

<b>MEETING NOTES:</b>	Meeting of the Learning Disability Partnership Board
<b>DATE:</b>	Tuesday 21 September 2021
<b>LOCATION:</b>	Via Teams

## ATTENDANCE

Name	Position	Organisation
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall
Helen Newton (HN)	Administration Officer	Healthwatch Cornwall
Amanda Wilton (AW)	Representative of the Patient Council and Carer	University Hospitals Plymouth NHS Trust
Anne Bowdler (AB)	Primary Care Liaison Nurse for Adults with a Learning Disability	Cornwall Partnership NHS Foundation Trust
Ann Smith (AS)	Head of Commissioning for LD, Autism and Mental Health	Cornwall Council
Ben Law (BL)	Self-Advocate	CHAMPs
Claire Martin (CM)	Deputy Director of Nursing	NHS Kernow Clinical Commissioning Group
Dina Holder (DH)	Community Engagement Manager	The Women's Centre / DIVAs
Fliss Hedge (FH)	Outreach Inclusion Worker	Cornwall People First
Sgt Flo Linscott (FL)	Diverse Communities Team Lead (Cornwall)	Devon and Cornwall Police
Hannah Welch (HW)	Primary Care Liaison Nurse	Cornwall Partnership NHS Foundation Trust
Heather Davison (HD)	Carer and Self Advocate	DIVAs and ICAN
Heather Sanders (HS)	Care Provider & currently studying commissioning	Autism Cornwall
Jenna Pulley (JP)	Co-Director	Cornwall Partners in Policymaking
Nory Menneer (NM)	Clinical Lead and Learning Disabilities Commissioner	NHS Kernow Clinical Commissioning Group
Rohit Shankar (RS)	Professor in Neuro Psychiatry and Clinical Director for local Adult LD services	University of Plymouth Hospital Trust and CFT
Sam Edwards (SE)	Nurse Consultant, Learning Disability Service	Cornwall Partnership NHS Foundation Trust
Sandra Ward (SW)	Parent Carers Cornwall and Chair of Carers Partnership Board	Parent Carers Cornwall
Steph Isaacs (SI)	Outreach Inclusion Worker	Cornwall People First
Steve Hillman (SH)	Health Practitioner for Inequalities	CHAMPs and Inequalities Team, Cornwall Council
Tasha Milton (TM)	Disability Employment Advisor covering North Cornwall	Job Centre Plus
Tina Sanford (TS)	Service Manager	Cornwall Council

## APOLOGIES

Name	Position	Organisation
Allison Kirk	Learning Disabilities Community Nurse	Cornwall Partnership NHS Foundation Trust
Cllr Andy Virr	Portfolio Holder - Adults and Public Health	Cornwall Council
Catherine Sims	Speech and Language Therapist	Cornwall Partnership NHS Foundation Trust
Christine Bateman	Advocacy Manager	Cornwall Advocacy
Helen Childs	System Director - Integrated Communities	NHS Kernow Clinical Commissioning Group
Cllr Jayne Kirkham	Cornwall Councillor for Falmouth and Penryn	Cornwall Council
John Groom	Director of Integrative Health and Care	NHS Kernow Clinical Commissioning Group
Kay Riley	Self-Advocate	DIVAs
Lesley Saunders	Coordinator	Shared Lives South-West
Lynda Berry	Parent Carer of a person with LD	
Natalie Brown	Health and Wellbeing Project Support	Seetec Pluss
Neil Carpenter	Volunteer Advocate, principally for people with LD	Cornwall Advocacy
Paul Toon	Contract Manager, Health Works for Cornwall	Seetec Pluss
Paula Varndell-Dawes	Strategic Manager	East Cornwall Primary Care Network
Paula Volkner	Project Manager, Transforming Care Programme	NHS Kernow Clinical Commissioning Group
Penni Charteress	Community Engagement Worker	The Women's Centre / DIVAs
Rebecca Goodey	Clinical Psychologist	Cornwall Partnership NHS Foundation Trust
Scott Fuller	Adult Social Care	Isles of Scilly Council
Shelagh Mitchell	Liaison Lead for Healthy Cornwall and CHAMPS Manager	Cornwall Council
Steve Dymond	Self-advocate	
Suzanne Wixey	Service Director Adult Social Care and Support	Cornwall Council
Tamsin Tripp	Assistant Psychologist	Cornwall Partnership NHS Foundation Trust
Tim Moss	Specialist Change Coach	Healthworks for Cornwall, Pluss
Vicki Allen	Adult Social Care Commissioning Manager with responsibility for Learning Disability and Autism	Cornwall Council

