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| MEETING NOTES: | Meeting of the Autism Partnership Board |
| DATE: | Tuesday, 20 September 2022 |
| LOCATION: | Via Microsoft Teams |

ATTENDANCE

| Name | Position | Organisation |
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| Cllr Sally Weedon (SW) | Councillor and APB Chair | Cornwall Council |
| Mike Hooper (MH) | Partnership Boards Officer | Healthwatch Cornwall |
| Tanya Falaschi (TF) | Partnership Boards Project Officer | Healthwatch Cornwall |
| Anna Ingleby-Oddy (AI) | Housing Manager | United Response |
| Anna Passmore (AP) | Patient Experience Manager | Cornwall Partnership NHS Foundation Trust |
| David Allkins (DA) | Autistic individual and Revenue and Benefits Admin Assistant | Cornwall Council |
| Dina Holder (DH) | Community Engagement Manager | Women's Centre Cornwall & Divas |
| Emily Nicol (EN) | Clinical Review Officer, Adult Mental Health | Cornwall Integrated Care Board |
| Ian Hutchinson (IH) | Autistic individual and Clinical Nurse Specialist - CAMHS | Cornwall Partnership NHS Foundation Trust and National Autistic Society Cornwall Branch |
| Jane Rees (JR) | Manager of the Learning Disability and Autism Team | Royal Cornwall Hospital NHS Trust |
| Jason Pape (JP) | Autistic individual | Proper Job Café |
| Julie Atwell (JA) | County Parenting Advisor for Early Help, Together for Families | Cornwall Council |
| Julia Wildfire-Roberts (JW) | Project Manager, Recovery College Cornwall, HC Director and autistic individual | Pentreath and Healthwatch Cornwall |
| Kate Kelly-Talbot (KK) | Service Director for Care and Wellbeing | Cornwall Council |
| Margee Polawski (MP) | Health Improvement Practitioner, Healthy Cornwall and CHAMPs | Cornwall Council |
| Marie Ralph (MR) | Autistic individual, Parent Carer and NAS representative | National Autistic Society Cornwall Branch |
| Nory Menneer (NM) | Commissioner for LD and Autism | Cornwall Integrated Care Board |
| Rachel Roberts (RR) | Compliance Co-ordinator and Head of Involvement | Brandon Trust |
| Tigger Pritchard (TP) | NAS Committee Member, Autistic and Neurodivergent individual, national and international speaker on advocacy and neurodivergence rights | NAS Cornwall |
| Tina Sanford (TS) | Learning Disability, Autism and Transitions Manager, Adult Social Care | Cornwall Council |

APOLOGIES

| Name | Position | Organisation |
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| Andrew Gray | Autistic Individual | |
| David Burns | Autistic Individual | Citizens Checkers |
| Jason Washington | Autistic Individual | |
| Karen Hooper | Head of Commissioning for LD, Autism and Mental Health | Cornwall Council |
| Michelle Lobb | Carer and Director | Parent Carers Cornwall |
| Philip Hanscombe | Autistic individual, Adult Autism Intensive Support Team and Chair of the Advisory Board to the All-Parliamentary Group on Autism | Cornwall Partnership NHS Foundation Trust |
| Rebecca Jelbert | Clinical Psychologist, Adult Autism Assessment Team | Cornwall Partnership NHS Foundation Trust |
| Sam Axon | Autistic Individual | |
| Steph Isaacs | Outreach Inclusion Worker | Cornwall People First |
| Tasha Milton | Disability Employment Advisor | DWP |

ACTIONS

| Action | Responsible | Status |
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| Liaise with Portfolio Holder re future Blue Light Day funding from CC. | SW | Ongoing. |
| Liaise re Police training issues. | PB Team/MR | Ongoing. |
| Utilising Hospital Passport App in lieu of Autism Alert Card. Liaise with Jason Howard, D&CP. | PB Team | Ongoing. |
| Language guidance for meetings. | PB Team/TP | Ongoing. |
| Possibility of audit of accessibility of services. | NM / VC / JG | Ongoing. |
| ER hospital letters. | JR | On Nov agenda. |
| Investigate setting up a focused group, with Mental Health colleagues, to consider issues discussed. | NM | Ongoing. |
| Pop-up mental health facility. Possibility of using a lorry. | NM / VC | Ongoing. |
| Update on possibility of rolling out staff autism training to CFT & CC. | IC / TS | Ongoing. |
| Invite CC Housing Options Team to future meeting to look at the implications for people with LD and Autism in accessing mainstream housing | PB Team | Ongoing. To be scheduled. |
| Provide details of statutory obligations within delivery of Better Lives Strategy. | TBC | Ongoing. Rollout of BLS on hold. |
| Further information on how to access the services of The Advocacy People. | PN | Incomplete. PN to present on the work of TAP at 15/11/22 meeting. Deferred to 2023. |
| Provide details of statutory obligations regarding advocacy support. | TBC | Ongoing. |

| Action | Responsible | Status |
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| Investigate changes to blue badge application process. | MH | Ongoing. MH to follow up again with Donna Collins and request somebody attends a future meeting. To be scheduled. |
| LeDeR updates to future meetings. | LN | Ongoing. Awaiting response from Lisa Nightingale, Head of clinical quality, CCG as to this year's report. |
| Convert Direct Payments information into easy read for circulation. | AS / CG | Ongoing. CC to produce. DP Agreement is available in ER. Policy currently being reviewed. |

| Item | What was discussed | Action |
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| 1. | Welcome, introductions and apologies | |
| | <p>SW welcomed everyone and advised that the meeting was being recorded for minute taking purposes.</p> <p>Apologies received are detailed above.</p> <p>SW invited everyone present to introduce themselves.</p> | |
| 2. | Minutes and actions of the meeting held on 14 December 2021 | |
| | <p>SW invited any issues from minutes of the last meeting to be raised.</p> <p>No issues raised and they were therefore accepted as a true record.</p> <p>MH provided the following updates on actions from previous meetings:</p> <ul style="list-style-type: none"> NM would update on three matters later in the meeting – The possibility of an audit of accessibility of services, the proposal to set up a focused group, with Mental Health colleagues, to consider issues discussed on 28/06/22 and the suggestion of pop-up mental health facilities. On the possibility of rolling out staff autism training to CFT & CC, IH had provided the following update: ‘We are still waiting for NHS strategic leads to decide how best to run a programme that includes the AU understanding and acceptance half day session that we have developed alongside the mandatory Oliver McGowan LD&AU training that is required for all NHS staff. This includes consideration of budgetary allocation and logistical arrangements.’ IH had also liaised with TS to link CFT's head of training and education with their counterpart in Cornwall Council. <p>Upon joining the meeting, IH added the following: The CFT trial of autism training designed and delivered by autistic people had been a success and</p> | |

