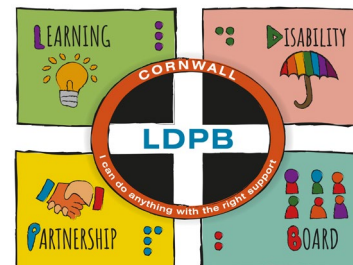


MEETING NOTES:	Meeting of the Learning Disability Partnership Board
DATE:	Thursday, 5 September 2024
LOCATION:	Moresk Centre, Truro and on Microsoft Teams

ATTENDANCE

Name	Position	Organisation
Sandra Ward (SW) (stand-in Chair)	Parent carer of a young adult with profound and multiple intellectual disabilities, Director of Parent Carers Cornwall and Chair of Carers Partnership Board	
Robert O'Leary (RO)	Partnership Boards Lived Experience Project Officer	Healthwatch Cornwall
Alex Seaman (AS)	Self-Advocate	Brandon Trust
Amanda Wilton (AW)	Parent carer of a young adult with profound and multiple LD	Patient Council Derriford UHP
Anthony Dunn (A)	Peer Advocate and Lived Experience Lead	Citizen Checkers
Bethany (B)		
Charlotte Polglase (CP)	Co-Facilitator	Citizen Checkers
Chris Ballett (CB)	Community Partner, Our Active Community – St. Austell and Clay Country & Project Manager – All Move	Mencap
David Burns (DB)	Lived Experience self-advocate and Community Promoter	Citizen Checkers and Healthwatch Cornwall
Debbie Gilbert (DG)	Chief Executive	Healthwatch Cornwall
Dina Holder (DH)	Community Engagement Manager / Divas Facilitator	The Women's Centre Cornwall
Ebony Rose Thomas (ERT)	Self-Advocate	Citizen Checkers
Francesca (F)	Self-Advocate	The CHAMPS
Gary Dymott (GD)	Community Connector (Bude)	
Heather Davison (HD)	Lived experience and parent to an adult with learning disabilities	DIVAS
Janet Jervis (JJ)	Supporting Anthony Dunn & mother to two disabled adults sons with learning disabilities	



Name	Position	Organisation
Jenna Pulley (JP)		Cornwall Partners in Policymaking
Julia Wildfire-Roberts (JWR)	Manager, Shine Together	Pentreath
Julie Pape (JP)	Self-Advocate	The CHAMPS / Healthy Cornwall
Karen Gregory (KG)	Service Director	Mid-Cornwall Hub
Karl Potts (KP)	Assistant Psychologist, Specialist Parenting Service	Cornwall Partnership NHS Foundation Trust
Kate Spenceley (KS)	Senior Manager	Citizen Checkers
Laura Keeper (LK)	Self-advocate, service user (BDS) and Trustee (CPF)	Blantyre Day Services & Cornwall People First
Lewis Henry (LH)	Self-advocate	Brandon Trust
Lizzie Dennison (LD)	Proper Job	Cornwall Council
Luanne (L)	Personal Assistant for DB	
Mary Fuller (MF)	Lived experience	DIVAS
Rachel Mellor (RM)		Brandon Trust
Rosi Van Dam (RVD)	Clinical Lead: Mental Health Liaison Practitioner	Cornwall Partnership NHS Foundation Trust
Ryan Sturgess (RS)	Lived Experience	
Samantha Mokarram (SM)	Advocacy Coordinator	The Advocacy People
Sharon C	Team Leader, Adult Social Care	Cornwall Council
Shelagh Mitchell (SM)	Healthy Cornwall Team Lead - Health Inequalities and Champs Team Manager	Healthy Cornwall
Steve Dymond (SD)	Self-advocate and Community Promoter	Healthwatch Cornwall
Vicki Allan (VA)	Strategic Commissioning Lead for Learning Disability and Autism, Working Age Adults Services	Cornwall Council
Wayne Williams (WW)	Self-Advocate	Mid-Cornwall Hub