## ACTIONS AGREED AT THE MEETING

Action	Responsible	Status
Obtain and circulate RCHT booklet on welcoming people into hospital.	MH	
Email LeDeR report for circulation	NM / MH	
Present small supports programme update to future meeting	NM / MH	
Circulate KCCG response to NHS England on the recommendations from the Cawston Park case.	NM / MH	
Invite new Area Director for Adult Care and Support to future meetings.	MH	
Discuss with Locality Managers and Directors the possibility of restarting drop-in sessions.	TS	
Liaise outside the meeting regarding STOMP and people with autism	SE / RS / MH	
Share LDPB Direct Payments information.	MH	
Discuss the service users recording at the LDA Programme Board.	NM	
Investigate housing solutions proposed.	AS	
Find out if CPF self-advocates would meet to discuss the Strategy in a face to face setting.	FH / AS	
Liaise re engaging the homeless.	AS / DH	
Investigate payments volunteers could receive without affecting their benefits.	MH / DH	
JR to provide the PB Team with details of RCHT training day for circulation, once finalised.	JR / PB Team	Ongoing. Update 21/09/21 - Training is still available, only open to RCHT and CFT staff - MH to follow up with JR
AS to provide details of where the employability service advertised job vacancies.	AS / PB Team	MH to circulate information. Awaiting Easy Read version of information
AS to email a briefing note to the PB Team with more info on employability services	AS / PB Team	MH to circulate information. Awaiting Easy Read version of information
NM to provide timely updates on the NHS Long Term Plan and associated matters.	NM / PB Team	Ongoing.

Item	What was discussed	Action
1.	<b>Welcome, introductions and apologies</b>	
	<p>MH welcomed everyone and informed that the meeting was being recorded for minute talking purposes. Should there be footage that could be shared beyond the meeting, permission would be requested from the individuals.</p> <p>Apologies received would be added to the minutes.</p> <p>Since the Board last met, a very popular and valued member had sadly passed away. Maurice Shermer, a member and Trustee of Cornwall People First, regularly presented to the Board and was always keen to speak up on the things that mattered to himself and to other self-advocates. He would be</p>	

	<p>greatly missed.</p> <p>MH put on record his thanks to Nuala Kiely, Partnership Boards Officer, who had moved on from Healthwatch Cornwall the previous month. The Board concurred and wished her well for the future.</p> <p>MH invited everyone present to introduce themselves.</p>	
<b>2.</b>	<b>Minutes of and actions from the meeting held on 8 June 2021</b>	
	The Minutes of the last meeting were confirmed as a true record.	
<b>3.</b>	<b>Updates from members</b>	
	<p><b><i>Cornwall People First</i></b></p> <p>CPF no longer had a Victim Service but did have a new outreach worker, Steph Isaacs, and had set up more peer support groups. Face to face meetings had started to take place outside and they were undertaking Easy Read commissioning work, which people could contact them about if they required such a service.</p> <p><b><i>CHAMPs</i></b></p> <p>The team had recently undergone a ‘modernisation’ and were now called the Inequalities Team. CHAMPs would continue and they were looking to recruit four new members. They were still doing the same work but would also be looking at other inequalities, including homelessness. Sheila Mitchell was now Inequalities Lead, supported by Steve, Susie and Margie, who were Health Practitioners for Inequalities. Face to face course delivery would start in January</p> <p>Ben had been doing a Patient Experience course, working in hospitals with Anna Passmore, and would be happy to investigate anything that any members of the group would like any help with.</p> <p><b><i>DIVAS</i></b></p> <p>The DIVAS had still not met face to face but had some training planned in Exeter for the Open Criminal Justice team, looking at the issues of working with women in custody with LD and autism.</p> <p>In October they would be involved in work on Claire’s Law, which included a leaflet, a video and information that would be available in Easy Read. This was a national project, working with the university.</p> <p>They had been invited by Cambridge and Sussex Rape Crisis to provide training for their teams. They were also hoping to do more face-to-face work and meetings after Christmas.</p> <p><b><i>Parent Carers Cornwall</i></b></p> <p>PCC had:</p> <ul style="list-style-type: none"> <li>• been working on preparing for adulthood and had co-produced the Multi</li> </ul>	