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| | <p>could now be rolled out throughout the NHS in Cornwall. With the training agreed in principle the issues left to overcome were logistical in terms of getting people to places to deliver the training and working out how resources could be shared. Also, it needed to fit in with the mandatory Oliver McGowan training, which was excellent but heavily focused toward LD. The newly developed autism training was aimed at promoting an understanding all of the autistic community, not just the small part that also had a learning disability.</p> <p>Another element was ensuring link up with Cornwall Council to develop a process across the whole of the health and social care sector in Cornwall.</p> <p>(Further information on Oliver McGowan training could be found here.)</p> <ul style="list-style-type: none"> • Invite CC Housing Options Team to future meeting to look at the implications for people with LD and Autism in accessing mainstream housing. This matter was still to be scheduled. • IH had met to with MH and Healthwatch Cornwall’s Communications Manager to discuss the wording used and other accessibility matters on its website. All of IH’s recommendations had been implemented. • Further information on how to access the services of The Advocacy People would be presented to the next meeting. This would include their work to get new self-advocate representation on the Partnership Boards. • Conversations on changes to the blue badge application process had not progressed. • An update with regard to the new LeDeR report was still awaited from Lisa Nightingale, Head of clinical quality, CCG. • Clive Gaylard, Adult Transformation and Commissioning, Cornwall Council, had requested that the Direct Payments Policy be converted into easy read. MP added that the CHAMPs had recently appointed three new members, to start in October, so they could have the capacity to undertake the production of more easy read material moving forward. | |
| <p>3.</p> | <p>Updates from Members</p> | |
| | <p>The CHAMPs</p> <p>MP said that walks were planned in Penzance, Hayle, Newquay, Camborne and Truro.</p> <p>Healthy Me was being held in Newquay, along with a fresh course in Camborne and a Healthy Weight course in Redruth.</p> | |

People were being supported through one to one sessions to lose weight or stop smoking.

There was also work with homeless communities to support people to live as healthily as possible.

Women's Centre Cornwall & The Divas

DH was working with Age UK and Safer Cornwall on the Domestic Abuse and Sexual Violence Strategic Group. A project was underway which focused on older people and DH requested that it be promoted to people with autism and/or a learning disability. It was important to understand what the barriers were that were preventing people experiencing abuse from accessing support. If it proved difficult to gain direct experience, professionals with Autism and/or LD were also invited to participate. MH would circulate further details following the meeting.

NAS Cornwall Branch

MR was now the Chair of NAS Cornwall. Its current focus was on revamping the group and gaining new members and new ideas.

Its AGM was on Wednesday, 12 September and there were vacant positions available. If people could promote it they should contact MR.

Work with Age UK's Social Prescribers was underway to set up a support group in Launceston. It was intended that this would then be rolled out across Cornwall for both parent carers and people with autism.

Fundraising was planned for the Autistic Coffee Shop to develop from online only to in-person. The intention was to have a caravan that could be taken across Cornwall and for it to be staffed by autistic people.

Youth Art Connect (<https://youthartconnect.org/>) continued to promote positive mental health for people aged up to 30. The majority of attendees were autistic or neurodivergent. MR asked if the group could be promoted.

Spectrum / Saludem Care and Education

The Chair relayed a Cornwall Council statement on the delivery of care services for adults:

'New providers have been found to take on the delivery of Spectrum's care services for adults in Cornwall.

Spectrum (Devon and Cornwall Autistic Trust) have decided to focus on their specialist services for autistic children and young people and transfer their adult services to new providers.

The majority of services will transfer to Saludem Care and Education. This

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| | <p><i>provider has extensive experience in running residential care homes for adults with autism and learning difficulties and will take on services at most Spectrum homes in Cornwall.</i></p> <p><i>There will now be a period of transition with an expectation that the new arrangements will be in place by the end of September 2022.</i></p> <p><i>Cornwall Council is currently working in partnership with NHS Cornwall and Isles of Scilly Integrated Care Board (ICB) to make sure that people living in Spectrum’s adult residential care homes are provided with stability and security.</i></p> <p><i>All Spectrum staff have been informed of the change and will be transferred to Saludem with the aim of providing as much continuity of care as possible. Under the new management they will be supported to deliver the care and support that each individual needs.</i></p> <p><i>A small number of people will have their care transferred over to different providers in new settings. All providers involved are experienced in delivering the care and support required.</i></p> <p><i>These moves will be kept to a minimum and will only happen where it best meets each resident’s individual needs.</i></p> <p><i>Residents and their families have been informed and work is now being undertaken to make sure there is as little disruption as possible to their daily lives.</i></p> <p><i>Anyone who has concerns is advised to contact the organisations involved.’</i></p> <p>TP said that he had worked with Saludem for many years and had found its standard of care to be really high.</p> <p>MR was con concerned that Spectrum was retaining responsibility for children’s services. Her family’s view of their services, from personal experience, was that they were the worst provider they had encountered. It needed to be recognised that the level of service received during childhood had a massive impact on that required during adulthood. She asked how the decision had been made. SW asked that MR email her directly for her to gain a response.</p> <p>IH echoed the comments of MR. Through his NHS role he had worked with Spectrum’s children’s services and had real concerns about its general philosophy, which he said was based on outmoded concepts of disability and disfunction.</p> | |
| <p>4.</p> | <p>Self-Advocates and Service Users Meetings</p> | |
| | <p>TF reported on recent additional meetings held by Healthwatch Cornwall’s Partnership Boards team to ensure that the voices of self-advocates and</p> | |

service users could be heard by the LD and Autism Partnership Boards.

Department for Work and Pensions

A meeting of DWP service users with LD and/or autism had been held primarily to consider communication concerns. Questions since submitted to the DWP for response are appended but some key points arising were:

- People felt that they were seen as less of a priority than others.
- There is a lack of staff trained in how to communicate with people with additional needs.
- Accessible Information Standards are not being adhered to.
- Vulnerabilities were not recognised, meaning that adequate support was not provided.

The 14 questions raised are detailed in Appendix 1.

Delivering Better Care

The team had held two engagement sessions with Martha Reed to enable conversations on the rollout of the Delivering Better Care strategies. It was intended that further sessions would be held in the coming months.

Peer Review

An event had been held in July to enable autistic members of the Board to participate in the Peer Review of Cornwall Council's Adult Social Care services. The Review would be discussed in more detail later in the meeting.

The event had been scheduled to be held at Truro Library but had to be moved the afternoon before due to a broken down lift, which meant that it would not be accessible for all. It was moved to the Council Chamber at County Hall. Whilst the team recognised that acoustically that room was not ideal, the decision was taken to progress with the event as it provided the only opportunity for members to participate in the review. Those in attendance were thanked for their understanding.

Autism Post-diagnosis Support

Dr Rebecca Jelbert and Lucy Freemantle of the Adult Autism Assessment Team had engaged with self-advocates and service users on the design of online information that could be provided in lieu of funding for formal post-diagnostic support.

In addition to how online information could and should be provided, discussion also focussed on the possibility of diagnosis letters being made bespoke to the individual and containing the information necessary to present to the DWP and local authority. Whilst the conversation was autism-focussed, such a letter could provide the blueprint for other diagnosis letters.

The Advocacy People

The team had met with Penny Newman of The Advocacy People and a Council Commissioner to discuss The Advocacy People’s role in introducing self-advocates to the Board. Updates on that work would be provided at future meetings.

Events & Community Promoter Role

Blue Light Day and The Royal Cornwall Show had provided excellent opportunities to promote the role of the Boards and gain new members, both people with LD and carers.

TF encouraged more people to put themselves forward for the Community Promoter role and join the team at events.

The team would be working more closely with Healthwatch Cornwall’s Engagement Team to ensure that they were able to promote the Boards more within their work and to ensure increased link-ups at events.

TF also highlighted work associated with the Older Persons and Carers Partnership Boards.

MH added that at the recent LD Partnership Board Sergeant Flo Linscott had highlighted the limited funding for this year’s Blue Light Day, the need to investigate new funding streams for next year and the need to address the transport issues faced by many.

