

MEETING NOTES:	Joint Meeting of the Autism & Learning Disability
	Partnership Boards
DATE:	Tuesday, 13 October 2020
LOCATION:	Via Teams

ATTENDANCE

Name	Position	Organisation
Nuala Kiely (NK)	Partnership Boards Officer	Healthwatch Cornwall
Mike Hooper (MH)	Partnership Boards Officer	Healthwatch Cornwall
Amanda Wilton (AW)	Representative of the	University Hospitals Plymouth NHS
	Patient Council	Trust
Amy Claridge (AC)	Commissioner for Day	
	Services, Respite and Shared	Cornwall Council
	Lives	
Anne Bowdler (AB)	Primary Care Liaison Nurse	Cornwall Partnership NHS Foundation
	for Adults with a Learning Disability	Trust
Caroline Finlayson (CF)	Speech and Language	Cornwall Partnership NHS Foundation
	Therapist	Trust
David Allkins (DA)	Revenue and Benefits Admin Assistant and Self Advocate	Cornwall Council
Deborah Rees (DR)	Clinical Review Officer for	NHS Kernow Clinical Commissioning
	the Transforming Care	Group
	Programme	
Dina Holder (DH)	Community Engagement	The Women's Centre
	Manager	
Ebony Rose Thomas (ET)	CHAMPS	Cornwall Council
Elizabeth Campling (EC)	CHAMPS	Cornwall Council
Fliss Hedge (FH)	Outreach Inclusion Worker	Cornwall People First
Ginette Trewen (GT)	Senior Employment Support	Employability Cornwall, Cornwall
	Officer	Council
Jane Rees (JR)	Learning Disability and Autism Team Manager	Royal Cornwall Hospital NHS Trust
	Councillor and Chair of	
Jayne Kirkham (JK)	Learning Disability	Cornwall Council
	Partnership Board	
Jenna Pulley (JP)	Director	Cornwall Partners in Policy Making
Katherine McQuay (KM)	Social Worker, Kerrier North	Cornwall Council
Katie Wheeler (KW)	CHAMPS	Cornwall Council
Sgt Kevin Silver (KS)	Diverse Communities Team Leader for Cornwall	Devon and Cornwall Police
Neil Carpenter (NC)	Volunteer Advocate,	Cornwall Advocacy
	principally for people with	
	LD	
Neil Oats (NO)	CHAMPS	Cornwall Council
Nicky Abrahams (NA)	Project Worker and Advocate	Cornwall Advocacy
Nory Menneer (NM)	Clinical Lead and	NHS Kernow Clinical Commissioning
	Programme Manager for	Group
	Learning Disabilities	
Paula Volkner (PV)	Project Manager,	NHS Kernow Clinical Commissioning
	Transforming Care	Group
	Programme	



Penni Charteris (PC)	Community Engagement Worker	The Women's Centre
Rebecca Jelbert (RJ)	Clinical Psychologist, Adult Asperger Assessment Team	Cornwall Partnership NHS Foundation Trust (previously under Outlook South
	Asperger Assessment ream	West)
Richard Gittens (RG)	CHAMPS	Cornwall Council
Sam Edwards (SE)	Nurse Consultant, Learning	Cornwall Partnership NHS Foundation
	Disability Service	Trust
Sandra Ward (SW)	Parent Carer and Chair of Carers Partnership Board	Parent Carers Cornwall
Scott Fuller (SF)	Adult Social Care	Isles of Scilly Council
Shelagh Mitchell (SM)	CHAMPS Manager	Cornwall Council
Tasha Milton (TM)	Disability Employment	Job Centre Plus
	Advisor covering North Cornwall	
Tigger Pritchard (TP)	Autism and PDA Advocate,	National Autistic Society Cornwall
	Consultant and Trainer	
Vicki Allen (VA)	Adult Social Care	Cornwall Council
	Commissioning Manager with	
	responsibility for Learning	
	Disability and Autism	