	<p>Agency Transition Protocol which had now been signed off and was available on the Cornwall Council website.</p> <ul style="list-style-type: none"> <li>• continued to do virtual coffee and chat sessions for those carers that felt vulnerable and needed support and they were trying to reach out to the hidden families with SEN children.</li> <li>• produced a Summer news booklet that went out to all families across Cornwall and was distributed to Cornwall Council frontline staff to give out.</li> <li>• worked with KCCG and Young People Cornwall to produce a survey to find out young people’s views on future health services.</li> <li>• arranged an event to be held that month to meet with young people and families.</li> <li>• continued working on a key worker pilot for families with young people with mental health issues to help to prevent them from escalating. The project had been a huge success.</li> <li>• remained very busy with Parent for Parent, with referrals coming from all areas to provide services to support families. The greatest need had been to support families with DLA and PIP forms.</li> </ul> <p>CM congratulated RCHT on receiving the Patient Safety Award for their book about welcoming people into hospital. Nicky, one of the CHAMPs, had visited Treliske the previous week with Jane Rees to do a photo shoot for the adult book.</p> <p><b><i>Kernow Clinical Commissioning Group</i></b></p> <ul style="list-style-type: none"> <li>• The LeDeR annual report was due to go to the Quality Committee for sign off over the next couple of weeks.</li> <li>• A Small Supports programme, mainly led by the Council, was being launched to address the needs of people coming out of hospital and coming back to Cornwall. The programme was designed to provide support to groups and organisations across Cornwall who were interested in providing support to people but were unsure where to start.</li> <li>• KCCG had been asked by NHS England to respond to the recommendations from the Cawston Park case. It was in the public interest to see what they were doing to prevent people being admitted to hospital.</li> <li>• Tomorrow was the first meeting of the Learning Disability and Autism Programme Board, a joint meeting with Cornwall Council, the Council of the Isles of Scilly and KCCG, bringing system leaders together to look at the objectives of the long-term plan and joint strategies for Learning Disability.</li> </ul> <p><b><i>Adult Social Care</i></b></p> <ul style="list-style-type: none"> <li>• TS had been working with NM to look at the support required for people in hospital out of county to return home.</li> <li>• She had also been supporting the three locality areas to think about the ways in which people in transition and their families were helped. Following feedback from Parent Carers Cornwall, a new role had been developed to work alongside the Transition Social Workers to improve transitions for young people and the new team would start early in the new year.</li> <li>• Kevin Beveridge had taken over as Area Director for Adult Care and Support and would need to be invited to future meetings.</li> <li>• A panel was taking place that week to look at where Changing Places toilets would be best located. The team had listened to feedback from</li> </ul>	<p>MH to request copies of the book to share</p> <p>NM to send MH LeDeR report for circulation NM to present update to future meeting</p> <p>NM to send MH response for circulation</p> <p>MH to liaise with Kevin</p>
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	<p>service users in putting together a bid for more Changing Places. Service users would also be involved in the planning and designing of the toilets to ensure they were user friendly.</p> <p>FH asked whether the Social Worker Drop-In sessions were likely to be restarted in Camborne. TS agreed that the concept of the drop in was something that they should be doing across all locality areas. FH would send TS feedback on the previous scheme.</p> <p><b>Primary Care Liaison Team</b></p> <ul style="list-style-type: none"> <li>The team had been very short-staffed, meaning that some people had not been receiving timely intervention. AB apologised if people had not received their normal support.</li> <li>Interviews were taking place for a two-year fixed term project role to promote annual health checks</li> </ul> <p><b>STOMP Programme update</b></p> <ul style="list-style-type: none"> <li>SE gave a brief overview of who could be supported through the STOMP programme. <b>Note: this information was provided following the meeting:</b> ‘The STOMP programme is for people with a learning disability and/or Autism but the Learning Disability Service can only support people who have a learning disability with any medication reductions. Therefore, there is currently a gap for people who need support who have Autism but no learning disability.’</li> <li>A multi-agency meeting had taken place the previous week where that matter was discussed. It had been acknowledged that some progress had been made in reducing the use of anti-psychotic medication but there was a risk that people would be put on alternative medications.</li> <li>RS added that a paper had been issued looking at the last 10 years of prescribing which shows that the use of anti-psychotics had reduced dramatically but the use of both anti-depressants and anti-epileptic drugs had risen significantly.</li> </ul>	<p>TS to discuss with Locality Managers and Directors</p> <p>MH to liaise with SE and RS outside the meeting regarding STOMP and people with autism</p>
<p>4.</p>	<p><b>Feedback from the 7 September 2021 Learning Disability, Autism and Carers Service Users Event</b></p>	
	<p>MH updated the group on the outputs from the Service User event on 7 September.</p> <p>The main topics of conversation were:</p> <ul style="list-style-type: none"> <li><b>Hospital passports</b> - Jane Rees had provided the latest version of the hospital passport for people with learning disabilities for the group to comment upon. Some very good practical feedback was received which Jane would be taking back to share with other acute hospitals.</li> <li><b>Direct Payments</b> - the new Cornwall Council lead officer for Direct Payments would be discussing how they could be used with the Autism PB. That information would be fed through to this Board.</li> <li><b>Access to NHS services, particularly GP’s</b> - accessing GP services had been raised at previous meetings throughout Covid, and whilst it needed to be stressed that this was not indicative of all GP practices, self-advocates</li> </ul>	<p>MH to share DP information.</p>