APOLOGIES

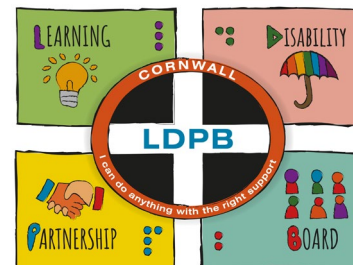
Name	Position	Organisation
Christopher Jordan	Self-advocate and Volunteer book keeper (CPF) and Parish Councillor	Cornwall People First
Sgt Flo Linscott	Diverse Communities Team Lead (Cornwall)	Devon and Cornwall Police
Jane Rees	Manager Learning Disability and Autism Team	Cornwall Hospitals NHS Trust
Jo Cope	Disability Employer Advisor	Jobcentre Plus
Jo Pike	Screening Liaison Nurse, Primary Care Liaison Team	Cornwall Partnership NHS Foundation Trust
Karen Hooper	Head of Commissioning for Working Age Adults Services	Cornwall Council
Marie Martin	Self -advocate	
Marie Lobb	Parent Carer	
Neil Carpenter	Advocate	Cornwall People First
Paula Volkner	Transforming Care Project Coordinator	NHS Cornwall and Isles of Scilly Integrated Care Board
Professor Rohit Shankar	Clinical Director - Adult LD services	Cornwall Partnership NHS Foundation Trust
Sam Maddern	Lead liaison and Screening Nurse, Community Adult Learning Disability Team	Cornwall Partnership NHS Foundation Trust
Dr Victoria Parnell	Clinical Lead, Specialist Parenting Service	Cornwall Partnership NHS Foundation Trust
Zoe Rawlence	Specialist Nurse	Specialist Parenting Service

ACTIONS AGREED AT MEETINGS

Action	Responsible	Status
Working together to design and shape a Learning Disability Strategy	VA	November 2024 agenda item.
Charter and Mission Statement – Convert to easy read	TBC	November 2024 agenda item.
Reconvene DWP working group.	PB Team	Not started.
Share details of Cornwall Council vacancies for people with learning disabilities.	KH / PB Team	Ongoing. To be shared with the Board as vacancies go live.

Action	Responsible	Status
Update on opening the Safe Places Scheme to neurodiverse individuals.	FL / SM	Updates as the work develops.
Updates on Accessibility Advisory Group for RCHT as appropriate.	MH	Updates will be shared as received.
LeDeR report updates.	SS	Updates will be shared as received.

Item	What was discussed	Action
1.	Welcome, introductions and apologies	
	<p>SW welcomed everyone and advised that the meeting was being recorded for minute taking purposes. Permission would be sought from individuals if it was to be shared beyond the meeting.</p> <p>SW ensured that everyone understood the meeting etiquette and how to contribute to the meeting if they had joined online.</p> <p>SW explained that she was standing in as Chair for the meeting as Jayne Kirkham had stood down as a Cornwall Councillor following her election to Parliament. It was expected that the Leader of Cornwall Council would nominate a new elected member of Council as Co-Chair of the Board soon.</p> <p>The Board expressed its thanks to Jayne for her years as Chair and wished her well for the future.</p> <p>SW invited everyone present to introduce themselves.</p> <p>Apologies were received, as detailed above.</p>	
2.	Minutes of and actions from the meeting held on 28 May 2024	
	<p>The notes of the previous meeting, which had kindly been produced by the Citizen Checkers, were confirmed as a true record.</p> <p>SW emphasised what a special event the last meeting had been, with full participation from all. Feedback received post-meeting had been very positive.</p> <p>There were no matters arising.</p>	



3.	Agreeing a Charter and Mission Statement	
	<p>At the last meeting of the Board, members had considered if the Board would benefit from the development of a charter and Mission Statement, developed by its members, to inform its future direction. It was agreed that it would.</p> <p>Through various activities led by the Citizen Checkers, as detailed within the notes of the meeting, members had put forward what mattered to them the most. From that, Citizen Checkers had created a draft Charter and Mission Statement</p> <p>KS began to present the drafts, as circulated with agenda, apologising that they were not in easy read format but emphasising that they were not the final version.</p> <p>DH expressed concern that some members of the Board would not be able to fully understand the content or what was being asked of them.</p> <p>It was agreed that KS discuss each element in detail with the people in the room. There was only one lived experience member online, DB, who had participated in the production of the documents.</p> <p>JP emphasised that the information had been circulated in advance of the meeting to afford people time to consider it. She felt that there had been confusion in communication with Healthwatch Cornwall as she had not anticipated it being presented in its current format, although it had only recently been shared with the Partnership Boards team.</p> <p>Further concerns were expressed by HD and AD that some members may not be able to fully participate in consideration of the matter due to it not being in easy read format. AD asked people in the room if they understood what KS had started to present.</p> <p>RS said that whilst he understood some of what had been said, there was a lot that he had not. He said that too much information</p>	

could become jumbled for him, so how it was presented was very important. AD felt that he was speaking for all people with learning disabilities in Cornwall when saying that information needed to be in easy read.

