



Autism Partnership Board

Agenda - What we will talk about

(Microsoft Teams link: <u>Click here to join the meeting</u>)

| March 14 | Meeting Date: 14 March 2023 |
|-------------|---|
| | Venue: Truro Library Top Floor meeting room Union Place Truro TRI 1EP |
| 10:00 | Welcome and refreshments 10.00am |





| 10 10 10 10 10 10 10 10 10 10 | Please sit down (Meeting time: 10.30am to 12.30pm) |
|--|---|
| | Welcome, introductions and apologies Councillor Sally Weedon, Chair (10:30-10:45) Meeting Guidance – Page 5 |
| | Minutes and actions from the last meeting. Easy Read version – Page 6 Standard version – Page 14 10 minutes (10:45-10:55) |
| Any updates | Updates from members 30 minutes (10:55-11:25) |





| | Break 10 minutes (11:25-11:35) |
|---|--|
| CORNVALL COUNCIL one and all • onen hag oll | Individual Service Funds Antony Bell-Thorn, Cornwall Council Page 30 (11:35-11:50) |
| Cornwall and Isles of Scilly | Health Update and Feedback from the LDA Programme Board Nory Menneer 10 minutes (11:50-12:00) |
| Department for Work & Pensions | DWP – Response to Questions from Service Users Trudie Binnie and Anna Clemens Page 40 10 minutes (12:00-12:10) |





| Âû 🚫 | The Autistic Community of Cornwall |
|---|---|
| The Autistic Community of Cornwall Supporting our neurokin - promoting understanding and acceptance | Update on its work |
| Website: theautisticcommunityofcornwall.org Email: info@theautisticcommunityofcornwall.org | 15 minutes (12:10-12:25) |
| | Any Other Business 15 minutes (12:25-12:30pm) |
| 11 12 1 9 8 7 5 12:30 | End of the meeting |

Future Meetings:

It is intended that all meetings are in person and on Microsoft Teams.

Venues will open at 10:00 am for refreshments.

Meetings will begin at 10:30 am online.

Tuesday, 20 June 2023 - Venue to be confirmed

Tuesday, 12 September 2023 at County Hall, Truro

Tuesday, 12 December 2023 - Venue to be confirmed

Meeting Guidance – Keeping Members Safe

- Everyone has the right to meet in a safe atmosphere.
- All voices have the right to be heard.
- Work in partnership with each other. Listen and respect each other's views
- Do not single out individual Members.
- Do not interrupt. Be guided by the Chair.
- Do not share private information outside of the meeting.

Healthwatch Cornwall operate a Zero Tolerance policy on Bullying and Harassment.

This applies to both face to face and online meetings.



Autism Partnership Board Meeting



15 November 2022



Who was there

| Name | About them |
|---------------------------------------|---|
| Tanya Falaschi (TF) (In the Chair) | Healthwatch Cornwall |
| Mike Hooper (MH) | Healthwatch Cornwall |
| Christopher Burns (CB) | Service User and disability campaigner |
| David Allkins (DA) | Cornwall Council |
| David Burns (DB) | Citizen Checkers and Healthwatch Cornwall |
| Ian Hutchinson (IH) | Cornwall Partnership NHS Foundation Trust, National Autistic Society Cornwall Branch and Autistic Community of Cornwall |
| Jason Pape (JP) | Proper Job Café and Maritime Museum |
| Julie Atwell-Cook (JA) | Cornwall Council |
| Julie Pape (JP) | Cornwall Council |
| Julia Wildfire-Roberts (JW) | Pentreath and Healthwatch Cornwall |
| Karen Hooper (KH) | Cornwall Council |
| Marie Ralph (MR) | National Autistic Society Cornwall Branch and Autistic Community of Cornwall |
| Michelle Lobb (ML) | Parent Carers Cornwall |
| Nory Menneer (NM) | Cornwall and Isles of Scilly Integrated Care Board |
| Paul Owen (PO) | Cornwall Council |
| Philip Hanscombe (PH) | Cornwall Partnership NHS Foundation Trust |
| Rebecca Jelbert (RJ) | Cornwall Partnership NHS Foundation Trust |
| Shelagh Mitchell (SM) | Cornwall Council |
| Tina Sanford (TS) | Cornwall Council |

What we talked about at the meeting



Everybody agreed that the minutes of the September meeting were correct.

Updates from members



Mike said that the **DWP** had not replied to the questions that Board members had asked.

Department for Work & Pensions

He would try to get answers.



Money was needed to hold **Blue Light Day** in 2023.

Sally Weedon will talk to the Council to see if they will give funding.





Board members will be speaking with the **Police** about some things.

- Training to understand mental health and autistic meltdowns better.
- Adding an autism alert to the new Hospital Passport app.

That would be instead of having an Autism Alert Card.



Cornwall Council and the **NHS** want to work together to make sure that they train their staff about autism.

It is very important that training is led by autistic people so they are working with The Autistic Community of Cornwall



The Advocacy People now has staff to work with the Partnership Boards.

They would tell us their plans at the next meeting



Adult Social Care



Cornwall Council was reviewing its **Direct Payments** Policy.

They want to make the process easier.

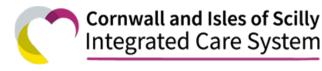
If you receive Direct Payments you can go to a meeting at the Venton Conference Centre on 30th November.

You need to tell them what questions they need to ask people.



The **NHS** and **Adult Social Care** has to make sure that staff had **Oliver McGowan training.**

They want to work together to make sure they all receive the same high standard training. People have to wait a long time for autism assessments.



Young people told the **NHS** that their parents need help to support them while they wait.

There are 3 events to talk about making changes.

Mike will email the details.



Autistica wants to make sure that every autistic person can have an Annual Health Check.

Nory will invite them to work with this Board.



Julia Wildfire-Roberts was doing a project for **Pentreath** called **Shine Together**.

She wants to make sure that autistic people get good mental health care.

By helping people into work, education or training it will help others to learn too.



The Women's Centre Cornwall is working with **Age UK** on the abuse of elderly people.