APOLOGIES

Name	Organisation
Allison Kirk	Cornwall Partnership NHS Foundation Trust
Chris Elliot	Kernow Carers Group
Georgia Jenkin	Cornwall Council
Helen Childs	NHS Kernow Clinical Commissioning Group
Councillor Jacquie Gammon	Cornwall Council
Katy Neve	Cornwall Council
Kerry Crawley	Cornwall Council
Laura Truswell	Mencap
Linda Byrne	Kernow Carers Group
Martin De St Aubin	Mencap
Michelle Lobb	Parent Carer Council
Councillor Rob Rotchell	Cornwall Council
Sarah Thorneycroft	Cornwall Council
Stuart Whittaker	Mencap
Suzanne Wixey	Cornwall Council

ACTIONS AGREED AT MEETING

ACTION	RESPONSIBLE	<u>STATUS</u>
Contact AC for examples whereby outreach had not been received and the CC response.	NK/MH/AC	
Contact AC for CC responses to issues raised regarding Direct Payments.	NK/MH/AC	
AC to contact the Direct Payments team re support CC offered to individuals transferring to a Direct Payment. Feed back to NK/MH.	AC	
Write, on behalf of the Joint PB, to David Coleman, CC, to ask if the letter regarding	NK	DC responded to say that it was not produced in easy read



day services not reopening would be produced in easy read format.

format. In-house day services should have ensured communications were in easy read and would for all other communications.

ltem	What was discussed?	Action
1	Welcome, introductions and apologies	
	MH opened the meeting, stating that it was being recorded for minute taking purposes only.	
	MH relayed apologies received (listed above).	
	Everyone present introduced themselves, detailing their organisation and role.	
2	Feedback from 6 October 2020 Learning Disability and Autism Service Users and Carers Event on experiences throughout the COVID-19 pandemic	
	NK stated that the key purpose of the meeting was to relay the feedback on the experiences of individuals throughout the COVID-19 pandemic, as received at the Learning Disability and Autism Service Users and Carers Event held on 6 October 2020. She emphasised that as the pandemic continued, the issues raised should be considered to be current and continuing.	
	The reasoning behind holding a separate event for Board Members that were service users had been to create a comfortable space in which to address issues around online meeting access and to provide a less formal setting in which people could voice their views. It was hoped that this Joint Partnership Board meeting could provide professionals with the opportunity to consider the issues raised and how organisations could address associated needs.	
	Short clips were from played from the Service Users Event in relation to Access to GPs and hospital treatments, with the following being highlighted:	
	 Fear of catching Coronavirus, both carers and service users, leading to cancelling or deferring appointments; Phone consultations with physios - they couldn't see if exercises were proving to be beneficial or not; Difficulty in explaining ailments over the telephone, which in turn created fear that diagnoses could be incorrect and treatment unsuitable; For people with autism, understanding a tone of voice or the meaning behind words was not easy. Anxiety could be triggered which could be very difficult to switch off from. Even reassurances from doctors could then be questioned, with individuals unsure as to whether they were genuine or not. The ability of the individual to relay the extent of their insecurities and worries varied greatly; Making a GP appointment was more difficult as you could not visit the surgery and the process for some included call back services; 	

 Regular appointments, such as those for eye tests and diabetes tests, were not being carried out; Virtual clinics had been a positive for those service users that were averse to visiting clinical settings or new venues. They could also ease the burden on carers as stressful situations were avoided and appointments were much shorter. 	
NK asked how people thought things could be improved for people with autism with regard to telephone consultations in general practice.	
JR said that the hospitals were attempting to hold Teams chats or phone calls prior to appointments so that people could be prepped with information such as the questions that the consultant could ask, giving them time to prepare and therefore less likely to miss the opportunity to put forward the questions that they want to ask. The calls also provided reassurances on how to use technology that may be new to them. In response to NK, JR added that patients could ring the hospital in advance if they chose to. NK asked if the service could be publicised for both hospitals and GPs. JR agreed and wondered if AB could do the same for Primary Care as for Acute. AB said that the difficulty was that unless individuals were identified as requiring additional need at the point of contact, GPs would not have that knowledge. What would help would be the ability to use flagging systems such as those used in the hospitals.	
NK asked NM why LD health checks did not allow individuals to be flagged up at GP level. AB responded that health checks ensured that people were on a register but it was not the same register as those used for receptionists' front screens. It was not possible that the health checks register could be cross referenced when patients called practices due to the large number of people registered with each surgery.	
NK said that she felt that some service users did not understand why some services, such as feet checks or eye tests, were not currently available or the alternative options available. AB said that was interesting as she knew that retinopathy had restarted a couple of months ago and was continuing. The issue could be that that information had not been relayed back to all patients or it could be that there was a backlog of appointments. She added that individuals could contact the service if they had not received appointment details.	
NK fed back information received regarding flu jabs, that they were not available in some areas and that in others they were only available via drive-ins. AB said that, in co-ordination with NHS South West, CPFT had produced a flu vaccination pack that had been sent out to every GP practice which included an easy read invitation and encouraged consideration of reasonable adjustments that could be made in order for individuals to have the vaccination. It had been promoted through internal communications and the weekly local cascade so GP practices should be aware of the ability to make reasonable adjustments for anybody, including the nasal spray. NM added that there was a load of information detailing how people with LD could access flu jabs either at a practice, a pharmacy or a drive-in. Further to that, a communications campaign with the CHAMPs was expected to be launched within the next fortnight with the aim of stressing that it was doubly important that those deemed vulnerable received their jab this year. Information would	