	<p>reported that they felt that access had worsened in recent months.</p> <p>MH played a very impassioned recording from the Service Users event in which people with learning disabilities and/or Autism highlighted the difficulties people with communicative issues were experiencing in trying to get support from their GP.</p> <p>RS stated that all health professionals would soon have to undertake the mandatory ‘Oliver McGowan training’.</p> <p>TS added that everybody needed extra support to understand what good conversations looked like. She had undertaken research to help people in front line roles to determine how people were being supported through good communication and good conversations and, if that was not being done effectively, what needed to change. E-learning did not work in transferring knowledge, skills and understanding in such situations.</p> <p>HD stressed that GPs were the gateway to all other services. A video was produced several years ago to address these issues and to provide training but GPs had not been engaged.</p> <p>AB said that the Primary Care Liaison team could provide training but it was important to have a collective, whole service approach to take matters forward. Small teams did not have a loud enough voice and it was important to hear peoples’ experiences. GPs had never been under so much pressure but it was essential to support them productively and positively to respond to people with disabilities.</p> <p>NM wanted to ensure that where people had clearly been mistreated by a service, the route to making a complaint was easily understood and accessible.</p> <p>DH added that she had been working with three different women recently on GP complaints. It had been very difficult, with huge barriers to overcome and information on websites not always clear or up to date. A service had been commissioned to work with GPs around domestic abuse and violence and DH would remind them that they need to be inclusive to people and women with learning disabilities and autism and stress the need for an effective communication strategy around that.</p> <p>AW commented that she had used AB’s team previously for support and they had been a great help.</p>	<p>NM to discuss the recording at the LDA Programme Board and agree next steps</p>
<p><b>5.</b></p>	<p><b>Learning Disability Strategy</b></p>	
	<p>Adult Social Care were running a programme called Delivering Better Care working closely with NM, Tim Francis, Head of Mental Health and Learning Disability Joint Strategic Commissioning for Cornwall and the Isles of Scilly, and all those who supported learning disabilities. This was the first part of developing the Learning Disability Strategy.</p> <p>Adult Social Care commissioned and provided services such as help at home, care homes, day services, accommodation etc.</p> <p>A new Strategy was needed due growing demand alongside increasing budget pressures. It was necessary to look at ways to do things differently. It was</p>	