Dina Holder is making sure that autistic individuals are able to tell their stories.

Phillip Hanscombe said the **Autism Intensive Support Team** service would start online in the new year.

It will offer urgent help to autistic adults or people with mental health issues.

Dr Rebecca Jelbert from **The Adult Autism Assessment Team** said it can take up to 4 years to get an autism assessment.

They have taken on more staff to slow down the waiting list.



David Burns said **Citizen Checkers** are supporting 2 people that have been put in hospitals out of Cornwall.

One has been able to return home.

The other person will go home later that week.





Paul Owen from **The CHAMPs** said the **Safe Places** was running again.

The CHAMPs have a new song to get people to get their vaccinations

Shelagh Mitchell said they would love to record it and asked if anyone could help.

Mike Hooper from the **Partnership Boards** team wants to plan for next year.

Members talked about what the Board needs to be the best it can be.

People said:

- A plan of what we will talk about at every meeting.
- Small groups to look at different topics.
- More money.
- Meetings in person are better than online.
- The Board needs to celebrate all of the good things that it does.
- Talk to Boards from other areas about their work.

Meeting dates for 2023 will be sent out soon







| MEETING NOTES: | Meeting of the Autism Partnership Board | |
|----------------|---|--|
| DATE: | Tuesday, 15 November 2022 | |
| LOCATION: | Via Microsoft Teams | |

ATTENDANCE

| Name | Position | Organisation | |
|--|--|--|--|
| Tanya Falaschi (TF) (In the Chair) | Partnership Boards Project Officer | Healthwatch Cornwall | |
| Mike Hooper (MH) | Partnership Boards Officer | Healthwatch Cornwall | |
| Christopher Burns (CB) | Service User and disability campaigner | | |
| David Allkins (DA) | Autistic individual and Revenue and Benefits Administration Assistant | Cornwall Council | |
| David Burns (DB) | Autistic Individual and Community Promoter | Citizen Checkers and Healthwatch Cornwall | |
| Ian Hutchinson (IH) | Autistic individual, Clinical Nurse Specialist – CAMHS and Neurodevelopmental Practitioner | Cornwall Partnership NHS Foundation Trust, National Autistic Society Cornwall Branch and The Autistic Community of Cornwall | |
| Jason Pape (JP) | Autistic individual | Proper Job Café and Maritime Museum | |
| Julie Atwell-Cook (JA) | County Parenting Advisor for Early Help, Together for Families | Cornwall Council | |
| Julie Pape (JP) | Autistic individual and CHAMPs Team member | Cornwall Council | |
| Julia Wildfire-Roberts (JW) | Project Manager, Recovery College Cornwall, HC Director and autistic individual | Pentreath and Healthwatch Cornwall | |
| Karen Hooper (KH) | Head of Commissioning for LD, Autism and Mental Health | Cornwall Council | |
| Marie Ralph (MR) Autistic individual, Parent Carer and NAS Cornwall Chair | | National Autistic Society Cornwall Branch and The Autistic Community of Cornwall | |
| Michelle Lobb (ML) | Parent Carer and Director | Parent Carers Cornwall | |
| Nory Menneer (NM) | Commissioner for LD and Autism | Cornwall and Isles of Scilly Integrated Care Board | |
| Paul Owen (PO) | Autistic individual and CHAMPs Team member | Cornwall Council | |
| Philip Hanscombe (PH) | 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 (RJ) | Clinical Psychologist, Adult Autism Assessment Team | Cornwall Partnership NHS Foundation Trust | |
| Shelagh Mitchell (SM) | Health Improvement Practitioner, Healthy Cornwall and CHAMPs | Cornwall Council | |
| Tina Sanford (TS)Learning Disability, Autism and Transitions Manager, Adult Social Care | | Cornwall Council | |





APOLOGIES

| Name | Position | Organisation | |
|--|--|--|--|
| Cllr Sally Weedon | Councillor and APB Chair | Cornwall Council | |
| Alison Bulman | | Cornwall Council | |
| Andrew Gray | Autistic Individual | | |
| Claire Martin | Deputy Director of Nursing | NHS Cornwall and Isles of Scilly Integrated Care Board | |
| Dina Holder | Community Engagement Manager | Community Engagement Manager Women's Centre Cornwall & Divas | |
| Gemma Dyson | Adult Autism Assessment Team | | |
| Kevin Beveridge | Area Director – West, Adult Care and Support | Cornwall Council | |
| Jane Rees | Manager of the Learning Disability and Autism Team | Royal Cornwall Hospital NHS Trust | |
| Jason Washington | Autistic Individual | | |
| Lorna Brydon | | Mencap | |
| Martha Reed | Strategic Commissioning Manager | Cornwall Council | |
| Rohit Shankar | Consultant in Adult Developmental Neuropsychiatry | Cornwall Partnership NHS Foundation Trust | |
| Sam Axon | Autistic Individual | | |
| Steph Isaacs | Outreach Inclusion Worker | Cornwall People First | |
| Tigger Pritchard | NAS Committee Member, Autistic and Neurodivergent individual, national and international speaker on advocacy and neurodivergence rights | NAS Cornwall and The Autistic Community of Cornwall | |
| Trudie Binnie Disability Employment Advisor Leader | | Department for Work and Pensions | |