go out direct to individuals, their families and care providers to create the demand for GPs. NM reported that NHS Kernow had a very low supply of transparent masks but were looking to get more. From his experience of working directly with a person with autism he had found that wearing a face covering mask had made him unrecognisable to the individual and it was very difficult to communicate. The CHAMPs reported the following: • Not everyone had received the easy read flu jab information; • They were hoping to create a virtual presentation about the flu jab; NK queried how practices knew who the people that needed to receive flu vaccination packs were. AB replied that when the packs were sent out, GPs were asked to look at their learning disability registers, which were updated annually, and that everybody on those lists receive an easy read. AW provided positive feedback, saying that herself and her daughter, who had LD, had their flu jabs the previous week. The surgery had sent a text so they could make the appointment and they had also received support from the Intensive Support Team. The whole experience that the surgery provided had been very positive. NA raised concerns about virtual calls. Many people with LD had been invited to join meetings but had not received support on how to download or use the app. Cornwall Advocacy had been providing assistance but felt that it would be good practice for the professionals inviting people to such meetings to make sure that they had the right support or to offer them the right support to use those facilities. Short clips were from played from the Service Users Event in relation to outreach and day services, with the following being highlighted: • One carer said that she had received weekly phone calls from the day centre that her son attended but the pressure that she was under had meant that she had practically cried down the line. A worker from the centre was due to take her son for a walk in the coming days but up until that point he had turned down the opportunity as they could not take him anywhere in a vehicle, meaning that they could not take him anywhere that he couldn't already go without them. One service user said that his experience of lockdown had been very lonely and he had realised how much he needed a human connection. He really missed and had been affected by not being able to touch someone's shoulder every week. However, he felt that the experience had provided everyone with the opportunity to take a step back and look at how services were provided and to find solutions that worked for everybody. We needed to look after people because if we didn't he feared that the faces that he'd seen in the last three months via Zoom would continue and they were the worst that he'd seen for many years. NK said that the two clips displayed the loneliness and isolation that service users had been expressing, as well as the exhaustion felt by

carers that had 24/7 responsibilities with no respite. Some carers had

said that they simply did not have the energy to fight for the services that they felt were required.

Referring back to NA's concerns about virtual calls, NK reported that Healthwatch Cornwall had found that, no matter the help and advice provided virtually, some people were still unable to join meetings. She opened the matter up to the Board for ideas.

DH said that the Divas had a range of different experiences and abilities. A couple of the women with LD were using Zoom fairly confidently for both Divas and other meetings. However, one was still struggling despite having the support of her mum and the Divas working to help to embed the process on a weekly basis. There was another example where the reluctance of a carer had led to a service user being unable to join. Lots of practice was required to help people to learn how to take part in online meetings and it was important that professionals recognised the amount of time it took. The benefits of doing so, however, were great.

NO said that it was not easy for people to follow links to join online meetings and that more support was needed. The loss of contact and support during the initial lockdown was particularly difficult. SM added that there were activities on offer but without one to one support, people could not access them.

VA suggested WhatsApp video calls. SM said that the CHAMPs had utilised it but people would accidentally delete contacts and links. Support was essential.