<p>essential to enable people with Learning Disabilities to live as independently as possible and work was needed to support providers, hospitals, GPs etc. to do that.</p> <p>The Strategy aimed to deliver the right care at the right time in the right place but to do that it was vital to understand what was important to people and what needed to change.</p> <p>AS gave a presentation focused upon the five topic areas in bold, below. Feedback received from the Board is bulleted:</p> <ul style="list-style-type: none"> <li>• <b>Where people live:</b> <ul style="list-style-type: none"> <li>○ People were interested in shared ownership but the amount of money needed to get on the scheme was a huge barrier. <ul style="list-style-type: none"> <li>▪ Would the Council consider helping people with funding the deposit?</li> <li>▪ Could a charge be put on the property so that the Council could recoup the money later?</li> </ul> </li> <li>○ Cornwall Partners in Policymaking had held several conversations regarding shared ownership and they had been able to put families in touch with other families who had been through the process to share experiences. There was a network of families who were willing to share their knowledge and experience. That would also help those self-advocates who lived independently and did not have family support.</li> <li>○ Many people did not have a social worker and did not know who to speak to as there was no obvious point of contact. Requests for new needs assessments for people to live on their own were not being processed.</li> <li>○ Several parent carers who were in adapted social housing were looking to the future and considering whether their cared for could remain in the property while they moved out as the investment had already been made.</li> <li>○ More support was needed and a broader offer for families from Cornwall carers service around helping carers to navigate and understand finances, Court of Protection processes etc.</li> <li>○ ‘In Control’ had families nationally who could provide support and advice to other families and were asking for more families willing to provide such support.</li> <li>○ The type of accommodation available seemed to be for those with more financial resources and did not make allowance for people who were homeless. Those people were not being consulted as many did not have social workers. Consideration should be given to how they could be reached.</li> </ul> </li> <li>• <b>What people do during the day</b> <ul style="list-style-type: none"> <li>○ Give people an option and make it really clear as to what the options are. People were not aware what was available to them. There was</li> </ul> </li> </ul>	<p>AS to investigate</p>
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	<p>security in staying in familiar situations and people may not feel inclined to ask about something new/different.</p> <ul style="list-style-type: none"> <li>○ What people did during the day went beyond day services. The Women’s Centre could be commissioned to provide different services and work with other organisations to provide something that could become part of the community. The DIVAS were excelling in their role and making a positive impact. DH queried whether funding means could be looked at further to enable more creative solutions to be developed.</li> <li>○ Everybody with a learning disability was different and many people would aspire to do something different, if it was available.</li> <li>○ Day services remained very important to meet the needs of those individuals that used and benefited from them.</li> <li>○ AS assured the meeting that the exercise was not about removing day services, it was about offering a wide range of options to provide the best solutions for different individuals</li> </ul> <ul style="list-style-type: none"> <li>● <b><i>Preparing for Adulthood (transitions)</i></b> <ul style="list-style-type: none"> <li>○ More person-centred planning to help young people and their families could contribute to what they wanted to do in the future would be beneficial.</li> <li>○ Many parents found the transition process extremely daunting and understanding when they needed to start planning was not clear. Transition Link Workers were definitely needed. However, transition did not just involve the 17-18 age group. The next stage of transition was often harder for many families, when young people left full time education, which could be as late as 24.</li> <li>○ Peer support for families and getting involved with schools and the EHCP stage was vital. There was an opportunity to work with the Preparing for Adulthood Board to take that forward.