | <p><u>Matters Arising</u></p> <p>NK wanted to start off airing her frustration that since she took over facilitation of the partnership boards in March 2018, nothing has been done towards implementing the autism strategy. We will go through the previous meeting's actions with this shortcoming in mind.</p> <p>Action #1: JJBM said Devon & Cornwall Police are considering accessibility of the 101 non-emergency police number. The police central switchboard would like to hear the views of different community members on how the automated response could be set up. JJBM's details will be circulated - please send any views to her and she will forward them on to relevant teams. She will also make a presentation about the consultation for the following board meeting.</p> <p>Action #2: NM was hoping this year to have a wider service for people with autism at risk of crisis commissioned, however the KCCG unfortunately made the decision not to commission this service this year. Tim Francis and I at the KCCG have this wider service for prevention as a top priority and are hoping for it to be commissioned next year. With regards to a defined pathway for people with autism, NM is working with mental health colleagues to improve access to mental health services for people with autism. We do have an escalation service currently for people with think are at risk of crisis. The lack of autism services in Cornwall is a "red risk" on the corporate register with the KCCG. Ideally we would like to adapt existing services such as the liaison service in hospitals to improve provision for people with autism.</p> <p>KY is meeting with Tim Francis, John Price and John Groom from the KCCG to look at integrating the autism strategy into children's services. The Board can help with this, NK to meet KY after this meeting to discuss how.</p> <p>Action #4: NK divulged that at the LDPB it was mentioned there is only £16 fuel allowance per month for day centre minibuses. Amy Claridge was going to take this back to Cornwall Council and get an answer to why it was so low. KY offered to liaise with Amy Claridge and see what the answer was. The Board again echoed concerns minibuses were being taken away or that funding didn't allow for any use of them. People can't get to crucial events such as Blue Light Day.</p> <p>Action #7: Since Katherine Nissen came to speak at the Board about her project "Living Well to Work" SM has referred a few people to her and said she was fantastic, two of them are now in work. NK will write an acknowledgement and thank Pentreath and Katherine on behalf of the Board for this excellent projet. SM lamented that this project is now closed due to lack of</p> | <ol style="list-style-type: none"> 1. All - Please send any views about how the non-emergency police number should be set up to improve accessibility for people with autism to Julie Jamaa Ben M'Hand. Contact details circulated by email. 2. JJBM - Present at the next Board meeting about Devon & Cornwall Police's consultation on improving accessibility of 101 number for people with autism 3. KY to organise meeting with NK after meeting with KCCG commissioners on integrating the autism strategy across children and adults' services 4. KY to liaise with Amy Claridge to see what the answer was to day centre minibus fuel allowance being so low |

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| | <p>funding as it worked so well. NK speculated that with funding, the service may be made again using current voluntary organisations, e.g. Spectrum, CPF, and DiH mentioned Positive People who the DIVAS are working with.</p> | <p>5. All to contact NK if you are interested in recreating Pentreath's "Living Well to Work" programme or have any ideas for funding streams</p> |
| <p>2</p> | <p><u>Cornwall Women's Centre - DIVA project</u></p> <p>DiH: The Women's Centre (WC) supports women at risk of (and experiencing) domestic/sexual abuse or exploitation. Women with an LD and/or autism were noted to be at risk but not accessing services. Devon & Cornwall Police were also aware that there were issues supporting these women and recognising those at risk of abuse. Rod Landman of the Association for Real Change(ARC) and 8 peer educators who have LD and/or autism +/- other disabilities developed a programme around domestic abuse and sexual violence. They are the 'DIVAS'. The DIVAS have now trained the Women's Centre, WC advisory group, a pilot group of 60 different police personnel on understanding domestic/sexual abuse and violence from their viewpoint. Sessions have conversations as well as presentations and include what it's like growing up with a LD or autism. Feedback from training the DCP police & crime commissioner was excellent. Our plan is to continue rolling these trainings out. We are also developing Us Too, a group of women to take training out to women and girls with LD/autism to recognise abuse and how they can seek support. We've just got some more funding and are going to recruit an extra worker and will continue to deliver additional training. I wanted to come here to start a connection with other organisations and see if we can do ongoing work. I'm very interested in looking at employment issues. We're based in Bodmin and aren't doing anything in west Cornwall at the moment but are looking to expand into that area.</p> <p>JJBM: Officers that have taken the training that are already highly trained in sexual abuse and domestic violence have said how good it is and how much they learnt about how to interact with people with an LD and/or autism in general.</p> <p>AG: At CPF we are hoping to set up a We Can Learn group, it would support people with ASD and mild LDs to link up and learn together. I have personally had experience of the difference a teacher who can effectively teach people with LD and ASD can make.</p> | |
| <p>3</p> | <p><u>Direct Payments Review</u></p> <p>Background: DeH is an independent adviser that was asked to come into Cornwall Council to review direct payments for service users</p> | |