DB emphasised that everyone's opinion was of equal value. There was no hierarchy of opinions.

WW stressed the importance of recognising the issues faced by everyone. He added that the documents did need to be easy to understand.

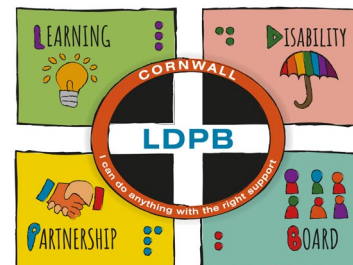
The Chair proposed that the Charter and Mission Statement be converted to easy read for consideration at the next meeting. The Board agreed.

JP stated that she had undertaken the work as a favour to the Board and now felt uncomfortable about its current position. RO said that he understood and agreed with peoples concerns about the draft not being in easy read but there were significant time and cost implications to producing multiple versions. He added that the content consisted solely of the views and information put forward by Board members with lived experience at the last meeting. JP conceded that they should have considered the need to circulate the drafts more immediately following the last meeting while the conversations were fresh in peoples minds.

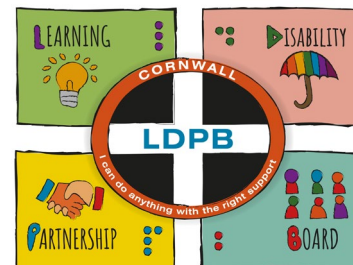
HD reiterated the need for accessible documents. DH encouraged members not to lay blame on individuals and proposed that working groups be set up at the end of each meeting, with members and who will be chairing agreed. The group could then determine and allocate responsibility for each individual task. She added that it would not have to be Healthwatch Cornwall that does everything.

Via the chat function, VA proposed an amendment to the previously agreed action, suggesting that the Charter and Mission Statement be converted to easy read and circulated to the Board for comment ahead of the next meeting, where the final versions could be agreed. DH added that it was important that members had enough time to digest the content ahead of the meeting.

Action



4.	Updates from members	
	<p>Proud to Care Awards</p> <p>AD reported that Cornwall Council had asked Citizen Checkers and Cornwall Partners in Policymaking to participate in the Proud to Care Awards 2024.</p> <p>The team had considered nominations for a number of categories and had chosen their favourites. The awards evening would be held on the evening of 20 September 2024 and the team would be presenting one of the awards.</p> <p>Co-production in Cornwall – Getting it right, together, for Cornwall Residents</p> <p>DB reported that the Citizen Checkers had made a short film about what co-production means to people. Click here to view it.</p> <p>DH said that she had seen it and had circulated it across The Women’s Centre service. It was brilliantly put together and everyone that spoke on it was amazing. It was a great way to demonstrate to wider audiences how co-production should be undertaken.</p> <p>A change to the agenda was agreed to allow the film to be shown in the second half of the meeting.</p> <p>Mencap</p> <p>CB promoted the first Our Active Community St Austell and Clay Country Forum, to be held on 25 September at Studio 4, St Austell.</p> <p>For more information, a flyer and agenda are attached as Appendix 1.</p> <p>A number of people in the meeting expressed an interest in attending. In response to a question asking if neurodivergent individuals or people with other disabilities could attend, CB said</p>	



that while it was targeted towards people with learning disabilities, Mencap was an inclusive organisation and would

Autism Strategy Update

VA gave a short presentation, attached as Appendix 2, detailing the Autism Strategy Governance Pathway. She apologised to the Board for the presentation not being in an accessible format and added that the draft Strategy, which the Board would receive, would not yet be in easy read either. Due to this, VA encouraged groups and support systems to work with people to understand its content and to help to formulate suggestions around it.

The Citizen Checkers were leading engagement sessions to improve support to autistic people in Cornwall. Members were encouraged to join the sessions to share their views and improve autistic lives in Cornwall.

KS added that there would be a session each in the East, the West and online. Details were currently being finalised and would be shared with the Partnership Boards at the earliest opportunity.

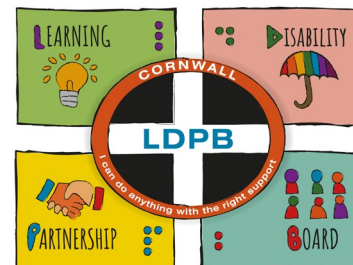
AW asked how sessions and the consultation would be publicised. KS said that the Partnership Boards team would circulate information and encourage partners to share it widely. There would also be a form of launch at the next Autism Partnership Board. VA added that it was hoped that they could be promoted through Chaos Radio and Cornwall Council would be circulating details to all of their providers that support autistic people and people with learning disabilities.