ACTIONS

| Action | Responsible | Status |
|---|--------------|--|
| Liaise with Portfolio Holder re future Blue Light Day funding from CC. | sw / ts | Ongoing. Funding to hold the event in 2023 is secure. It is unclear as to contributions from CC. |
| 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. Members of the Board are invited to meet with PC Howard to discuss. |
| Language guidance for meetings. | PB Team/TP | Ongoing. |
| Possibility of audit of accessibility of services. | NM / VC / JG | Ongoing. |
| ER hospital letters. | JR | To be scheduled. Awaiting update, |



| Action | Responsible | Status |
|---|-------------|--|
| Investigate setting up a focused group, with Mental Health colleagues, to consider issues discussed. | NM | Ongoing. |
| Rolling out staff autism training to CFT & CC. | IC / TS | Ongoing. Updates on progress to each meeting. |
| 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 | To be scheduled. |
| Provide details of statutory obligations within delivery of Better Lives Strategy. | TBC | On hold due to review of rollout of BLS. |
| Further information on how to access the services of The Advocacy People. | PN / AS | To be scheduled. |
| Provide details of statutory obligations regarding advocacy support. | TBC | On hold due to review of rollout |
| Investigate changes to blue badge application process. | MH | To be scheduled. |
| LeDeR updates to future meetings. Easy read version available yet? | ln / pv | Ongoing. Awaiting response from Lisa Nightingale, Head of clinical quality, CCG as to current year's report. |
| Convert Direct Payments information into easy read for circulation. | AS / CG | On hold due to review of Policy. |

| Item | What was discussed | Action |
|------|---|--------|
| 1. | Welcome, introductions and apologies | |
| | SW welcomed everyone and advised that the meeting was being recorded for minute taking purposes. | |
| | Apologies received are detailed above. | |
| | SW invited everyone present to introduce themselves. | |
| 2. | Minutes and actions of the meeting held on 28 June 2022 | |
| | SW invited any issues from minutes of the last meeting to be raised. | |
| | No issues raised and they were therefore accepted as a true record. | |
| | MH provided the following updates on actions from previous meetings: | |
| | DWP – questions formulated by the user group in July had been forwarded to Tasha Milton on 2 August. Initially she had said we'd have responses by the 20 September meeting but emails had not been responded to since August. The matter had been escalated to Trudie Binnie, new Disability Employment Adviser Leader, who was meeting with MH on Thursday. | |



CB added that an additional issue for the Board to raise with the DWP was the stigma attached to claiming benefits and the effects on people that don't claim because of it. Through a conversation with a DWP Advisor he had learnt that was an issue affecting many.

• The Chair, Cllr Sally Weedon, had undertaken to liaise with the Portfolio Holder regarding future Blue Light Day funding from Cornwall Council. TS had since taken the lead on the matter and was in the process of arranging discussions regarding issues experienced this year and ensuring early input for future years.

The Board had previously heard that the Office for the Police and Crime Commissioner could withdraw funding for future years. MH reported that PC Sarah Treeby was liaising with the OPCC but had so far received noncommittal responses.

- The PB Team had not yet met with MR to discuss the need for the Police force to train officers to better understand the differences between, for example, mental health situations and autistic meltdowns, so that they were better prepared to manage situations.
- MH had been in touch with PC Jason Howard, Mental Health Liaison Officer, regarding the potential for including an autism alert element to the new Hospital Passport app. He said that his 'fear is that those working within Autism are looking at the single issue, rather than the fact there is a much bigger issue of how vulnerability is communicated and shared with partner agencies. This is subject to ongoing work and really should be considered within the bigger picture.' He's offered to meet to discuss in more detail so what I need to know is who from here should be involved in that conversation.

JW said that she would be interested to learn more about PC Howard's take on the issues, what he thought was needed, what training Police Officers received around mental ill health and what assistance they may require to help to develop more robust pathways. She had recently spoken with a PCSO who had stated that around 75% of their work centred around mental health but Mental Health First Aid training was not being kept up to date. Their certificate had expired but they had been told that if they wanted to keep their training up to date they would have to pay for it themself.

ML suggested that a question be drafted for her to share with parent groups. She added that she knew that not all officers understood the Hospital Passport.

The PB Team would liaise with PC Howard with a view to discussing the matterLiaise with PCin more detail at the next meeting.Howard

PO offered the assistance of The CHAMPs in any discussions outside of Board meetings.



CB highlighted that digital poverty meant that many could not access the app. MH said that one of the questions to ask at the next meeting would be what the alternatives are for those in digital poverty.

Via the chat function, CB said that there was an autism card in operation in Devon and when travelling by train he always made sure to wear his Mencap lanyard, which normally worked well.

- At the last meeting we spoke about all doing our best to try to use appropriate terminology at these meetings. The PB Team hoped to catch up with Tigger Pritchard about that soon.
- Easy Read hospital appointment letters. Jane Rees had reported that this had not yet been signed off yet. It would be considered at the next meeting.
- Possibility of audit of accessibility of mental health services. Jo Green had said that they would be willing to do this. However, NM reported that Vicky Crowther had informed him that due to a number of long term absences, the team had not yet progressed this.

The Psychological Therapies team would be starting work on improving access to services soon.

NM would be meeting with Inpatient Services that afternoon to discuss proposals around training and accessibility.

MH asked if there was still a possibility of setting up a focused group with Mental Health colleagues to consider issues discussed by the Board. NM confirmed that was the intention.

RJ said that she had been liaising with clinicians from across the mental health system and she was keen to set up a clinicians working group to identify gaps and to advise senior management of them. There seemed to be a real intent to improve. NM suggested that he and RJ meet outside of the meeting to try to join up the many different pockets of work that were being undertaken across the system. RJ agreed that work needed to be aligned.

• Pop-up mental health facility and/or the possibility of utilising a lorry to regularly visit sites around the county. NM said that would be something to consider following the identification of gaps in services. The matter would be removed as an action with a view to revisiting the idea at an appropriate should members choice to.

DA said that he couldn't grasp what the benefits of such a service could be.

• Possibility of rolling out staff autism training to Cornwall Council. Since the offer from IH and MR, for which TS thanked them, she had accepted an alternative one from PH. He had been supporting the roll out of autism training sessions to front line teams, which also enabled him to share with





wider teams the role of Autism Intensive Support Team.

Phil had met with TS and the 3 lead locality Social Workers leading on the work. A number of Lunch and Learn sessions had been booked in in each locality area. PH's time was only made available as the AIST was not yet fully operational and it was hoped that the expertise of IH and MR could be utilised for any future sessions.