</li> </ul> </li> <li>● <b><i>Staying Healthy and Well</i></b> <ul style="list-style-type: none"> <li>○ More could be done to understand how services worked together to ensure a collaborative approach to support good health for people with a learning disability. It was not just the responsibility of social care or health, it required a wholistic view.</li> </ul> </li> <li>● <b><i>Increased choice and control</i></b> <ul style="list-style-type: none"> <li>○ Very few people had social workers or a single point of contact. To have somebody that visited a day service and was accessible and easy to talk could help to drive real change.</li> <li>○ Family carer involvement needs to be embraced and continue to be recognised.</li> <li>○ The Family Charter was signed up to by Council, NHS and RCHT. It was discussed whether that work needed to continue and be extended to include social care providers - care homes and supported living.</li> </ul> </li> </ul>	
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	<p>Resource was available from NHSE to continue that work.</p> <ul style="list-style-type: none"> <li>• <b>Staying safe</b> <ul style="list-style-type: none"> <li>○ People were more at risk of sexual violence and exploitation within the home and the Women’s Centre were undertaking work on hate crime, a significant area of pain that could lead to suicide and self-harm.</li> <li>○ CPF ran ‘Speak Up groups’ on keeping safe and they could offer Keeping Safe forums, but that would require additional funding. A neighbourhood police officer could attend the meetings which would help with engagement.</li> <li>○ Most of the funding was currently committed to residential care but some of the outputs of this meeting would help direct where the money could be better spent.</li> <li>○ The Inequalities Team were hoping to change the way they deliver services to be more locality based and to offer a more continuous service that would include healthy weight, Fresh and a staying safe course on a regular basis.</li> <li>○ Autism specific support services were non-existent and when GPs did not understand it was extremely difficult to get needs met.</li> <li>○ With the right trauma informed approaches people could have much happier and safer lives. It required a collaborative approach to ensure that those who needed support had their needs met at the right time.</li> <li>○ There was a Trauma Inform Network focusing on domestic abuse and sexual violence, led by a member of the CFT Psychology team.</li> </ul> </li> <li>• <b>Next steps</b> <ul style="list-style-type: none"> <li>○ Suggested to give this presentation to a group of self-advocates and get their feedback. Unfortunately, a lot of self-advocates did not have access to the internet.</li> <li>○ AS would be happy to attend various smaller group sessions to discuss the Strategy.</li> <li>○ Consideration should be given to how to reach the homeless. Look at contacting ‘We are with you’. DIVAS would also be happy to arrange a meeting.</li> <li>○ AS would be presenting to the Autism Partnership Board on 5 October</li> <li>○ If anybody had any thoughts following the meeting they could email AS on <a href="mailto:ann.smith@cornwall.gov.uk">ann.smith@cornwall.gov.uk</a>.</li> </ul> </li> </ul>	<p>FH to ask whether CPF self-advocates would meet face to face and liaise with AS</p> <p>AS to liaise with DH</p>
<p><b>6. Any Other Business</b></p>		
	<p>SW stated that there was a significant lack of paid home carers and with the requirement for them to now have Covid vaccinations she was concerned about the potential for further impact. Some people had not had a shower for</p>	

	<p>a month because of the lack of a carer who was able to support them to do so.</p> <p>DH asked for information on what payments volunteers could receive without affecting their benefits.</p> <p>AW asked for an update on funding for the Derriford Autism service. Plymouth City Council and Devon County Council had agreed their funding but were waiting for an update from Cornwall. NM advised the KCCG was committed to funding the service for a year and that Devon were proceeding based on funding being available.</p>	<p>MH to investigate</p>
<p><b>7.</b></p>	<p><b>Future meetings</b></p>	
	<p>All agreed that the next round of meetings should be online.</p> <p>Next scheduled meetings (all 10am to 12pm on a Tuesday unless otherwise stated):</p> <p>Joint Learning Disability &amp; Autism and Carers Service Users Event - 23 November - Zoom</p> <p>Learning Disability Partnership Board - 10am, Tuesday 30 November - Teams</p>	