AD emphasised that all people with disabilities, regardless of what those disabilities are, should have their voices heard and be able to help to develop the services that they need.

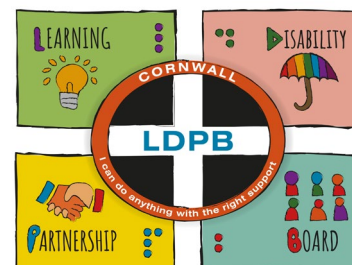
WW said that it was important that everyone had the chance to have their say to help to make services better in the future.

Learning Disability Strategy Update

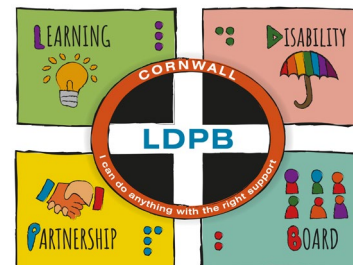
VA reported that Integrated Care Board (ICB) colleagues were



	<p>supposed to be leading on the LD Strategy but that had not happened yet. As a result, VA's team would be working with the ICB and she would like the next meeting of this Board to consider how we work together to design and shape a Learning Disability Strategy. The process could not start before Christmas as the team was focussed upon the Autism Strategy and other work so they did not have the capacity to start right now.</p> <p>VA stated that how the work was taken forward was not down to her, it was down to the people in the room, she was just the conduit</p> <p>The Women's Centre Cornwall / Diva's</p> <p>DH shared the following via the meeting chat function:</p> <p><i>The DIVAS are offering Healthy Relationships training to different organisations in Cornwall. Please contact penni.charteress@womenscentrecornwall.org.uk for information or call Penni on 07958 611948 .</i></p> <p><i>Also we are going to start up Cuppa and Chat groups for any women with learning disabilities and/or neurodivergent women who have experienced domestic abuse. We are planning these groups at the moment and will send out information to the Learning Disability and Autism Partnership Boards very soon.</i></p> <p><i>And finally, we are delivering individual support to women with learning disabilities and/or neurodivergent women who have experienced Domestic Abuse and or Sexual violence. Please contact penni.charteress@womenscentrecornwall.org.uk for information or call Penni on 07958 611948.</i></p>	Action
5	Break	
	The Board had a 10 minute comfort break.	



6	Change to scheduled agenda – Co-production in Cornwall – Getting it right, together, for Cornwall Residents	
	<p>As agreed earlier in the meeting, the Board watched a short film entitled Co-production in Cornwall – Getting it right, together, for Cornwall Residents, which had been co-produced by Rory from Citizen Checkers and Cornwall Council.</p> <p>Following the film, AD said that we were all proud of what we do in Cornwall to help other people out and we were all proud of the production.</p>	
7	What does freedom mean to you?	
	<p>As previously agreed by the Board, meetings would now be themed in line with the 7 Keys to Citizenship, with this meeting focussing upon ‘freedom’.</p> <p>RO</p> <p>SW opened the conversation with the question, what does freedom mean to you?</p> <p>SD said that he lived in a Cornwall Housing house. Whilst that provided him with the freedom to live independently, the organisation undertook regular 6 weekly checks on, for example, the cleanliness of the property but were often not interested when he highlighted necessary repairs. It could feel like his private space was being invaded and also that he was not listened to.</p> <p>DB had been in touch with the Partnership Boards team when information about the theme of the meeting was circulated. He reiterated what he had written then, that people had fought for many years to gain freedom but it had come at a cost. As humans, everyone had a right to exist and to be respected and society should treat everyone properly. That was fundamental to our existence.</p> <p>RO asked DB what aspects of the health and social care system he felt had an impact on his freedom. DB said the process for booking</p>	



GP appointments was a problem as the phonenumber was not user-friendly and then people were left waiting for call backs rather than being given specific times.

Also, not everyone had access to healthy foods. Isolation was a big issue in Cornwall and access to supermarkets was a part of that. Many people were unable to drive and a lack of access to or availability of public transport was a particular problem.

WW encouraged people around the table with lived experience to speak up and share their opinions. This Board was an opportunity to be heard.

KS said that many issues centred around choice.

HD said that her son would like the freedom to access his community and to do that he required Personal Assistant support, which was not available, and public transport, which was not available in outlying villages. These issues were preventing him from gaining employment.