DH said that she had spoken to the organisers of Blue Light Day. They had done a fantastic job but it would not be appropriate for the event to continue in its current form. It needed to be led by people with LD and autism and funding contributions should be made from lead organisations across Cornwall. MH said that his understanding was that Cornwall Council had not financially contributed to this year’s event and that funding from the Police and Crime Commissioner could be severely reduced for 2023. It was agreed that the conversation be relayed to Cornwall Council for consideration of its future involvement. DH suggested that a festival style event could be the way forward.

TS suggested that the Chair liaise with the Cabinet Portfolio Holder around Council funding for Blue Light Day. It was possible that a breakdown in communication had led to the lack of funding this year and that could be prevented for future years.

MR had liaised with PC Sarah Treeby, Diversity Officer and Teresa Berridge, Equality Diversity and Human Rights Officer, Devon and Cornwall Police, for some time to encourage the force to train officers to better understand the differences between, for example, mental health situations and autistic

SW to liaise with Portfolio Holder

meltdowns, in order that they are better prepared to effectively manage situations. Some young adults with LD or autism had not had good experiences with the Police. She gave an example of a 10 year old being restrained face down and put in handcuffs whilst having a meltdown. MR felt that the organisations represented on the Board needed to work together to push for the necessary training. The PB team would liaise with MR to learn more on the subject and to determine how to progress the issue.

TS said that she had spoken to the Police on utilising passports to ensure that officers make necessary adjustments in order to respond to people appropriately. Unfortunately, she felt that the suggestion had been met with resistance due to Police systems being unable to hold such information due to GDPR. She asked if anyone on the Board had worked with the Police on accessible information and/or passports. DH was an independent advisor for the Police and sat on the Violence Against Women and Children Group. She had delivered training for the Police but it had been focussed towards LD. She was currently working with the Police on potential autism focussed training offers and suggested there was an opportunity to undertake a wider piece of work and urged others to put themselves forward as independent advisors.

IH had been involved with Police passports through work, specifically clients within the children's service. In the LD service there was an agreed process whereby information would be held on a database and would be accessible by officers. Feedback showed that process had not worked well. Clinicians had ensured that all of their clients had Police passports and that they were updated every 3 months but the system that the Police had meant that information was held centrally and was not accessible for officers at ground level. To counter that, IH had encouraged clients and family to carry cards on them as that was the most effective way to present information to officers. However, training and understanding was key.

TS and MR emphasised that accessing necessary information was an issue that affected services across health and social care and wider discussions were required.

MR added that she had liaised with the Chief Executive of Boardmasters following a number of families approaching her about autistic young people struggling with various elements of the festival. They had agreed to ensure that all staff, including security, received equality and diversity training and to set up a sensory area for people to use as a safe space. The Chief Executive had also said that he would like similar rolled out at other festivals run by his organisation.

Members continued this conversation at the end of the meeting:

TP said that around 6 or 7 years ago, Devon had an Autism Alert Card that was funded by a local charity, linked in with the Police and held information on a database. The intention had been to then trial it in Cornwall but

PB team to
liaise with MR

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| | <p>feedback from the autistic community, both locally and nationally, was that they did not want their personal details held on a database. MH said that Sgt Flo Linscott had recently tried to attain funding for a revised Autism Alert Card but was now working with the CHAMPs to look towards adapting the Safe Places cards to allow people to include information specific to themselves, therefore allowing it be rolled out to multiple groups.</p> <p>JR said that an issue for the Police was not only holding the information but ensuring that it was regularly reviewed. She suggested that a card could somehow be linked with the newly developed Hospital Passport app. Jason Howard was the Police contact to get in touch with.</p> <p>IH said that CAMHS had successfully managed to embed the reviewing of information held into their working practices. The problem was the wider system was not fit for purpose. He felt that there needed to be more consideration of passports in a wider sense. Many of the people that used them were in receipt of numerous services, for example, mental health, LD, and it could be the case that autistic people that don't receive other such services miss out. A more integrated approach was required, such as allowing people to choose to go on to a database in which information is amalgamated and is available to whatever health service the individual comes into contact with.</p> <p>RR said that the Brandon Trust had recently undertaken a quality check of Southmead Hospital in Bristol. One of the recommendations is that a hospital passport being on a sheet of paper was of no use when it came to managing key risks, especially in a crisis or emergency situation. There should be a central system through which Social Care and Primary Care operate, therefore eliminating the need for and associated risk of an administrator being tasked with relaying information between departments in a timely manner. RR added that they were completing an Accessible Health Action Plan as in her auditing role she often found that they had not been filled in or the individual had not been involved in writing their own action plan, rendering them irrelevant and not fit for purpose. Her Involvement Group had designed a brilliant Accessible Health Action Plan that she would be happy share once signed off.</p> <p>RR invited any assistance from members in highlighting and progressing the issue.</p> | <p>PB team to liaise with JH</p> |
| <p>5.</p> | <p>Shine Together – Pentreath</p> | |
| | <p>JW informed the Board of Pentreath's Shine Together project.</p> <p>JW had questioned whether or not the organisation was reaching neurodiverse people who were experiencing mental ill health. She felt that it needed to consider the way that it communicated, the way that it held meetings and more.</p> | |

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| | <p>She put together autism acceptance training, which was then made mandatory within the organisation. What it highlighted was that all staff should have the opportunity to understand their feelings around working with people that may communicate or present differently to them and also how to work together effectively and ensure equity of service for all.</p> <p>That had led onto conversations about whether or not an autism and neurodiverse specific project was required. Were those people currently receiving the same level of linked up mental health support that other sections of the community received. The Pentreath Board then decided to self-fund a project to look at wide ranging issues including how it interviews applicants and ways of working. Everything about the project was aimed at hiring people that have lived experience or a diagnosis.</p> <p>The people that they would be working with would be able to work through their own understanding and self-awareness around their mental health, their autism and how they impact upon their lives, the lives around them and their environment. By building up that picture, when they were supported into work, education or training they would be able to educate the people that they worked alongside or received teaching from, hopefully creating a ripple effect of learning.</p> <p>As a starting point, only people with a diagnosis of autism would be asked to refer into the project.</p> <p>Recruitment would be underway soon, with the project live by January. Details would be shared once confirmed.</p> | |
| <p>6.</p> | <p>Break</p> | |
| | <p>The Board took a 10 minute comfort break.</p> | |
| <p>7.</p> | <p>Updates from Adult Social Care</p> | |
| | <p>Adult Social Care Peer Review Outcomes</p> <p>Kevin Beveridge, Area Director, Learning Disability and Autism, Cornwall Council had been unable to join the meeting but had recently given a presentation on the Peer Review to the Learning Disability Partnership Board. For information, that is attached as Appendix 2.</p> <p>TS thanked all of those who took part in the Peer Review. The feedback received from members of the Board had been important in informing the reviewers and the Council of the issues that needed to be addressed in working with people with autism.</p> <p>A priority would be around awareness and learning and development of</p> | |

staff. Another was the need to increase working in co-production.