PH added that he used to be a part of an autism social care team in a local authority in Hertfordshire. The sessions were to share the practices that had been developed in that team, specifically around interesting challenges and ways of working that did not transfer from either mental health or learning disability services. This was an opportunity speak about the adaptions and reasonable adjustments to be made when engaging someone and successfully assessing their needs under the Care Act. It was about finding solutions to help people isolated in communities that were often grossly under employed and open to vulnerabilities such as mate crime, exploitation etc. Discussions had been productive so far and there were a few more scheduled up until the AIST went live.

PH concurred with RJ's comments that a more collaborative approach to training was required. Upskilling was required across health, social care and the third sector and he was happy to be involved.

TS had also liaised with the Council's Learning and Development department within Adult Social Care. Historically, the NAS had delivered two levels of autism awareness training – baseline training and assessors training for staff undertaking social care needs assessments. Currently, there was no training booked for the remainder of the financial year. Consideration was being given to what Oliver McGowen training did not cover and also the fact that levels 1 and 2 e-learning was not yet established so it was not known what that would look like in Cornwall. Pragmatically, available funding had been identified for the sessions during the period up to the end of the financial year. The NAS could be approached or equally partners present could put a proposal forward to provide such sessions.

Via the chat function, DA stressed the value of staff receiving training in how to communicate with autistic individuals.

JW said that she had developed and delivered autism acceptance in-house training for Pentreath, who had around 150 members of staff. The training was easily adaptable and she had delivered to NHS commissioners and staff, as well as to communities. The course focused on what autism is and isn't and the impact on the individual and those around them. It asked staff to consider the impact on them in terms of adapting their own practices when speaking with someone that has a different communication style. It concludes with discussions around solution building, costs, implementation and practicability.

healthwatch



MR said that NAS Cornwall were only permitted to deliver the very basic acceptance training, having moved away from awareness. Herself, IH and Tigger Pritchard were in the process of setting up the Autistic Community of Cornwall (ACC), which was training delivered, designed and produced by autistic people. She added that an element currently missing was a human library. The group were due to meet with Alison Bulman, Strategic Director, Adult Social Care to discuss delivering training there.

TS asked if herself and Kerry from the Learning and Development team could meet with ACC to consider what the offer needed to look like moving forward. MR agreed and said that there was a good opportunity to begin to roll out good practice across the sectors.

Via the chat function, MR encouraged more actual autistic people to contact us to get involved in the delivery of the training we are currently delivering as part of the autistic library of people.

CB said that it was ridiculous that conversations were still being had about the need for autistic people to be the ones that teach others about autism. He had been part of such training 7 years ago. PO agreed, stating that it was a terrible decision when Cornwall Council pulled funding for it.

Via the chat function, CB added, There is massive stigma against disability from Torpoint to Penzance in Cornwall. Sorry time to continue to talk time and again is over. Learning disability has already lost its future in the county due no independent living. A job, lucky earn enough to buy a sandwich.

ML concurred and said that she had experienced a lot of discrimination and "dodgy practice" from reception and clerical staff at a GP surgery just the previous week. Her parting words with the staff member was that they needed additional disability training and their supervisor should be sacked for suggesting the use of restraint. ML added that medical staff at the same surgery were brilliant.

KH suggested conversations with NM and TS needed to be had outside of the meeting. Hearing real examples was essential to improving services.

IH said that many of the challenges faced within the autistic community were driven by a lack of understanding and acceptance and training was an important component in overcoming that. A training package had been developed as a collaboration between the NHS Autistic Staff Network, the local NAS and the Autistic Community of Cornwall. It had been accepted as a really good way of rolling out training to health staff in parallel to Oliver McGowan training, which was learning disability focused and quite prescriptive in its nature.

• CB shared details from a brochure for a Citroen Ami, a small electric car with a top speed of 28 miles per hour, with no gear lever or clutch, that could travel up to 46 miles on a single charge. It was not available through the mobility





scheme but he hoped it would be eventually.

- CB said that he was disgusted at continued conversations about addressing digital poverty and housing issues. It was clear that actions needed to be taken so Cornwall Council should be getting on with it.
- Two items Invite CC Housing Options Team to future meeting to look at the implications for people with LD and Autism in accessing mainstream housing and changes to blue badge application process. They hadn't been scheduled yet due to capacity.
- The Advocacy People were now fully staffed in relation to the element of their contract to bring self-advocate voices to the Board. Penny Newman would update to the next meeting.
- Statutory obligations within the delivery of the Better Lives Strategy. Rollout was currently being revisited so the Board would be updated when plans were clearer.
- LeDeR updates Lisa Nightingale had not responded to emails from MH so Paula Volkner was chasing this up. NM said that the report had now been published but the easy read version was not yet available due to the difference between easy read and Accessible Communication Standards.
- The Direct Payments Policy was currently being reviewed. More later in the meeting. The Partnership Boards team would be holding an event at the Venton Conference Centre on 30th November at which people in receipt of Direct Payments would be invited to help to frame and phrase the questions that should be asked when communicating with service users.

The agenda item had overlapped with the 'Updates from Members' and discussion had already been had on many topics that were due to be discussed later in the meeting. It was therefore agreed that the agenda items 'Update on Partnership Boards Work and Events', 'Health Update and Feedback from the LDA Programme Board' and 'Updates from Adult Social Care' continue under the current item.

• TF provide a shortened update from the Partnership Boards team. She reported that the Learning Disability Partnership Board had recently followed the lead of this Board and was changing its logo.

TF had recently attended the Cornwall Partners In Policy Making event 'Where do we go from here?'. It had been great to see both speakers and performers with lived experience. DB echoed that.

She also reminded members with lived experience that the Community Promotor role was open to them if they wanted to join the team in promoting the Boards and the wider Healthwatch Cornwall at events. David Burns, Steve Dymond and Marie Lobb were doing an excellent job and would be willing to





speak with anyone that wanted to join the team.

MH reported that the Safeguarding Adults Board Annual Conference would be held in March 2023. The PB team were liaising with some Board members with lived experience about the possibility of devising anonymised case studies from their personal experiences of safeguarding. Members were invited to contact the team if they wished to contribute either from a carers or safeguarding perspective.

• NM provided an NHS Update.