NK highlighted security concerns around some video messaging services.

FH said that Cornwall People First had found that many people didn't want to take part in group chats, preferring one to ones. Reading cues and recognising whose turn it was to speak was difficult. Phone calls, texts and Messenger chats had worked but they had not had any success with Zoom.

NA echoed the comments of others, saying that Cornwall Advocacy had also found that many people required support in person.

More short clips were from played from the Service Users Event in relation to outreach and day services, with the following being highlighted:

- A carer said that her son did not access local authority provision but received support from Hft. It had closed at the outset of the pandemic before reopening at a reduced capacity and schedule. He had been unable to access any day care but overnights had resumed. The family could not thank his PAs enough. They had isolated themselves to ensure that they could provide support and had found new ways to do so. However, no contact had been received from Social Care, despite it stating that everyone in receipt of Direct Payments had been contacted. There had been two or three changes of allocated Social Workers but not one had made contact.
- Another carer added that issues were not unique to those in receipt of Direct Payments, central care had simply left people to get on with things themselves. Some carers had told her that there was an

 element in their Direct Payment specifically for PPE but nobody was told about it. NK asked a carer, whose daughter's day centre had been closed since March, if they had received any outreach. The carer said there had been a call to say that that day care had been suspended but no contact at all following that. 	
NK opened discussion around day centres.	
FH shared the experiences heard by Cornwall People First. For months following the beginning of lockdown people had been reporting that they had received no contact from day services. It wasn't until August that contact restarted via phone calls or Zoom and, for example, Blantyre began daily classes such as music or dance. However, many day services had still not made contact with the people they had been supporting. Those people were really struggling from the loss of structure and contact. Such examples were really disappointing and it seemed that there was no overall plan.	
JP echoed the comments made by FH, saying that Cornwall Partners in Policymaking had received similar feedback.	
DR said that the matter had been raised at the Experts by Experience Group the previous day - the way that private providers could open and provide a COVID-secure setting could be looked into by the Council with a view to doing similar.	
DR reported that the feedback that she had received from a Support Worker for HFT Day Services was that some people were at home living with elderly parents that did not want them going out with Support Workers due to the risk of COVID. Such people that had profound learning disabilities or Autism may not have had a voice of their own in such a situation. She asked what oversight there was for such people as it felt as though taking decisions on their behalf may not have been conducive to a best interest process. Consideration needed to be given to the detrimental effects on individuals.	
JK said that since the start of the pandemic she had been hearing that the Council's day centres and respite services had closed and that both service users and carers were struggling. Herself and Councillor Barbara Ellenbroek, Vice-Chair of the Carers Partnership Board, had raised the matter at the Council's Health and Adult Social Care Overview and Scrutiny Committee and were told that the Council's direct services had closed due to the pandemic, that outreach had been offered and that people could contact Access if they were struggling. Whilst obviously not making up for the loss of services, she had been informed that commissioned services were reopening on a reduced capacity. However, there was no sign of Council run services doing the same, even with a limited service on offer. It would be nice to know what future plans would be but there were concerns that the financial impact of the pandemic, along with need to reduce in year costs by around £8m, could impact day services, which were already under review prior to COVID.	
NO said that he frequented Kehellend Day Centre, which was not Council run. From the beginning of the pandemic they had called all regular users on a weekly or fortnightly basis. Subsequently, they had reopened	