The key findings from the report were:

- *Recognising the ambition to have people and communities at the heart of your systems (the fundamental 'flip' you talk about) – this is a big jump from where you are now and perhaps a step too far at the moment. We suggest making a smaller 'flip' to enable you to work on some fundamental areas that will help inform and guide your journey to the bigger 'flip' over time.*
- *Fundamentals to focus on:*
 - *Working together – all organisations, all agencies and people and families to have one vision of where you are going that you are all signed up to.*
 - *True co-production – there is some great work going on around engagement but taking a step further and making sure that 'nothing about us without us' is embedded at all levels is key.*
 - *Risk – working to develop a consistent approach to risk to enable people to get the lives they choose and reducing/removing a risk aversion culture.*
 - *Can-do culture – moving to a 'do with' rather than a 'done to' position. Giving all levels of the system (including people and families) the permission to be creative and solutions focussed so that you have shared problems to develop shared solutions.*
 - *Co-ordinate and build on what you have – you have great, values driven and passionate people in the system with lots of good things happening. Find a way to bring these together in a co-ordinated way to enable them to grow and develop.*

The Partnership Board and its members had been praised and the PB team, TS and Kevin Beveridge had already met to have initial discussions about progressing the recommendations.

TS referenced MR's idea for taking the Autistic Coffee Shop around Cornwall and said that the Peer Review had evidenced that people with LD liked to have the opportunity to talk with Social Workers, "in place", around the county. There could be an opportunity for the NAS to work in partnership with the Council to provide people with the chance to have conversations "in place" rather than waiting for reviews to come around.

As the Peer Review had drawn attention to how the mental health needs of people with autism were being addressed, TS invited NM to comment. NM highlighted that there had been a recognition that there was very little provided between the urgent crisis end for people with autism that don't have learning disabilities. Also noticed as gaps in provision were post-diagnostic support and cross agency support. MR cited the recent experiences of an autistic friend that had reached crisis point, highlighting

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| | <p>that it is not only the individual that is affected but also their immediate family and also the impact upon the additional services required due to the lack of early provision. NM agreed and said that it was vital that Cornwall Foundation Trust attended and contributed to the work of the Board in increasing focus on mental health issues.</p> <p>Following a request from DH, TS undertook to liaise with Kevin Beveridge to condense the slides into shorter but more accessible presentation. TS would share with DH direct.</p> <p>MH closed the item by saying that the outcomes of the Peer Review were very much in line with what the Partnership Boards had been pushing for for years – better cross-organisational working, increased and improved co-production with people with lived experience, and a structure that empowers the Boards to progress their work and recommendations to the bodies with the power to affect decision-making.</p> <p>Delivering Better Care – Update on Engagement Plans</p> <p>MH relayed the following update, which had been provided by Martha Reed, Strategic Commissioning Manager, Cornwall Council.</p> <p><i>Thank you to those who recently took part in the autism self-advocate and service user group discussion on care and support services. The findings from all of the Partnership Board and group discussions are being pulled together and will inform our future plans.</i></p> <p><i>Adult Social Care has a new leadership team and we are taking this opportunity to review our plans, projects and timescales. We are going to pause our engagement while we work together to ensure that our plans will deliver the right care, in the right place, at the right time.</i></p> <p><i>We are keen that experts by experience are involved in designing our engagement plans, and are also involved in facilitating future engagement events. We are committed to engaging with the Partnership Boards, self-advocates and service users and will provide a further update on our findings so far and next steps as soon as possible.</i></p> <p>MH said that whilst people may be disappointed with the delay in rollout, he viewed it as the new management looking to make sure that the correct approach was taken in order to achieve the necessary outcomes.</p> | |
| <p>8.</p> | <p>Mind The Gap – Bridging the Neurodivide CIC</p> | |
| | <p>Having run NAS Cornwall for 5 years, TP had spent a great deal of time sharing and promoting documents and information with organisations and the media. It was that experience that had led him to build a free online resource area for individuals, families and professionals to access.</p> | |

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| | <p>It was currently a "work in progress" so it would be tweaked and added to over the coming months and new links were always invited.</p> <p>The site could be accessed at: Resources Mind the Gap (tiggertraining.com). Members were encouraged to widely share the link to the site.</p> <p>It was designed to help people with language, with symbols and images and with knowledge of what it means to be autistic, PDA, ADHD etc. It was neurodivergent-led so the knowledge was shared by someone with lived experience.</p> <p>Members thanked TP for developing a resource that was accessible and educational for all.</p> | |
| <p>9.</p> | <p>Health Update and Feedback from Learning Disability and Autism Programme Board</p> | |
| | <p>NM referred back to the autism training referenced by IH earlier in the meeting. He had been working with the Workforce Development team within the health service and local authority to rollout Oliver McGowan training for people that had face to face contact with neurodivergent individuals. The training consisted of a couple of hours online followed by a full day in-person. The training was to be undertaken by all CQC registered services but the training in itself wasn't statutory, it was a recognised tool to meet a statutory aim. NM wondered how it could be adapted to meet the needs of people with autism but without a learning disability. TP added that the accessibility to tender for the programme was hugely neurodivergent unfriendly and he had raised that issue. With regard to making adaptations, there were many individuals in Cornwall that could contribute to helping with that. NM agreed and added that there was an opportunity to cram as many additional extras as possible in with the mandated training.</p> <p>Referencing the mental health discussions had at previous meetings, NM stressed the importance of having CFT representatives with knowledge in community services and access for people with autism at Board meetings. Jo Green, Service Manager, Community Mental Health Services, had provided the following feedback:</p> <p><i>I have discussed with Vicky Crowther (fellow Service Manager, Community Mental Health Services) as we are covering things together.</i></p> <p>1) <i>The mapping exercise – I think that this will be a good idea however I question doing this right now whilst in the biggest changes to the processes and systems across the whole of mental health in more than 30 years are being implemented. This is radical and cultural and particularly in relation to community Mental Health Services means that the map will not make any sense as even now the sands are changing so it is a movable thing. I</i></p> | |

am happy as is Vicky to engage and make this piece of work happen but would say that it may be futile to do this right now as would be outdated before even finished.

- 2) *People experiencing communicative issues when presenting to primary care and GPs & People not feeling comfortable in expressing their mental health with professionals.*
- *I think that we need to consider the needs highlighted when reviewing all the contact and process through transformation – since we are working on a more cohesive, accessible and more trauma informed way for people to access what they need.*
- 3) *Accessibility of information. – I am more than happy for us to collaboratively work on how to best present information to make it more accessible – and actually I believe we should be doing this for a variety of vulnerable groups we are ; I would also suggest if you have someone who is connected with this group who has lived experience of using our services then I think we should like to look at which engagement events would be helpful them to be involved in as an expert in their area to ensure we consider key things in transformation. I think that this is the best way for you to enable us to make effective changes to the way we do things that increases accessibility and it ensures you have a voice in the changes;*

To provide context, community services for mental health were undergoing transformation as part of the NHS Long Term Plan. Jo's suggestion was that it would be preferable to see that process through before addressing pathways and accessibility. Through the chat function, MR said, 'Surely working together now on that strategy and pathway is better than "waiting until the dust settles". While things are being changed that's the perfect time to work with others to change them for the better.' DH added, 'I think Autistic people should be involved with the decisions being made in the Transformation process now not after it's happened.'

NM had also provided Jo and Vicky with information on proposals within CFT to roll out training to psychologists and other mental health professionals on working with people with autism who were experiencing mental health crises. A response as to whether funding was available was awaited.

The Autism Intensive Support Team continued to be developed but hadn't gone live yet due to further recruitment delays. Some work was being undertaken but they were not fully functional. The intended go live date was now December. TS added that Philip Hanscombe was working with the Council's Partnership Managers and Lead Social Workers to promote awareness sessions, designed by autistic people, within the Social Care workforce.