The NHS and Adult Social Care were increasingly commissioning the voluntary and community sector to undertake training in order to ensure that it was led by people with ground level expertise and lived experience. There was an implementation group for health and social care for Oliver McGowen training and there was an opportunity for every CQC registered body to come together collaboratively, a statutory service collective, to offer out delivery of expert standardised training. TS asked NM how that suggestion could become reality. NM said that he wasn't sure but there was so much expertise in the meeting that it wouldn't make sense not to utilise up. MR said let's just do it. A meeting needed to be arranged between all those that would be involved in the process. NM agreed and added that he and TS needed to work together to try to ensure that the multiple organisations and departments. They agreed to consider who the ultimate accountable lead should be but it may be that they approach KH and Tim Francis, Head of Mental Health and Learning Disability Joint Strategic Commissioning, to progress. They would ensure that the Board was updated.

Liz Cahill, Associate Director of Commissioning covering Children and Young People, had shared the following information on the new Cornwall and Isles of Scilly developmental differences plan:

'Parents have told us that it is difficult to find help whilst waiting for an assessment.

Often having had an assessment there is little in the way of help available. They have told us that they need access to better help and earlier, including access to experts to support managing the challenges children and young people are facing.

Young people have told us they want us to help their parents to help them. We think we might have found a way of supplying better support and help but this will require changing the way people are currently referred for an assessment or diagnosis for Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and other neurodevelopmental need.

We know that too many people are waiting too long for an assessment for Autism, ADHD and other developmental differences. Despite investment, our teams are struggling with the volume of referrals. Referrals often do not meet Regular updates on progress



| the criteria for assessment, but we know that help may still be needed. We would like you to come and discuss how we might make this work for Cornwall and Isles of Scilly. There are three dates when you can join in across Cornwall. Isles of Scilly has a dedicated virtual event in December. | |
|---|--|
| Dates, times and venues. Each event 9:30 am to 3 pm: | |
| Shire House Suite, Bodmin, 25 November 2022 Queens Hotel, Penzance, 28 November 2022 The Knowledge Spa, Truro, 29 November 2022' | |
| MH would circulate a flyer about the events. | |
| MH reported that he had also been in touch with Liz Cahill to find out if and when the Children's Autism Partnership would be restarted. Liz had said that she had plans that she would like to share with the Board but didn't expand any further and MH had believed she would attend today's meeting to do so. NM said that he understood that flyers detailing consultation had been produced and were being circulated. | PB Team to liaise with LC |
| Autistica had been in touch about the development of Annual Health Checks for People with autism as part of its 2030 Plan. They had asked NM to advise them but he intended to suggest that they should liaise with the Board instead. The Board agreed. Via the chat function, PH suggested that this was a piece of work that a small group of members of the board do and then feedback to the main group. | NM to liaise with Autistica. |
| Break | |
| The Board took a 10 minute comfort break. | |
| Updates from Members (continued) | |
| Shine Together – Pentreath | |
| JW updated on Shine Together, the exclusively autistic autism project which would work with diagnosed individuals. It was felt that the delineation between those with and without a diagnosis was necessary as the aim was to get autistic individuals into work, education and support. | |
| The project would run for 18 months and they had successfully recruited to administration and advisor posts, with a further vacancy in the West of Cornwall to which autistic individuals or people with lived experience were invited to apply. Across the whole organisation, recruitment and interview practices were changing to make them more accessible and equitable. | |
| | We would like you to come and discuss how we might make this work for Cornwall and Isles of Scilly. There are three dates when you can join in across Cornwall. Isles of Scilly has a dedicated virtual event in December. Dates, times and venues. Each event 9:30 am to 3 pm: Shire House Suite, Bodmin, 25 November 2022 Queens Hotel, Penzance, 28 November 2022 The Knowledge Spa, Truro, 29 November 2022' MH would circulate a flyer about the events. MH reported that he had also been in touch with Liz Cahill to find out if and when the Children's Autism Partnership would be restarted. Liz had said that she had plans that she would like to share with the Board but didn't expand any further and MH had believed she would attend today's meeting to do so. NM said that he understood that flyers detailing consultation had been produced and were being circulated. Autistica had been in touch about the development of Annual Health Checks for People with autism as part of its 2030 Plan. They had asked NM to advise them but he intended to suggest that they should liaise with the Board instead. The Board agreed. Via the chat function, PH suggested that this was a piece of work that a small group of members of the board do and then feedback to the main group. Break The Board took a 10 minute comfort break. Updates from Members (continued) Shine Together – Pentreath JW updated on Shine Together, the exclusively autistic autism project which would work with diagnosed individuals. It was felt that the delineation between those with and without a diagnosis was necessary as the aim was to get autistic individuals into work, education and support. The project would run for IB months and they had successfully recruited to administration and advisor posts, with a further vacancy in the West of Cornwall to which autistic individuals or people with lived experience were invited to apply. Across the whole organisation, recruitment and interview practices were |





The Women's Centre

IH gave an update on behalf of Dina Holder, The Women's Centre and Divas, on the work that they were undertaking with Age UK on abuse of elders and with survivors. Dina had been adamant that there should be representation from autistic individuals.

A date had yet to be set but there would be a discussion of the work on BBC Radio Cornwall, to which IH would provide a neurodivergent perspective.

Autism Intensive Support Team (AIST)

PH reported that the AIST would go online as a live service in the new year when a new psychologist and manager was in post.

It was not a full autism team in the sense that its remit was more that of prevention of crisis and working with people with complex needs who were Continuing Healthcare (CHC) funded, came under Section 17 of the Mental Health Act or at danger of entering the prison system.

It was hoped that the team could provide the foundations for wider support to be developed for autistic individuals.

The South London and Maudsley NHS Trust had set up an Autism Practitioner Network that was open to all professionals that worked within specialist autism teams. He added a link to the chat function for anyone in such a role that was interested in joining.

Seminars would be held in the new year, with the first being 'What is Autism?'.