from the middle of September, albeit operating on a different basis to usual. AC said that the Council had worked closely with them to help them to open up a limited service on site and to help with outreach. NK reported that another issue that arose at the Service Users Event was how people were informed that day services would not be reopening. People were not notified until some time after the decision was taken and only after Healthwatch Cornwall had raised the issue with the Council. A copy of the letter was displayed on screen. NK suggested that the format was not suitable for many of its recipients and that an easy read version should have gone out. JP stated that she thought that the letter was appalling and it should be raised with the Council. It was received by service users and their families at a particularly difficult time and more thought should have gone into it. Similarly, the closure of More Choice was communicated in a letter, leaving people with no understanding of when they might be able to see friends and people who were really important to them again. It was now October and there was still no sign of any resolution. People had been told in a second letter that they could maybe access other services and that that would be addressed during Social Worker assessments. However, people weren't seeing Social Workers. Contacting the Access service took a long time and, for other services. you often had to leave messages or send emails. She cited other services that weren't straightforward such as raising safeguarding alerts. For exhausted carers, being held on a call or waiting for responses could feel like the last straw. FH had spoken to a lot of people that had received the letter and not one had understood it without assistance. It contained long blocks of text, long words and sentences and complicated language. It seemed that there had been no forethought that it was going out to people with a learning disability. The Council knew that CPF and the CHAMPs produced easy read so it made no sense that they hadn't been asked to. AC said that commissioned day services were nominally her responsibility. She asked that FH provide details of the people that had not received any contact regarding their day service, if they permitted her to. AC provided background, saying that when lockdown began in March most of the commissioned day services had already closed, either through their own decision or because the numbers of service users had already dropped off so much. On 23 March, the Council asked that all services MH/NK to close on the provision that they continued to provide a level of outreach contact AC re to all and that they provide activity logs. Should anyone know of any examples instances where no outreach was received, they could let AC know at submitted and amy.claridge@cornwall.gov.uk. CC response. From July/August, the Council had worked with each of its commissioned services for them to write plans detailing, in the event of restrictions being eased, the level of limited onsite provision could they safely provide. The vast majority had since achieved limited on site services. SW commented that she had been impressed with the level of innovation

showed by providers.



AC undertook to feed back issues raised regarding Direct Payments to the Direct Payments Team. On the matter, NK said that one of the issues that had arose was the difference between people that had a Personal Budget for Council commissioned services and those that received Direct Payments. She had then asked if an individual that was unable to go to a Council commissioned day service because it was closed could be supported in getting a Direct Payment to be used for a PA or to attend a different service? The Government had encouraged flexibility of use of Direct Payments and the fast tracking of people not currently in receipt of one. The Direct Payments Team had provided NK with a very detailed response about what they could be used for and who to contact but there was a lack of acknowledgement that the people in receipt would not be able to understand such information or carry it out without support. A system needed to be installed that allowed those people to be able to make informed decisions and it needed to be done quickly as nobody knew how long the current pandemic would go on for.	MH/NK to liaise with AC re CC response to issues raised.
AC cited the Direct Payments Review and said that the Council had made a huge push to get people with a learning disability onto Direct Payments. With hindsight, that may not have always been the most suitable thing for all. Direct Payments were complicated and required a lot of responsibility of the recipient or of individuals supporting them. Maintaining receipts as records could be quite onerous.	
AC undertook to contact the Direct Payments team to find out what support the Council offered to individuals transferring to a Direct Payment.	AC to feed findings back to MH/NK.
With regard to an individual being in receipt of a Direct Payment and using it to attend a commissioned service, that was something that, ideally, wouldn't happen as the providers of such services would have already been paid by the Council.	
Although not within her remit, AC said that officers were working on a clear plan of action for people that could not attend in-house services. She understood that at the beginning of the pandemic, some of the in-house services staff had been redeployed to hospital and hotel bed provisions. That was no longer the case and staff were now back in their substantive roles and they were providing outreach. AC again invited members to submit to her any examples whereby outreach had not been received and she would forward them on to David Coleman, Head of Service, for a response.	
The pandemic had been a testing time for all and AC stated that any future changes to services would not be undertaken without firstly liaising with the Carers Partnership Board and service users and carers to find out what they felt had worked well, what could be improved upon and what hadn't worked well.	
NK asked if the letter would be produced in easy read format. AC said that she would ask the Head of Service and feed back but NK undertook to send a letter direct from the Joint Board.	NK to write to DC on whether or not easy read letter would be produced.
A lot of questions and comments about day had been submitted via the chat function. AC asked that they be collated and fed to her for	