NHS England wanted to hear about waiting lists for people with a diagnosis of autism. Dr Rebecca Jelbert and Sue Newman, Children's Services, had provided figures which were way beyond what NHS England had anticipated.

| | | |
|------------------|---|----------------------------------|
| | <p>CFT were expanding its diagnosis service for adults and were in the process of recruiting, having almost doubled resources in that area. That would address the current level of referrals but wouldn't necessarily reduce the waiting list.</p> <p>RCHT was expanding access to its services to 7 days per week.</p> <p>NM had been looking at Cornwall's previous Autism Strategy and had wondered if there would be value in the Board revisiting it and particularly its implementation plans, which were still relevant as many of them had not been achieved. From a Health perspective it was important to have clear intentions that held people to account. MH agreed that the Board needed to be able to hold both health and social care to account through scrutiny of the implementation of plans, both statutory and local. NM suggested that an overarching strategy owned by the Board would allow that.</p> <p>TS asked if a system wide approach to Oliver McGowan training had been developed. She said she ensure that Council Practice Education and Development were linked in. NM said that an initial discussion had taken place within the Integrated Care System but a steering group had not yet been formed. He would request an outline plan and request that it comes to the Board. TS suggested that the Learning Disability and Autism Programme Board could adopt the work to be completed over the next few months. MR emphasised the need to have autistic people lead on the design and delivery of training. It was also essential to have autistic people involved in conversations from the start of the process, not brought in when plans had already evolved.</p> <p>JR said that she had voiced to Health Education England that the training was very heavily LD based and was not for neurodiverse people. With regard to employing people with lived experience to deliver the training, that had not yet been possible as the training packs had not yet been provided. She added that RCHT were working with CFT to ensure that rollout was uniform and across service. TS said that the Council's Learning and Development Team and its provider workforce should also be included.</p> | |
| <p>9.</p> | <p>Any other business</p> | |
| | <p>Language</p> <p>Through the chat function, IH asked, <i>'Can I make a plea to everyone regarding language? I know that its difficult due to decades of established practice but can we try to avoid using terms such a people 'with Autism' or 'having Autism'. Many of us regard ourselves as Autistic as opposed to having or suffering from something! Use of 'condition orientated' terminology is quite triggering for many of us (albeit not all!).'</i></p> <p>TP guided everyone to his Mind The Gap resource, which provided links to up to date information on the matter. TP agreed to assist the Partnership Boards team in devising a short piece of guidance to be relayed at the start of future</p> | <p>PB Team to liaise with TP</p> |

| | | |
|------------|--|----------------|
| | <p>meetings.</p> <p>Easy Read Appointment Letter</p> <p>JR had progressed plans for an easy read letter for all hospital appointments and asked if it could go to the next meeting of the Board for comment.</p> | To Nov meeting |
| 11. | Future meetings | |
| | <p>The next Autism Partnership Board meeting was scheduled for Tuesday, 15 November at 10 am on Teams.</p> <p>MH said that the other Partnership Boards were all now hybrid and asked if this Board wanted meetings in 2023 to be held that way. To hold a hybrid meeting the team would need input from autistic Board members about the suitability of a venue prior to booking.</p> <p>RR suggested that the Brandon Trust's Bodmin offices could be suitable. TF would liaise with RR.</p> | |

Questions Submitted to DWP

1. What training do DWP staff receive in understanding Autism and learning disability?
2. First question(s) to ask any person when they first present, be it in person, on the telephone or online – Do you identify as someone with additional needs? If yes, how would you describe your additional needs?
3. Should the answer to the above be yes, a Needs Assessment needs to be obtained within a set timeframe. The knock-on effects are life restricting – no bursaries, dental treatment etc. Refused Work Capability Assessment – no access to work support groups. Lacking in NI contributions, leading to pension access issues.
4. People require not only support to find work but also a “buffer” which ensures that they are not financially worse off for attempting or undertaking work. There are people with Autism that want to work but have conditions that are limiting in terms of committing to set hours and/or regular working patterns. How will you supply the support required for your staff to source appropriate work and for customers to understand requirements and restrictions within the system? Do you recognise how limiting working hours to 16 per week rather than having a system that permits people to do more when they are able to, people can become trapped within the poverty threshold?
5. Do you recognise that undertaking X amount of hours of voluntary work does not necessarily mean that an individual could undertake the same hours in paid employment. Employers see free labour as a bonus and therefore expectations and pressure on staff are lower.
6. Following on from 3., it feels as though staff are instructed in ways in which to avoid offering support. Even when appropriate support is provided, people are not instructed of the potential for sanctions or reduced/complete loss of support. Early Needs Assessments and Work Capacity Assessments would proactively reduce such issues from occurring.
7. Questions posed by DWP staff verbally or in paperwork/online are always phrased in terms of why the individual cannot work. This leads to negative responses in which people feel the need to “play dumb” to emphasise disability or restrictions rather than positively focus on what they could do. For people with a learning disability in particular, friends, support workers and family build up their confidence by emphasising what they

can do; the DWP approach makes them focus in a dispiriting way on what they can't do. Why is this approach adopted and would you be willing to review it?

8. In an ideal world, the Job Centre would have a department with specialist knowledge of LD, Autism and other disabilities in order to ensure individuals are effectively supported. In the presumed absence of funding for such a department, how could you mitigate the issues?
9. Personal interests and peer support are key elements in empowering individuals to work and to have the confidence to progress. How do you take these factors into consideration when supporting people with Autism and/or LD?
10. Would it be possible to produce a map of how systems interlink across health and social care?
11. Letters are sent in standard format, which leads to people being unable to read them, missing deadlines and then being subject to the consequences, which can be debilitating and life-changing. Please detail how the DWP meet the Accessible Information Standard law, which states that people with a disability or sensory loss are given information they can understand, as well as the communication support they need.
12. Following on from 11, please could you detail the safeguarding measures in place to protect both your staff and customers? This should apply both to interactions within Job Centre premises and through postal communications.
13. Cornwall is currently suffering from a severe lack of advocacy support. What could the DWP do to mitigate that? Would it be possible to form independent advocacy arrangements to ensure that those that require support and guidance receive it?
14. What measures do you take to identify carers or other support for your customers, as well as "legacy support" in place, should something happen to their carer/support?

Members really emphasised that many of the issues could be overcome through training. Key to that would be neurodiverse individuals leading in both design and delivery.

Tasha Milton, our DWP representative on the Partnership Boards, has undertaken to ensure that responses are provided to the matters raised and attend Board meetings in the Autumn.

Local Government Association

Cornwall Building the Right Support Peer Review

Feedback Presentation

22nd July 2022

Care and Health Improvement Programme

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Local Government Association

Agenda

1. What is a Peer Review
2. The Peer Team
3. What the peer review team do (the process)
4. What is looked at (the scope)
5. Feedback
6. Your thoughts and questions
7. Discussion
8. Next steps

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Peer Review explanation

Peer reviews look at what and how things can improve (get better) and what is working well already

A peer team is invited by the area as 'critical friends'. This means the team all bring their experience of doing this work.

We have given daily feedback to colleagues so they understand what we are finding out and there are no surprises.

All the feedback and recommendations the peer team give are checked from what we have read, heard and seen. We also make sure it is found three times or more. We call this triangulation.

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Peer Review explanation

We don't share who has said what
People have been open and honest with us.