(SUs) and commissioners. Direct payments are an alternative way of arranging and paying for services compared to the council arranging services. Direct payments provide a budget for the service user so they can buy their own services. In Cornwall there are 1500 people using direct payments. One third of population (who are eligible for support from social services) are using direct payments, compared to e.g. Manchester where it's 3%. In age group 18-64, 50% of (eligible) people in Cornwall use direct payments. Of people 65+ the figure is 16%. The largest proportion of direct payments are spent on employing a personal assistant (£16.5 million). Next biggest area of spend is on agency support (£11 million), some money on respite, (£1 million), and then day services (£1 million).

The issues include:

- Setting budgets which cover needs set out in care and support plan.
- Rates that are used to set the budgets,
- Aligning adults and children's services to make transitioning easier.
- Linking prices of services to the market price.
- Some people have too much money in their bank-accounts or on their card ,which may indicate they aren't spending their DP because they have less needs or that they can't find a service to spend it on.
- Some people have developed greater needs and need reviewing.

CC will be sending out an Easy Read guide to explain to clients their responsibility and the payments' purpose. We also be running self-help groups to help people understand. Each person will have a care manager who the point of contact if the service user has any questions along the way. We will be undertaking reviews of people's budgets, with a view to some reviews becoming less frequent or more frequent depending on the person's needs. Consultation will be starting in September to avoid starting in summer when fewer people are available to engage with.

Q&A

NK: You've asked the CHAMPs to help create a document in Easy Read - am I correct in thinking this document will help to explain the contract, the contract itself won't be in ER?

DeH: That is correct. The contract has to be written so that it is legally compliant, but so that people have an understanding of what they would be agreeing to we are developing this adjoining ER document. We will be testing this with direct payment users.

JJBM let DeH know about Blue Light Day and its significance for the LD/autism community. DeH said he would be booking a stall there for engagement.

HD: Are you continuing the prepayment card? Do you have to

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| | <p>take a prepayment card if you don't want to?</p> <p>DeH: We will be continuing it. Prepayment cards are preferred by Cornwall Council for direct payment users as they have some benefits: 1) you can't go overdrawn, 2) you can't accidentally spend direct payments on things you can't use it for, e.g. water bill, petrol; we can block these payees on this card. If you don't want to use one that is fine, you can use a normal bank account. This does come with some obligations, for example every 3 months you would need to send the Council bank statements and reconciliation forms.</p> <p>NK expressed her admiration for the lengthy period of engagement DeH and the Council were undertaking for this process. DeH said it was key they get it right as it will underpin direct payments for many years to come. In the past policy documents have not been very transparent.</p> <p>HD: Are social care/health budgets separate?</p> <p>DeH: The direct payments pay for social care services. I am talking to colleagues at the KCCG about possibly having a joined up approach to social care and health budgets.</p> | |
| 4 | <p><u>Autism Strategy</u></p> <p>Re. action point #3 KY will be meeting with Tim Francis, Jonathan Price and John Groom to discuss an integrated approach to the autism strategy between adult and children's services, and implementing the strategy. Once completed, KY will contact NK to set up a meeting to determine how the Boards will be involved.</p> | |
| 5 | <p><u>Day Services</u></p> <p>KY updating for Amy Claridge in her absence:</p> <p>We will be sending out a survey to everyone who attends day services, they will be circulated in ER as well. You may get it more than once as we will be sending it out as much as possible. This will ask service user views on day services. We will have a dedicated project site on our website so if you don't have a copy but want to get involved you can access it easily. We will also have a dedicated email address and a publicised phonenumber. Colleagues will also visit day services if requested and will talk to groups there, we will also talk to groups who will want to access day services but aren't already. There are three planned drop-in sessions, they will run from 10am - 4pm each day, there is no need to book. Venues are TBC and will be circulated as soon as we know:</p> <p>Tuesday 9th July, west Cornwall (venue TBC) Thursday 18th July, east Cornwall (venue tbc) Monday 22nd July, mid Cornwall (venue tbc)</p> | <p>6. Venues for drop-in engagement sessions for proposed day service changes will be circulated when ready.</p> |