Members had a brief discussion about the availability of PA support in different areas of the county. KS suggested that was something that Cornwall Council could look into.

KS wondered if it would be feasible for Personal Budgets to be utilised for a form of joint transport.

RS stressed the importance of having the necessary support to help people to fight for the financial benefits that they are entitled to. He added that having control of your own money, rather than parents or carers managing it for you, gave you freedom. SW said that RS was correct to highlight how essential money was to ensuring an individual's freedom and some very important conversations would be had when the Board meeting with that theme came around.

DB said the most important thing was understanding the different ways in which money can be spent. He cited a personal example of having previously sourced a PA through an agency but now employing one privately, who he considered to be a 'Godsend'.

VA explained that Adult Social Care worked with people with eligible needs under the Care Act but transport was not considered to be an eligible care need. Benefits could be used to pay for their bills, food and getting around. The Council did not have a bottomless pit of money and it only received monies relating to the Care Act and to meet care needs.

VA supported DB's comments, stating that giving people a Direct Payment or a Personal Budget provided them with control and choice about the care and support they can purchase to meet the needs in their care and support plan in a personalised way. That equalled more freedom.

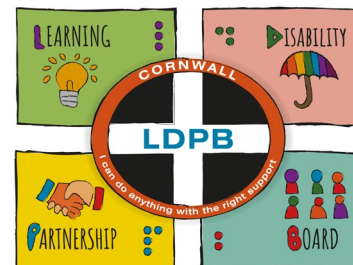
B felt that the Board would benefit from an in-depth session on the 7 Keys to Citizenship to ensure that all lived experience members fully understood the concepts, adding that Money being voted as the last of the themes to be considered demonstrated that not everyone did. SW, as a parent carer of a young adult with complex needs that could not communicate such matters, agreed.

B perceived the scheduling of the consideration of the seven themes to be a tiering of how important they were, as opposed to a practical matter. SW replied that it was never supposed to be a list of what was the most important, it was simply a matter of scheduling consideration of each. RO added that it was also an exercise in educating people on the concept of voting ahead of the General Election.

WW stressed the importance of people coming together to find ways to address the transport issues they face as transport provides freedom.

AW supported SW's comment around the support her daughter requires, saying that parent carers of non-verbal children are really the only people that can understand what makes them happy, through body language, facial expressions etc.

With regard to transport, AW said that Derriford were focussing on an equity standpoint. It was important to recognise each persons different circumstances and to ensure the allocation of the exact



	<p>resources and opportunities needed to reach an equal outcome.</p> <p>JWR agreed, adding that we all talk about equality and the Equality Act but equality was actually disabling for some people. Providing everyone with equal resources did not provide equity, which is what everyone should be aiming for. Being a Disability Aware or Disability Positive organisation because you have, for example, a wheelchair ramp, a hearing loop and accessible toilets, was great but in what way are you making things easier for autistic people or people with other physical disabilities. Equality can result in a thin veneer of compliance whereas, for example, easy read, was an example of equity. Both AW and JWR emphasised the need to be person-centred. JWR added that while it may sound like a huge piece of work it really wasn't if it was a way of working and central to your ethos as it became automatic.</p> <p>DH agreed with the views put forward by AW and JWF but expressed concern that some people in the meeting may not have understood some of the big words used. She said that Heather and Mary were undertaking work to address the issue for The Women's Centre. An example of positive change coming from this was the use of the word 'belonging'.</p> <p>RO linked what AW and DB had said. DB's example of the difficulty in obtaining a GP appointment highlighted a service taking an equality rather than an equity standpoint. Looking at systems overall, how people choices, freedoms and health are directly affected, is the type of systematic change that this Partnership Board can influence.</p>	
8	A Workplan for the Partnership Board	
	Due to the meeting overrunning, this item was not considered.	
9	Any Other business	
	<p>SW invited any other business.</p> <p>KS promoted an event to be held in Pool on 27 September 2024. It</p>	

was aimed at people in receipt of support or care or who cared for someone that is. The Checkers wanted to hear their views on how they think good change should happen.

RO shared details of work being carried out Danielle Carney of ICE Creates:

Partnering with Cornwall Council, we want to learn more about people's wants and needs from sexual health services. It is important that the voices of all people living in Cornwall and Isles of Scilly are amplified, to ensure their voices are heard and considered in commissioning decisions.

We are sharing a survey which is planning to run until the 22nd of September. There is a possibility we may extend it, however the survey will definitely be live until at least this date.