response or, alternatively, a meeting to be held to discuss them. NK suggested a working group be formed.Regarding Direct Payments, JP said that whilst the Government had encouraged flexible use, she had received feedback that families had almost felt bullied into returning money without anyone having discussed with them what might be the most suitable means for them. It felt as though the Council had not followed the Government guidance. NK said that she had heard similar and it was important that all such information was gathered.CF asked AC if, given that COVID-19 rates in Cornwall were so low, it was proportional that the Council had no intention of reopening in-house day services until Spring 2021. AC said that she believed that the current conversation was around whether or not closure until Spring was justifiable and could be maintained.CF said, from a health perspective, when it was found that an individual in receipt of a Direct Payment that was cared for in a family setting was not receiving the level of care required to meet their needs due to complex barriers in enabling them to access activities, it was almost impossible to change their support system as there was no one to collaborate with within the Council.3Any Other Business Development of Programme of Work for Working Age Adults, including Strategy Development - Vicki Allen & Nory MenneerVA reported on an initial Programme meeting around Working Age Adults - those from 18-65 years of age - that hel eligible health and social care needs and a range of enduring problems, covering physical disability,
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mental health, Autism and learning disability, predominantly. It was important to pull together a raft of provisions and services and engagement to shape what the local offer in Cornwall would be, including housing, care, support, community intervention and generally supporting that wider group of people.
The work would take around 18 months and as part of that there would be an engagement strand. NK and NM were due to meet with HK and MH in the coming weeks to provide further information.
VA and NM would also be working on Project Initiation Documents around a Learning Disability Strategy and an Autism Strategy. There was a lot of good work being carried out in Cornwall but a Strategy would allow it to be brought together and allow the Partnership Boards to drive it forwards. NM added that COVID had encouraged organisations to work together and, now that the Council and NHS Kernow CCG worked together under one Joint Accountable Officer for Public Health and Care, links were in place to make things happen.
In response to a question from NK, VA said that they needed to work out where strands would align and getting an overarching structure in place.

With regard to an Autism Strategy, priorities would need to be identified over the next 12 months, along with how they should be moved on. She gave assurances that even without strategies being in place, existing work would continue and it would be key to link in with the Partnership Boards.	
The lower age of 18 was with regard to those eligible adult social care needs but work would be undertaken with transition and as part of the Working Age Adult Group there would be colleagues from Childrens Services and Education Services. Transition would be looked at from 16 plus to enable plans for provision for the future.	
CF asked how the plans fitted in with the NHS England LD and Autism workstream that was currently coming online. NM replied that with regard to LD, there was a Regional LD and Autism Board on which he represented the CCG. On the health side of things, what they wanted was for the strategies to reinforce building the right support and other initiatives around the delivery of services for people with LD and/or Autism. Locally, it needed to be tied to working with the Council and VA and NM were due to take part in a meeting about how social care and health could better link up to provide the right sorts of care. VA added that the workstreams were part of the delivery of the initiatives of the NHS Long Term Plan.	
NM said that the NHS Long Term Plan did not cover health and social care provision, just NHS objectives, so it was necessary for the CCG and the Council to create the strategies in order for them to link things up.	
Informal Carers Engagement Report	
This had been circulated with the agenda for information.	
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the format wasn'	<u>von-cornwall.police.uk/reporthc</u> . KS ackno t perfect for everyone but the site had be he form simpler. He encouraged members	en updated to
	nline meeting platforms, the Police did not ential security issues but they would join e	
Derriford Update	<u>9</u>	
courses at Derrifo mandatory in the greater understa	t Learning Disability and Understanding Autord, which were currently optional for staf new year. It was very positive as it would nding of patients with additional needs, all es available within the Derriford Trust.	f, were to be I provide a
operating a sever	Learning Disability and Autism Services had n day per week service on a six month trial e slightly shorter on weekends than those o	basis.
support with com compliance to ca department it co pandemic due to in advance of visi	a learning disability or autism required one munication, understanding, emotional sup re or treatment in any outpatient, day cas uld be granted as a reasonable adjustment restricted visiting rules. The team could b its to request assistance. NK suggested that it similar procedures were available at Tr	port, e or inpatient during the e contacted at it would be
Future Meetings		
	ry Partnership Board - Tuesday, 8 Decembe ip Board - Tuesday, 15 December 2020	r 2020
Both meetings to	be held at 10am, via Teams	
	tation with partners, the above meeting er for the following meetings to be held:	swere
	isability and Autism Service Users and Ca 1, 3 December via Zoom	rers Event -
Joint Learning D	isability and Autism Partnership Board -	10 am.