We have held up the mirror and to reflect back what is happening across Cornwall

We have been really well supported and made to feel very welcome. Special thanks to Tamsin, Sarah and Suzanne for supporting us. Thank you to Proper Job who have kept us all well fed with lovely lunches

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Peer Review Team

- Di Domenico** is a Senior Programme Lead for Strategic Commissioning in NHSE England Learning Disability and Autism Programme, she brings her experience of commissioning in health and social care
- Sam Prowse** is an expert by experience and works for Hertfordshire Council as an Expert by Experience Advisor
- Kirsten Peebles** is parent of an autistic teenager who has been detained. She co-chairs the Building the Right Support Advisory Group and works with the British Institute of Human Rights and NHS England Parent Council delivering human rights training. Kirsten is part of the NHS England Children & Young People quality improvement taskforce
- Jez Harris** is an expert by experience; parent, who supports Lancashire with their Small Supports development. He also participates in C(E)TRs through NDTi and works on various projects to end restrictive practices
- Vicky Rogers** is a Head of Quality and Compliance for SECO support providing bespoke services to people leaving hospital and people at risk of admission supporting them to live well in their community

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Peer Review Team

- Kirstie Haines** is a specialist in learning disability and autism improvement programmes and is currently working with the Local Government Association
- Bev Stockton** has been a Director of Adult Services (DASS) in various Councils including Bradford and a Manager in a Learning Disability Team
- Catherine Nolan** is West Midlands Association of Directors of Adult Social Care (ADASS) regional lead for learning disability and autism. She was also a commissioner
- Nikki Henderson** is a Senior Adviser on the Building the Right Support programme at the Local Government Association Care and Health Improvement Programme
- Sue Gale** is a Assistant Director for Learning Disability and Autism, Building the Right Support, in Local Government Association Care and Health Improvement Programme
- Kay Burkett** is the Peer Review manager, she has worked with places and systems supporting health and social care integration and currently leads on public health improvement for the Local Government Association


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Local Government Association **The process** Information Classification: CONTROLLED



In 4 days we:
Read over 40 key documents



Met over 120 people including 4 visits across the county



Feedback on 22nd July 2022

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Local Government Association **What is looked at (The Scope)** Information Classification: CONTROLLED



How does the System work for people?
Do all the different services and parts of the system work together so people have good lives?
What are the barriers for people and families?

TCPs



Plans

Are the things the partnership is involved in Sustainable?
Is the everything planned to last or just fix a problem in the system now?
Is there a plan that people know about, and everyone is trying to make it happen?

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Local Government Association **What is looked at (The Scope)** Information Classification: CONTROLLED



Capacity to deliver: Can the partners provide the services that people need in their area
Can they keep the quality to a high level?
Can they develop new services and keep doing the work they need to do?
Can they make the priorities in the plan happen?




Service design: Is the partnership designing services and plans using the best practice guides? Building the right home & building the right support
How are people with lived experience and families involved in designing the services?


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Local Government Association **How we will give you the feedback** Information Classification: CONTROLLED



Things that you need to think about



Recommendations

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Local Government Association **Some quotes...** Information Classification: CONTROLLED



"a personal assistant I employ is a single parent with 2 kids in early teens... was given notice leave her property in lockdown, faced being housing in a premier inn, at the twelfth hour found a place... The rent was £1200 a month. It doesn't add up" re Direct Payment amounts

"I sat watching social care and CHIC argue in my own home"

"Some families are rejecting Adult Social Care due to charging"

"Diagnosis makes no difference to others, does to self"

*"Everybody thinks they know what people should be doing but..."
Re understanding of roles and responsibilities across organisations*

"What we need is a joined up approach to health and care so nobody falls through the gaps"

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Local Government Association **Key Messages** Information Classification: CONTROLLED

- We had the privilege of meeting passionate and committed people who are driven to improve the lives of people
- We know you are on a journey and we can see you have plans in place to move things forward and improve peoples' lives. As you move out of the pandemic there is an opportunity to accelerate the scale and pace of delivery taking people with you
- You have some fantastic self advocacy organisations for families of children and people with a learning disability from the legacy of previous investment - an opportunity for you to re-engage and benefit from hearing their voices
- Creative work is happening in pockets despite the system which is leading to good outcomes for some people - this needs to be enabled to have maximum impact across the system
- There is a disconnect between health and social care - and between strategic, operational teams and community
- There are some significant gaps around provision for autistic people which needs to be addressed urgently
- There is no defined crisis support pathway creating significant pressure in the system

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Local Government Association Information Classification: CONTROLLED

Key Messages continued

- The risk adverse approach is not enabling people or supporting them to live 'lives of wonderful ordinariness'
- Recognising the ambition to have people and communities at the heart of your systems will require a significant shift in your approach
- We recognise the challenges you face with helping people find their own home, find good quality support and workforce within Cornwall
- There are workforce challenges nationally that we see in Cornwall in securing a great workforce
- Working together and including people, families and providers everyone can benefit and develop new and more creative opportunities

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Local Government Association Information Classification: CONTROLLED

Issues important to self advocates and families

- Lack of autism specific services – mental health, local offer, drop in centre, front door to services
- Recruitment/retention of Personal Assistants – pay rates
- Crisis and prevention
- Training front line services
- Employment
- No provision/support after 25 – day services closing, transport issues, no activities especially for those with most complex needs
- Transition service needs improvement
- Poor communication & lack of consistency
- Respite services – no choice or control

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Local Government Association Information Classification: CONTROLLED

Co-production and recognition

"No self advocates on the ASD board are paid for their time"

"Easy read documents are not available"

"Lack of understanding of my autistic identity and a lack of reasonable adjustments impacts on my emotional state and my mental and physical health"

"We don't get listened to, we get fussed on"

"They say they're listening but they don't listen"

"I was one of the original members of the LD Partnership Board but left when I realised I was a tick box."

"We need help finding our neurodiverse kin. It's our informed therapy"

"we need understanding and acceptance of autism not awareness"

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Local Government Association Information Classification: CONTROLLED

Lack of Autism Specific Services

"There's nothing beyond the age of 25"

"There are NO autism specific mental health services. You fall through the gaps"

"Due to the lack of multi-agency collaboration, I missed opportunities to access support. I shouldn't feel I'm not worthy of that support"

"GP and frontline services do not understand Autism. Even though they are the gatekeepers"

"If you are autistic, mental health services will not touch you. They say they don't know how to help you"

"Children end up excluded from school because of the lack of support for parents at the end of their tether"

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Local Government Association Information Classification: CONTROLLED

Personal Assistants

"We have had to refuse direct payments because PA will not work for the wages on offer"

"The agencies are ripping off the council while parents can't recruit and retain good staff at only £10 per hour"

"The council will quibble over paying to retain good staff when I'm saving them thousands by supporting via direct payments"

"They paid for a sensory assessment but wouldn't then pay for the recommendations made"

"The funding for autism training by NAS has stopped. The need has not"

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Local Government Association Information Classification: CONTROLLED

Financial Assessments

"The Financial Assessors don't understand autism or learning disabilities. My son needs activities and a sensory diet. They asked – why can't he just walk round the block and get the wind in his face?"

"Everyone just argues about who's funding what. In the meantime people are suffering"

"I said I couldn't attend a financial assessment meeting because my mum had just died. The assessor said if you don't attend the meeting you'll have to pay for all the services."