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| | <p>We are also looking at survey options for parents, carers and future day service users. There will be one survey for providers, and one survey for interest groups. We're also planning three further workshops in August, specifically for providers. Responses will feed into the codesign of the future model in the autumn. The plan is to use an independent facilitator so the codesign isn't seen to be run by the Council or KCCG.</p> <p>HD and NK encouraged DeH to speak directly to service users, visit day centres, and engage with SUs and carers where the SUs aren't able to speak up for themselves.</p> | <p>7. Contact details, website and phonenumber for day service engagement project will be circulated when ready.</p> |
| <p>6</p> | <p><u>Whorlton Hall</u></p> <p>NK: We visit ppl in out-of-county placements regularly. Debbie Rees is the Clinical Review Officer for Transforming Care and she travels round the country visiting each of the people in out-of-county placements and checking they're okay. Two groups of people are currently placed outside Cornwall, one group is in secure care, and the other is in locked care. We commission locked care and are working to bring them back into Cornwall. Nineteen people are out-of-county. Eleven are in secure care, 8 in locked care. We need to get services right down here to prevent people being hospitalised in the first place. These numbers include both adults and children, 2 children are currently out-of-county. We are reassuring people that we didn't have any Cornish residents at Whorlton Hall. We do have some patients in hospitals run by the same company, although Debbie Rees visits them regularly and checks they are safe and well.</p> <p>SM: I am very concerned about service users who have a Personal Assistant (PA) who may not be giving an adequate level of care. From personal experience I have encountered and seen PAs who are out with the service user who do not engage with them at all. I have also seen this lack of engagement/care for the SU at meetings about the SU's own care. The PA is supposed to be attentive so that they can help the SU understand their care plan but I have seen sometimes that they are just on their phones or aren't paying attention. It is very worrying. It may be that in their own homes there is an unhealthy power dynamic between PA and SU.</p> <p>NK said Suzanne Leggett had echoed this concern at the last Learning Disability Partnership Board meeting. SM asked if there's any way to assess this? NM advised if anyone sees anything like that don't be afraid to challenge, if you know the organisation the PA comes from, report it to commissioning and the organisation itself. Four years ago in the LD Partnership Board we had a drive towards whistleblowing/spotting issues/safeguarding for the people with LDs to look out for their friends. JJBM said there is provision to safeguard these people, maybe we need to make the Board and others aware of what the provision is. For example, you can make professional referrals to safeguarding board, we also we have a partnership intelligence portal where concerns can come in. NM said he would be happy</p> | |

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| | <p>to receive any concerns himself. SM proposed educating SUs on what is appropriate behaviour from a PA. HD pointed out issues with this may be 1) encouraging SUs to have strength and courage to take it somewhere and know where to take it, 2) worries that “if you take my PA away, what is in their place?”</p> <p>NK: We will bring this back as a larger topic involving the Learning Disability Partnership Board.</p> | |
| 7 | <p><u>AOB</u></p> <p>NM: NB - Of the 19 people out of county, 6 ppl have autism as well as mental health problems. Also the Transforming Care Programme has two reference groups, one is for people with lived experience of hospital, and the other is for family and carers group with relatives in hospital, they have both developed charters and want to bring these along to blue light day.</p> <p>AG - We (trustees of CPF) will be contacting the MP in area to see how much the mental health budget for the area will overlap with autism.</p> | |

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| NEXT MEETING | 10.30am - 12.30am |
| DATE | Tuesday 17th September 2019 |
| LOCATION | Truro Community Library, Union Place, Truro, TR1 1EP |