Adult Autism Assessment Team

RJ reported that the wait time for a diagnosis continued to increase. Currently, it took around four years from the point of referral to assessment. However, new staff had been brought onto the team and some clinical time was also coming in. It would be difficult to turn the tide as referral rates were continually increasing, which was in line with the national picture. It would be necessary to take a wider system approach to address how the service could be resourced long term but it was hoped that increased staffing would at least slow down the increase.

Citizen Checkers

DB reported that Citizen Checkers had been working with and supporting a couple of clients that had been placed in out of county hospitals. One that had recently been able to return home and the other would be doing so in a couple of days time.

DB also promoted the Talk Together group, based in Liskeard, which offered the



| | opportunity for people with learning disabilities and autism to speak about their | |
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| | mental health and other issues affecting them. The group met on the second | |
| | Monday of every month between 1pm-3pm. TF would circulate a flyer. | |
| | The CHAMPs | |
| | | |
| | PO reported that the Safe Places scheme was back up and running. | |
| | TF added that The CHAMPs had performed a new song to promote vaccine update at the recent meeting of the Learning Disability Partnership Board. SM said that they would love to be able to record it and asked that anyone with advice on who could assist to please get in touch. | |
| 5. | Work Planning for 2023 | |
| | The intention of this item was to consider the key issues that the Board wanted to concentrate on over the next twelve months. | |
| | Whilst today's meeting had been very informative and actions to take forward had been agreed, MH highlighted how disjointed it had been in terms of focus on specific matters. A rolling work plan would enable greater meeting management and enable, for example, sub-groups to be formed to look at important issues in more detail. | |
| | To achieve that would require, 1. Professional members of the Board to advise on what work was coming up and how they could see the Board participating at a level where it could make a real difference, and 2. Consideration of the how Board meetings should be structured. The make- up of membership was excellent, with wide representation from neurodiverse individuals, groups and professionals but that meant that much of every meeting was taken up through updates and networking. | |
| | Current funding did not allow capacity for the Board to meet more regularly than quarterly, particularly with the ever growing need for sub-groups – seven additional meetings/events had been hosted this year – and participation in meetings of other bodies. An alternative option be to have alternating meetings whereby the focus of one is to share updates and agree upon key areas of focus and the next is to consider those areas in depth, possibly through day long sessions if necessary. | |
| | Another matter to consider was how meetings should be held – online, in person or hybrid. It seemed that most professionals had changed their ways of working since the pandemic and there was a reluctance or a lack of capacity to attend meetings in person. | |
| | MH asked NM about plans to develop an Autism Strategy. | |
| | TS wondered if there was merit in the Board having task & finish groups to | |



focus on specific issues and gave the example of such a group looking at how Oliver McGowen mandatory training could be rolled out collaboratively in Cornwall. MH said that the ability to take ownership of work was what the Partnership Boards team had always wanted and he cited examples of where that had happened. However, it needed to be recognised that funding allowed for only two part time staff, covering 49 hours per week, to support four Boards so capacity was limited. What would therefore be required would be members of the Board to take a more active role in its work and to lead on actions relating to their service areas. TS said that would require clear remits from the Board on what needed to be covered for any given piece of work. MH agreed, the Board needed to be clear on what it wanted and individuals needed to put themselves forward to take ownership, something that the Board had always lacked.

NM left the meeting.

RJ asked what happened with regard to the Next Steps sessions following the Adult Social Care Peer Review. MH said that the outcomes and actions had been heavily focused towards LD services and the LD Partnership Board. No negative feedback had been received about this Board. TS said that the autism related strands for Cornwall Council to address were the need to provide greater autism acceptance training for staff, which she was taking forward with PH, and the broader issue of communicative issues across the system, not just ASC. Another issue affecting individuals that came across very strongly was the impact on emotional wellbeing of individuals through not having effective adjustments made within mental health services.

KH summarised three areas of feedback received through the Peer Review. 1. Training and making sure that people had much greater awareness, 2. The support coming through from the Mental Health Board, and 3. The service provision for autistic people. That would come through Delivering Better care and Community Base Support Commissioning that herself and Martha Reed would bring to a future meeting. MH asked if that would potentially mean that there would be work for the Board to take ownership of. KH said that there 100% would be and what that should be could be considered once the Programme of Work had been agreed.

MH asked KH for her views on how Board meetings should be structured. KH said that she would take a steer from the Board as to whether it wanted to use its time for engagement or for task and finish style groups to be formed which commissioners would lead on, utilising the expertise of Board members, before reporting back to the next meeting. MH said that his preference would be the latter, which was also the consensus of others in attendance.

KH proposed that, should the plan of work and programme of engagement be finalised by the next meeting, she would invite members to work with commissioners on task and finish groups on what services should look like.





KH left the meeting.

MH said that another issue that affected the Board's ability to schedule effectively was that, historically, the Partnership Board team had always been notified of Cornwall Council's engagement needs at the last minute, meaning that agendas either contained too many items or other items were deferred. TS suggested learning from other Partnership Boards that had experienced similar circumstances. MH said that the team do check on the work of other Boards but relayed an instance whereby they had recently been directed towards an LDPB that was held up as an example of good practice only to find that they achieved much less than their own Board did. What it was better at though was promoting its successes.

Through the chat function, the CHAMPs expressed a preference for face to face meetings. MH said that would certainly be the better option if the Board adopts a task and finish approach. ML had concerns with the effectiveness of hybrid meetings. TS thought that it should either be in-person or online, not hybrid. MH said that the Carers Partnership Board and the Learning Disability Partnership Board meetings were all now hybrid and worked well. What had been found with the LDPB was that the majority of people with lived experience attended in person and the majority of professionals attended online. A consequence of that was that peer support empowered those in the room and participation had increased. The only difficulty came when presenters wanted to have breakout rooms without having planned for them in advance.

JP said that he found in person meetings easier as it enabled better communication and watching a screen for too long could be uncomfortable. He added that the last Partnership Board meeting that he attended in person was amazing and everyone on the Board was doing a wonderful job. He had previously lived in the Cotswolds and such interaction and participation was not available there. People should recognise just how much value this Board brings.