"Financial Assessors challenged the fact I'd bought my daughter's sheets from M&S and told me I should have bought them at Primark because it's cheaper. The difference is only a pound"

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Local Government Association
Information Classification: CONTROLLED

Advocacy, Employment and Activities

"All the money goes to statutory advocacy. There's no money left for advocacy groups to deliver the support we need"

"We want to work, we don't want to live on benefits"

"The local offer webpage is so outdated it's crap. Half the organisations on there don't exist any more"

"We want a mobile drop in centre. To overcome the need for multiple sites"

"Staff will listen to paid advocates. Self advocates should be taken seriously"

"Services should be staffed by autistic people"

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Local Government Association
Information Classification: CONTROLLED

People's views on the system

"There appears to be more people in NHS strategic positions who are listening more. But there is still the impenetrable middle layer"

"There's no crisis pathway. The council tells us to phone the police"

"It's the odd person who is good, not the systems. It's the extra milers who are good"

"I'm over 60 and trying to get my son settled for life. We're on the housing list but there's nothing to bid on."

"Front door is inaccessible by telephone. It's inaccessible unless you can use technology"

"They keep moving the deckchairs and your support changes"

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Local Government Association
Information Classification: CONTROLLED

Local Context & Whole System Working

Strengths

- There is a vision for adult social care in Cornwall – 'Delivering Better Care'
- There are creative and passionate people across Cornwall who want to see change and are motivated to be involved
- Robust self-advocacy and people with lived experience who can help shape policy and do quality monitoring with opportunities for this to have stronger recognition and impact
- Parent Carer Forum 0-25 is a real strength:--
 - parent-to-parent peer support
 - helps individuals and families to navigate through the system
 - For professionals for information
 - they are entrepreneurial and regularly secure new funding into Cornwall
 - Parent carers have a really good understanding of local systems and awareness of local pressures – and can provide innovative ways to overcome these
- There are good relationships between the adult and children's teams who are happy to support and challenge each other in a positive way to create better outcomes for people
- The parent carer forum for children and young people were positive about the CETR process and feel this is effective

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Local Government Association
Information Classification: CONTROLLED

Local Context & Whole System Working

Strengths

- Discharges from hospital have occurred and people are living back in their local area
- The Integrated Care Board have identified executive roles for people with a learning disability, autistic people and SEND
- We have heard really positive examples of the key worker pilot and the difference it has made to children and families
- We have seen some joint long term strategic approaches to housing in the Council
- Blue Light meetings were seen as a positive way to bring people together when there is an emerging crisis
- At operational level there is appreciation of the challenges being faced within adult social care

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Local Government Association
Information Classification: CONTROLLED

Local Context & Whole System Working

Areas for further consideration

- There is no clarity on what the collective vision is for people with a learning disability or autistic people within Delivering Better Care and other plans
- Lack of overarching strategies for people with a learning disability and autistic people
- The is no oversight in relation to the partnership boards with missed opportunities to:
 - meaningfully engage and hear people with a learning disability, autistic people and families
 - have collective responses to issues and actions
 - create a golden thread to inform practice, processes and all levels of decision making
 - For the partnership boards to be owned by people
- Access to the Intensive Support Teams is difficult to access for people who are not known to services
- Thresholds and processes are being interpreted differently in relation to safeguarding and this is making it hard for people and providers to enable consistency when making referrals
- There is a reliance on providers to conduct safeguarding investigations and report back to the system providing minimal evidence – we have not seen how quality oversight works when providers are required to undertake safeguarding investigations themselves
- The whole system isn't utilising the range of opportunities to be responsive and maximise best use of resources through conversations across health and social care within the localities e.g., decisions relating to respite
- Where people are working in silos there are examples of duplication and gaps e.g., production of learning disability strategies

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Local Government Association
Information Classification: CONTROLLED

Local Context & Whole System Working

Areas for further consideration

- Communication with the workforce, partners and families on key issues or changes is inconsistent and not joined up
- Centralised budgets are restricting opportunities for place based prioritisation and solutions
- The Council's website is not accessible for people and parent and family carers and can be confusing to navigate
- There is a lack of consistency regarding positive risk taking which is leading to individuals or teams holding all the accountability as well impacting negatively on people's lives and opportunities

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Local Government Association **Sustainability** Information Classification: CONTROLLED

Strengths

- Having some new key strategic permanent appointments is viewed as very positive and seen as an opportunity enable sustained change
- There are some great staff - practitioners, commissioners and managers - who are taking dynamic approaches in several areas of practice e.g., Learning Zones to complement formal training and continuous professional development
- There are pockets of innovation across commissioning and practice
- People working across the system are keen to hear about good practice and are committed to continuous improvement; and shared learning
- New approach to data reporting bringing together children's, adults and public health reporting – opportunity to think creatively about how outcomes and assets are report alongside areas for improvement.

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Local Government Association **Sustainability** Information Classification: CONTROLLED

Areas for further consideration

- There are a couple of key elements of work and functions being held by a few people – who are in demand with regard to their input and knowledge - with a lack of succession planning for these key roles
- People are getting on a doing things because they need to be done with elements of firefighting to respond to people's needs that are not necessarily addressed by the system
- People are keen for change - but wanting future changes to have the opportunity to be embedded based on clarity about direction, vision, partnerships and best practice
- Lack of a positive risk management agreement across health and adult social care
- Existing provider market not meeting the vision or needs of people causing pressure across the system e.g., respite, short break, Personal Assistants
- There is a shared acknowledgement that there is a tendency towards a risk averse culture and the need for the development of a positive approach to risk management that is shared and owned by partners, people with lived experience
- Access to data requires further work to ensure the depth and scope of this intelligence is available to inform decision making and provide insights to impact on outcomes for people
- Personal Assistant rates not in line with Care at Home rates means that people are struggling to recruit and retain PAs with missed opportunities for early conversations with people who have PAs which may have helped to understand the implications and impact
- A focus on cutting services to reduce spend – rather than looking at how investments on early intervention and prevention activities could reduce spend in the future

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Local Government Association **Capacity to deliver** Information Classification: CONTROLLED

Strengths

- Work by the Children's Trust taking an integrated approach is successfully keeping children at home and out of hospital
- Children's Multi Disciplinary Teams crosses organisations and includes youth workers and social workers
- Use of community education and treatment reviews for children is effective at keeping children out of hospital
- Social work training and development includes health, rights and strength based approaches.
- There was an example of individual's influencing how their provider trains staff – responding to the individual person's aspirations
- Evidence of positive approaches to support – for example someone was supported to go away over night to a concert
- Social care provider with a strong focus on reducing health inequalities where 100% of people supported have had a health check.
- Relaunch of adult dynamic support register – building on the Dorset best practice – just at the beginning but real opportunity to shift towards earlier prevention
- Recognition that a post-diagnostic autism pathway is an area needing some priority attention

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Local Government Association **Capacity to deliver** Information Classification: CONTROLLED

Strengths

- Innovative approach to working with inpatients by the ICS – including using life coaches
- Autism Diagnostic Team is becoming a multi-disciplinary team – and they have a clear aspiration to establish post-diagnostic support networks for autistic people.
- Mental health commissioners are clear that there is funding to invest in the autism pathway

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Local Government Association **Capacity to deliver** Information Classification: CONTROLLED

Areas for further consideration

- The diagnostic and support system for autistic people is underdeveloped
 - Creating long-delays for autism diagnosis
 - No pre or post diagnostic support
 - Peer support for autistic adults is not there
 - Family carers are unclear about the therapeutic offer for autistic adults (SALT, OT, physio and IAPT) is and how they access it
- Provision for autistic people is limited
- Outcomes from diagnosis referrals have been received via a letter, this is not good practice
- Carers spoke of their experiences of not being spoken to about large changes in care packages or closure of day services
- Family carers are not getting the information they need from the statutory agencies – at times of crisis or other transition points
- A 'waiting list' for accommodation with support of 136..