The below email comms can also be shared with stakeholders/people in your networks:

We want to help Cornwall Council shape sexual and reproductive health services for everyone who lives in Cornwall and the Isles of Scilly.

We need your help in two ways:

1. Share this survey across your network to the local people that you and your organisation support:

<https://www.surveymonkey.com/r/sexualhealthice>

2. Help us arrange conversations in your community.

WC 16th September, we are carrying out face-face groups in local communities. If you are a community leader, we would like to work with you to set up a group with local people in a trusted local venue. Can you help us arrange this and amplify their voices?

If you can help us, please contact

adam.courtney@icecreates.co.uk

The Chair closed the meeting and all members were thanked for their attendance.



St. Austell and Clay Country Forum

07427583638

chris.ballett@mencap.org.uk



APPENDIX 1



What is this forum? A place for people to meet and share their ideas to help **people with a learning disability move more** and have fun.



Wednesday
25th September



10.30 (morning)
until 12.00 (noon)



Where? Studio
4, St. Austell



We will provide some snacks and refreshments.



Let us know you are coming by text, email or **scan this QR code.**



Directions to Studio 4

Studio 4 is in St. Austell town centre. It is down the hill from the Barclays Pod.

The address is 12a, 14 Old Vicarage Pl, St. Austell, PL25 5YY.



You could use Google Maps on your phone to help you find it.

Parking

The closest car park to Studio 4 is White River Place.



You could also park at Priory Car Park or East Hill Car Park and walk 5-10 minutes.



Transport links

The South Street bus stop in town is a very short walk from Studio 4.



St. Austell and Clay Country Forum Agenda

07427583638

[chris.ballett@
mencap.org.uk](mailto:chris.ballett@mencap.org.uk)



Chris Ballett
Community Partner



Everyone will **get to know each other**.



Everyone will get to talk about things that they **like**, things that they **don't like** and things that they would **like to change**.



Chris will tell everyone about **seed funding** and how we can use it to get people with a learning disability more active.



Chris will tell everyone about a **paid job** called a Community Connector that will be for someone who has a learning disability.

APPENDIX 2

Learning Disability Partnership Board

05.09.24 Autism Strategy update

Autism Strategy Governance Pathway

Governance	Meeting Date	Paper deadline
People Commissioning Board- date to be agreed as was tabled for CBS	13/11/24	One week prior
Extended DLT	04/12/24	One week prior
LDAMH Prog of Care Group (poss clinical ref group, check Stuart Cohen)-ICB governance	Nov /Dec 24	One week prior
Autism Partnership Board	12/12/24	One week prior
Integrated Commissioning Partnership Group (IPCG)	Dec/Jan 25	One week prior
DLT TFF	03/12/24	One week prior
CDT	27.02.25	20/02/2025
Integrated Care Partnership/Health & Wellbeing Board	Check Dates	
Cabinet Workplan – Individual Decision Portfolio Holder sign off-Decision Report in EDRMS Director, Legal, Finance approval	26.03.25 or earlier March (There is no meeting in earlier March – the meeting before this is 12 th February 2025)	26/02/2025

Engagement Sessions

Autism Partnership Board Update 19.09.24

Share Autism Strategy V 2 Neurodivergent Café -council staff group 10.09.24, reach out to NHS Neurodivergent staff network and offer a session supported by working group members from CPFT

Experts By Experience sessions- 30/09/-06/10/24 (two F2F West/East, 1 virtual evening session)

Strategy Implementation/action Plan session Working Group 17/09/24

Public consultation Let's Talk Cornwall Early-Mid Oct

Callout Autistic people in Cornwall. We need your input-Citizen Checkers Engagement Sessions

- Cornwall Council are working to improve support to autistic people in Cornwall. Join our sessions to share your views and improve autistic lives in Cornwall.
- We will talk about • Improving understanding and acceptance • Improving support • Reducing inequalities • Increasing employment and education opportunities • Supporting independent living • Keeping Safe
- <https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fcitizencheckers.co.uk%2Fautistic-people-in-cornwall%2F&data=05%7C02%7Cvicki.allan%40cornwall.gov.uk%7Cea775fffe47a4decdf008dcd64b8997%7Cefaa16aad1de4d58ba2e2833fdfdd29f%7C0%7C0%7C638620867134712720%7CUnknown%7CTWFpbGZsb3d8eyJWljojMC4wLjAwMDAiLCJQIjoiV2luMzliLCJBTil6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=0HGQ78XJNNJlGvG%2F1tbMi6WYRM695iz2NBUBXEoLF4%3D&reserved=0>