TS added that any in person meetings required additional time for people to familiarise themselves with their surroundings and to network. ML said that public transport links were important. MH said that the team would like some of its members with lived experience to visit venues with them to enable them to consider accessibility issues. JP and JW said that they would be willing to assist.

PH said that the All Party Parliamentary Group on Autism had written a report reviewing the Autism Act, which had been produced through consultation within three major cities. It would be beneficial to consult the autistic population of Cornwall to find out what the key issues are to individuals, from which this Board's priorities could be agreed and task and finish groups formed. MH and PH agreed to meet outside of the meeting to discuss ideas in more detail. MH asked if any others would be interested and RJ and JW put themselves forward. TS said that it would be nice to have a 'plan on a



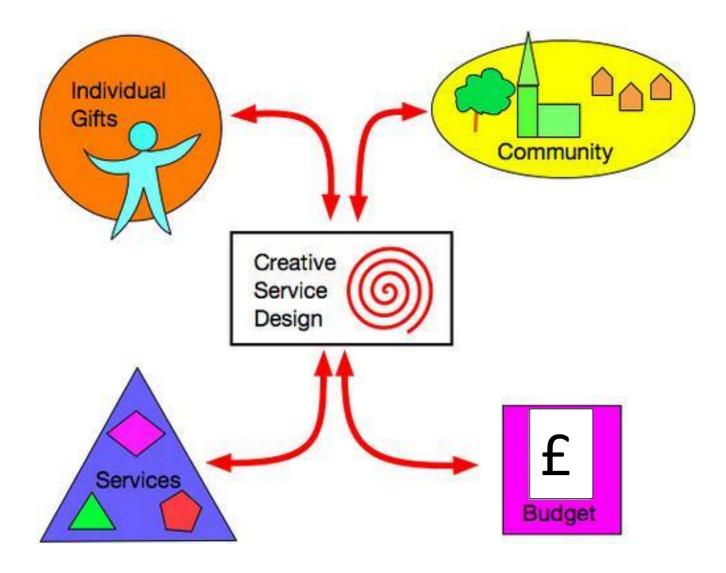
| | page' that identified realistic targets for 2023. JW stated the value of SMART targets. | |
|----|--|--|
| | ML highlighted concerns that she raised regarding Blue Badges a year ago not yet being adequately addressed. If that had been included as a recognised target that would give the Board more authority and make the responsible person more accountable. | |
| | MH what members felt they would lose out on if the format changed. Members gained a lot of value from the networking element of the Board and projects did stem from discussions held here but the value of that was not tangible in terms of demonstrating the success of the Board. A happy medium needed to be found between sharing the wide breadth of knowledge that the Board brought together and achieving tangible successes. | |
| | TS stressed that feedback from the Peer Review had stated that this was a strong Partnership Board with active participants and that people were coming together to effect change. Members should take pride in that but should also strive to continually improve. JW added that whilst soft outcomes were always difficult to quantify, they were often the areas in which the real magic happened. ML said that it was important that a section for soft data was captured in any plan. | |
| | JW asked if it would be possible for a pro-forma to be sent to Board members to enable them to demonstrate soft actions achieved through these meetings. Three could also be value in meeting with other local Healthwatch Boards. PH said that the Warwickshire Autism Partnership Board was a good example. | |
| | The Partnership Board team would consider the feedback received and discuss the way forward with commissioners and members of the Board. | |
| 6. | Any other business | |
| | The Women's Centre / Diva's | |
| | Dina Holder had asked the following via email: | |
| | I have been asked by a specialist support worker for advice about the below issue: | |
| | She is currently working with a woman who has a 12 year old daughter with severe autism traits. She has tried every agency and service without success and out of desperation walked her child into a local Police Station. The Officer on duty told her there was no hope! However since this she has managed to speak to another officer and has attended the Autistic Spectrum Disorder Assessment Team in Truro Health Park. The appointment was on the 7th of | |





| | October and she is awaiting the outcome. | |
|----|---|--|
| | She has seen the Divas online and feels something like it would be ideal for her daughter. But I have explained to the worker that the DIVAS is not appropriate for a 12 year old. Do you know of any autism specific or autism friendly groups for young girls? Could you put out my query to the Board on Tuesday and let me know if there are any suggestions. | |
| | MH had put her in touch with Liz Cahill, who was leading on the relaunch of the Cornwall Children's Autism Partnership. IH had also provided a list of resources, groups and signposting. | |
| 7. | Future meetings | |
| | Date for meetings in 2023 would be circulated at the earliest opportunity. The intention was to ensure that they aligned with Cornwall Council's rollout of Delivering Better Care. | |

About Individual Service Funds





What is an Individual Service Fund?

If you are eligible for support from the council you will have an assessment of your needs. The council advises how much your support may cost.



This is called your Personal Budget.



There are 3 different ways you get your Personal Budget.



1. You might be happy to manage your money by yourself.



You can choose to have your Personal Budget as a Direct Payment. The money will be paid into a prepaid card or a bank account in your name. You can buy the support you want.



2. Sometimes this is hard and you might want help to manage your personal budget.



The council can look after your budget and use it to buy support for you.



3. You can choose to have an Individual Service Fund. You choose a provider (not the council) to look after your budget. They use it to buy support for you.



Why would I want an Individual Service Fund?

With an Individual Service Fund, you get to choose your service provider and have more of a say over how your support budget is spent.



You get more choice of providers with an Individual Service Fund than you would if you wanted the council to look after your budget.



You do not have the responsibility of looking after the budget yourself.



Will I have to pay anything towards my care?

The council will do a financial assessment with you. This will look at how much personal money you have and if you need to pay a contribution towards your care and support.







Circle of Support





Who can help me with an Individual Service Fund?

Your chosen provider could be an organisation who helps with care and support in your own home or the family home.

The provider you choose to hold your Individual Service Fund will help you design your care and support plan.

Your care and support plan is about what your life outcomes are and the support you need to achieve them.

With an Individual Service Fund you, your circle of support and your ISF provider decide what support you want to buy.