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Local Government Association **Capacity to deliver** Information Classification: CONTROLLED

Areas for further consideration

- Leadership confusion amongst providers and practitioners about who will be leading work to redesign and commission the accommodation and support offer from '23 – when the current contract ends
- Gaps around training:
 - Learning disability and autism understanding
 - Reasonable adjustments
 - Communication
 - Sensory environments
 - offer to commissioners
- The employment offer that is being developed sounds really exciting and innovative, but there needs to be a plan in place that draws together the different agencies and sets out who is doing what – this would benefit people's employment opportunities external to the council
- We heard that communication from the council and the NHS to families and individuals is often poor and reasons for why things have changed is often unclear

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Local Government Association **Capacity to deliver** Information Classification: CONTROLLED

Areas for further consideration

- We heard from practitioners that risk is not always shared between agencies and senior managers understanding need to be aware of what risk in the community looks like for individuals on the Dynamic Support Register and inpatients
- Payment to social care providers – cashflow is key to the survival of services – but we heard that invoices can take a long time to pay especially if there are errors
- People with lived experience are not recompensed to attend meetings – this will mean that people who can not afford to have time off work or have caring responsibilities will be unable to attend these meetings

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Local Government Association **Service Design** Information Classification: CONTROLLED

Strengths

- Staff in the council and the NHS have shown a person-centred drive and really want to work in ways that allows them to do this
- Parents and family carers worked with the transitions team to identify what does/does not work and parent/family carers and influenced the neurodiverse pathway
- Parent Carers Forum and the Partners in Policy Team have developed services and are trusted by families and people with the potential to do more with a some additional funding
- Parent Carers Forum was provided with flexible covid funding from the CCG that could be used to meet sensory needs during lockdown – empowering decisions about how to spend money to meet communities needs

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Local Government Association **Service Design** Information Classification: CONTROLLED

Areas for further consideration

- Leisure and day opportunities for those who cannot access training and employment are not easy for parents to access and even when they can access transport becomes a barrier because some provision is many miles away from their home.
- Working and influencing DWP as the offer for disabled people is very slow and without reasonable adjustments, with long waiting lists causing unnecessary delays for people wanting to work
- The post Covid respite and social care placement offer is undeveloped in places and it feels to parents that hospital discharges are being prioritised; so an opportunity to prevent carer fatigue or care breakdown is lost
- Transition to adult services: pathways and transitions for social care and health need to be clear about what criteria are being use to set the age at which transition planning is initiated. We heard from parent and practitioners that this varies from 16 years to the day before their eighteenth birthday. How transition into adult services works needs to be better communicated for parents

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Local Government Association **Service Design** Information Classification: CONTROLLED

Areas for further consideration

- The current mental health community team offer and crisis support feels inaccessible to individuals and their families – with an individual's disability being used to explain their presentation rather than their mental health needs
- Why has the Autism Intensive support team taken a long time to get established and secure its staff base, this is welcome service but is currently closed to new referrals
- Current needs assessment for adult social care eligibility and care planning was too focussed on fitting people to available services – not enough building on strengths and helping them realise their aspirations
- Financial assessments feels clumsy and unhelpful to individuals and families.
- Communication in relation to Direct Payment; Individual Service Funds and Personal Budgets not clear or accessible

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Local Government Association **Service Design** Information Classification: CONTROLLED

Areas for further consideration

- Currently not maximising quality assurance to:
 - get ahead of potential failure/deregistration and supporting providers before they 'Require Improvement'
 - Respond to safeguarding and issues that are being flagged
 - Learning from recent events.
 - Share quality concerns between health and care partners
 - Work proactively with the whole provider market

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Local Government Association **Service Design** Information Classification: CONTROLLED

- Recognising the ambition to have people and communities at the heart of your systems (the fundamental 'flip' you talk about) – this is a big jump from where you are now and perhaps a step too far at the moment. We suggest making a smaller 'flip' to enable you to work on some fundamental areas that will help inform and guide your journey to the bigger 'flip' over time
- Fundamentals to focus on:
 - Working together – all organisations, all agencies and people and families to have one vision of where you are going that you are all signed up to
 - True co-production – there is some great work going on around engagement but taking a step further and making sure that 'nothing about us without us' is embedded at all levels is key
 - Risk – working to develop a consistent approach to risk to enable people to get the lives they choose and reducing/removing a risk aversion culture
 - Can-do culture – moving to a 'do with' rather than a 'done to' position. Giving all levels of the system (including people and families) the permission to be creative and solutions focussed so that you have shared problems to develop shared solutions
 - Co-ordinate and build on what you have – you have great, values driven and passionate people in the system with lots of good things happening. Find a way to bring these together in a co-ordinated way to enable them to grow and develop

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Things to think about (recommendations)



- You need to **dedicate time as a whole system with people and families, to design, commission and communicate the whole crisis pathway for Cornwall**, recognising and addressing the unique needs of people with a learning disability and autistic people and making sure staff can meet peoples needs
- You need to jointly address the quality and capacity issue you have in health and social care and work with good providers as equal partners to develop solutions
- Where people with a learning disability and autistic people are included within your mainstream offers and support, you need to ensure adequate training, support and understanding to communicate, respond and meet the needs of the person





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Things to think about (recommendations)




- Partners need to come together at all levels to develop a plan about how they move away from responding to crisis, to move towards working in a more cohesive way that ensures less firefighting and supports people to remain in their own homes and communities
- Take the opportunity to create an environment where staff are:
 - empowered to work creatively
 - feel supported
 - able to share when things might not go according to plan
 - provided with opportunities to have open conversations with senior managers
- Co-produce a vision for people with a learning disability and autistic people in Cornwall
- Consider refreshing the Carers Charter as a way of ensuring the role of a carer is acknowledged, respected, their needs are met and they have access to the services and support they need
- Plans to update the market position statement could be an opportunity to be specific about what is needed to support people with a learning disability and autistic people – and to really engage individuals with lived experience in what the market needs to do

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Your reflections and questions

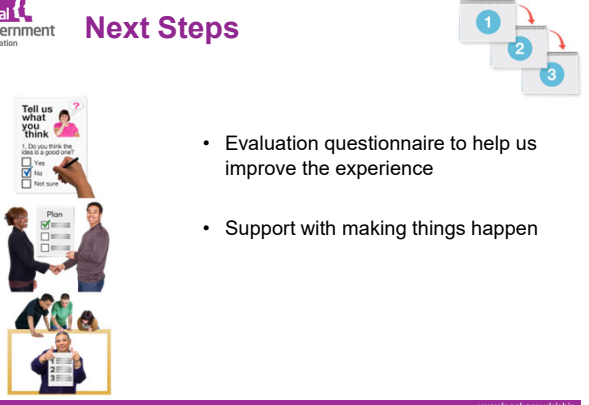


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Next Steps



- Evaluation questionnaire to help us improve the experience
- Support with making things happen

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Thank you

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