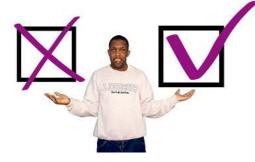
The council has a list of providers who can hold Individual Service Funds



Some providers will ask you to pay them to help you with your Individual Service Fund.



Some providers will not need you to pay them to help you with your Individual Service Fund.



If a provider wants you to pay them to help with your Individual Service Fund, they will tell you how much it will cost before you decide.



Planning your services

You will be able to talk to your provider about your care and support plan. They can help you choose what support will meet your needs.



Your provider can tell you how much money you have spent on services and how much you have left.



When you and your provider have made your care and support plan, your Care Manager at the council will check it.



They will check if your care and support plan has the right amount of support for you and will meet your needs.



What happens next?

When your care and support plan has been agreed, your provider will start setting up services for you.



Your ISF provider will support you to buy the services that you choose and from wherever you may choose within budget.



You could decide to buy

- Assistive technology
- A place at a day opportunity
- A gym membership
- And much more



You can tell your provider what you think when your services have started and let them know if there is anything you want to change.



You can ask for a review at any time.

You will also meet with your Care Manager at the council every year.

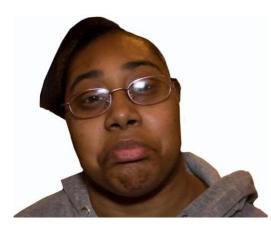


Your care manager at the council will talk to you to see if your care plan is still right for you and if anything needs to change.



If it has been agreed that you can afford to pay something, you will pay your contribution to your ISF provider. They will sort this out with you.

If you do not pay your contribution, you might not be able to carry on with your Individual Service Fund.



What if I am not happy with my Individual Service Fund?

You can tell your provider you are not happy so they can try to fix the problem.



You can tell a Care Manager at the council if you think your provider is not listening to you and you are still not happy.



You can change your provider if you are not happy.



Your Care Manager at the council can help you to do this.

1. What training do DWP staff receive in understanding Autism and learning disability?

DWP staff have received training from DWP Work Psychologists, Disability Employment Advisers, local Autism services and most recently from an NHS-linked trainer with lived experience.

 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?

Customers are asked when making a Universal Credit Claim online if they have any conditions they would like to declare. At their first meeting with their Work Coach they are then asked if they require any Additional Support and their Accessibility and Support Needs are recorded on their account. Every time a member of DWP staff accesses the account they are notified that the individual customer has declared support needs.

 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.

We would offer an interview with a Disability Employment Adviser at the start of a claim. The DEA would case conference with the individual's Work Coach to discuss best means of support.

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?

Claimants in receipt of Employment and Support Allowance can undertake Permitted Work up to 16 hours before benefit is stopped. Earnings under 16 hours is not taken into account against benefit.

Universal Credit there is no limit to hours that can be worked. Earnings are taken into account but you will keep wages amounting to 45 pence for every pound earned. Once an individual has had a Work Capability Assessment how earnings are taken into account will depend on the outcome of that assessment.

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.

Yes, we do recognise this. Voluntary placements tend to be more flexible in terms of absences, etc. There is also often a lower expectation in terms of speed of work, time it takes to learn tasks, etc. We do see great value in undertaking volunteering to build confidence, resilience and capability for work.

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.

DWP staff are certainly not instructed to avoid offering support. It is more likely that time restrictions prevent them from offering as much support as they would like to or, lack of understanding of an individual's circumstances mean they are unaware what support is required.

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

Can you provide us with specific examples of this? We are always willing to feed back to national policy teams about practices that do not work for our customers.

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?

Every Jobcentre has an allocated Disability Employment Adviser (DEA). DEAs have an understanding of LD, Autism, neurodivergence as well as mental and physical health. The DEA is there to support Jobcentre staff in supporting our customers. They also provide training and case-conferencing to Work Coaches.

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?

Our Disability Employment Advisers work closely with the Social Prescribing network in our local GP surgeries. We do this because we understand the importance of social interaction and activities in building well-being and resilience.

10. Would it be possible to produce a map of how systems interlink across health and social care?

Unfortunately, there are too many organisations. Health and Social Care are not DWP services and we would not have all the information to hand to map them over the are we cover, which is Penzance to Barnstaple.

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.

DWP correspondence, such as decision letters, etc. can be sent in accessible formats if a customer requests it. All Jobcentre staff had training recently on Alternative Formats.

The formats currently available are:

- Audio
- Audio recording of interview
- Braille
- British Sign Language (BSL)
- Easy Read format
- Hands on Signing
- Large print
- Lip speaking
- Paper (different colours)
- Relay UK
- Sign supported English
- SMS text
- Telephone
- Textphone
- Video Relay Services (VRS).

Please note that while Easy Read is available it is not a suitable format for some of our documents due to the complexity of the information contained in them.

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.

All Jobcentre staff receive training in Safeguarding Adults and Children. Staff are encouraged to raise safeguarding concerns with Adult Social Care and/or discuss concerns with a Vulnerable Customer Lead. Each Jobcentre has at least one Vulnerable Customer Lead. Concerns can also be escalated to the Advanced Customer Service Lead for the District. We also work closely with the Complex Needs Manager for Cornwall Council. In addition, if a member of staff is concerned that a customer may not be engaging with our services they can request a DWP Visiting Officer visit the customer's home to check on safety and advise them on how to comply with the requirements of their claim. Universal Credit Journal entries are monitored daily to highlight any safeguarding concerns. A daily scan is run to identify key words that may indicate safeguarding issues.

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?

We are aware there is a lack of advocacy support which is difficult to address as many advocates are volunteers. We are unable to fund advocacy positions but have asked the question from the Cornwall DEA Team. There is still support available from Cornwall People First who are currently recruiting.

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?

Care arrangements do not fall under the remit of DWP. They sit with Adult Social Care. However, our Employer Advisers in local jobcentres are constantly recruiting for care companies and campaigning to encourage new people into the care industry. We also actively signpost to organisations such as Disability Cornwall and the Community Gateway.