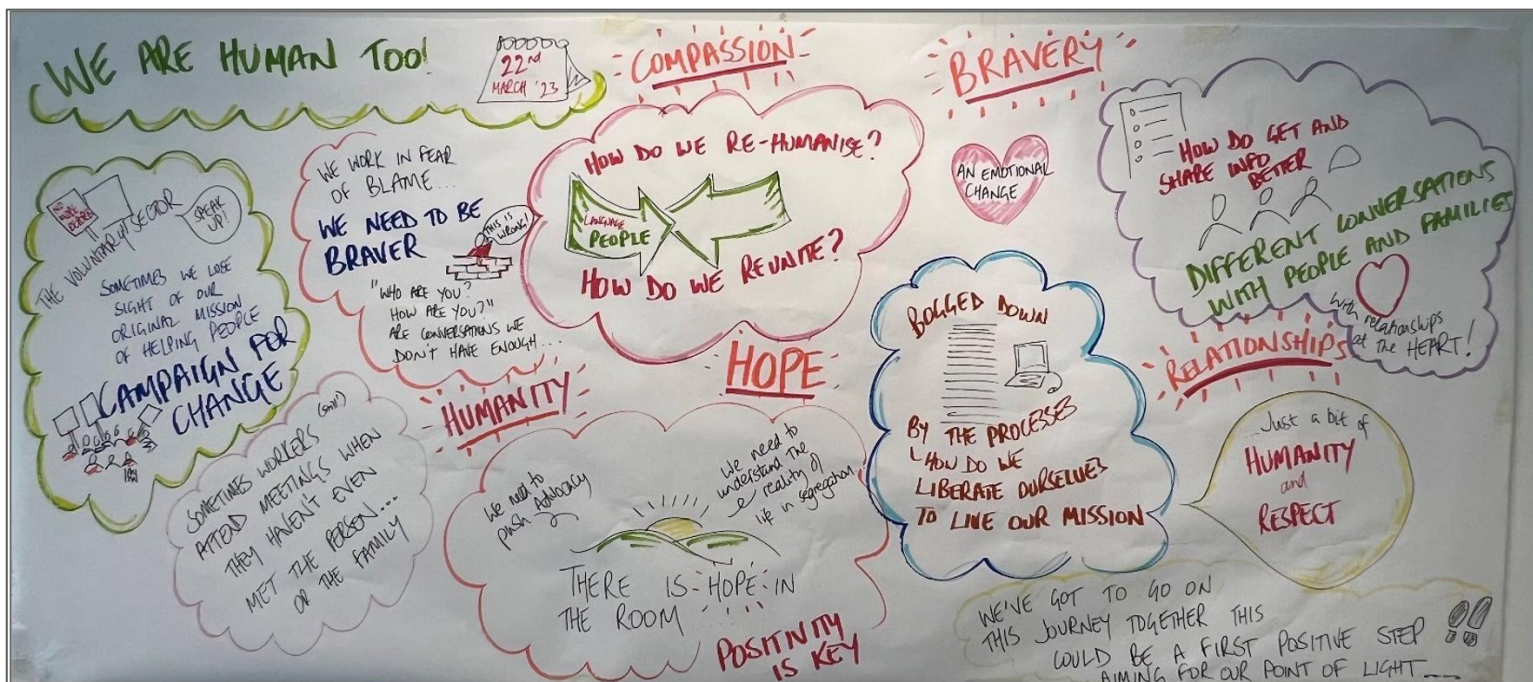


Beyond Urgent Build Community Capacity Now!

A We Are Human Too Event

22 March 2023



1. Photo of graphic facilitation at the event using words, symbols and pictures to record the conversation.

Report for sponsors: North East & North Cumbria Integrated Care Board & System Partners



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Introduction



This report is written by members of the **We Are Human Too** team.



We have tried to make the report **accessible**, but we know that there is a lot of information and that some of the words and language provided in the feedback maybe difficult for people to understand.



We have also thought about **different ways** that we could share information and findings from our report.



The We Are Human Too team are making a short **video podcast** to share a summary of the event.



We worked with a community interest company called Media Savvy to record our event. We will be sharing a **full video** which includes speaker presentations and interviews with people that joined our event.



The We Are Human Too team would be happy to meet with groups and organisations to talk through this report and next steps. Our contact details can be found on Page 34.

Contents



Our report is in 3 parts:



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- Who are We Are Human Too?

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- What happened at the event including Speakers, having safe space, what have you heard and key themes?

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Extra information including everything that people shared at the event.

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Summary of our event



The We Are Human Too group includes self-advocacy groups who came together to challenge the abuse of patients at Whorlton Hall in 2019.



Since then, our team has grown and joined with other self-advocacy groups and national teams to campaign for change.



We know that we all need to think very differently if we are going to support people with a learning disability and autistic people to live good lives.



As a team we know that there have been many failed promises about the money going into local community services.



The We Are Human Too group told the North East & North Cumbria Integrated Care Board (NENC ICB) that things needed to be different and asked them if we could work together to make changes.



The Board agreed to support this work and gave money for the group to hold an event to look at:



- How we build community capacity together to support individuals and families to live good lives in their own community.



- How we develop a workplan with health and social care and voluntary and community groups?



The Build Community Capacity event 22 March 2023 was the start of doing things differently.



This way of working is very new. We are all learning, so the report has several bits, feedback about the event, what it did and next steps. It also provides information about how we did the event as lots of other people want to copy what we did.



The event was planned and delivered by self-advocates. We worked with **allies** that support our work. This was a great example of what **coproduction** should mean in practice.



The event was only 4 hours and we had speakers who gave up their time to talk about things that have gone wrong in the system, some of the numbers but also shared some examples of things that work and that we can try.



We also talked a lot about being human and showing love and kindness and being brave enough to say when things are not working. We talked a lot about feeling safe to be honest.



78 people came from across health, social care and voluntary and community sector services from across the North East and North Cumbria.



People had lots to say and many people want to be part of a **bigger change**, which makes things better for people. People don't want any more reports – they want **action**, and they want it now! There are many changes happening in services now, so this is the time to be brave and try something new.



People took the time to share their feelings and views. We ask you to **take time to read** all the comments provided in the **extra information section on Page 22** to get a full idea of the views and feelings in the room.

Recommendations



2. Photo of post-it notes responses from people that attended the event answering two questions.



We need to build on the work that we have started together. We will do this in **different ways**.



We will share the event and the messages with our Integrated Care Board (ICB) sponsors and organisations that are part of the system.



Ask the Integrated Care Board to respond to and share the report across the NENC ICB including Mental Health and Health inequalities work programmes.



Ask Hospital provider Trusts to share and respond to the report.



Ask our Integrated Care Board to run a similar event and look at how they start to use the information and ideas in the transformation work across the learning disability, mental health and autism transformation programme.



Ask our Integrated Care Board how We Are Human Too can be involved in the transformation work plan for the Integrated Care System.



ICB to support and find out more about the Trieste model and Tim Keilty's proposal as part of wider community transformation work across the North East and North Cumbria.



Support an event to show and share good practice of community focused voluntary, community, and social enterprise (VCSE) or self-advocacy peer led projects.



Work with partners who have already expressed an interest in working together and planning next steps.



Share our learning in planning and organising an event that was **coproduced** and led by members of the voluntary and community sector.



Lots more building relationships, connections and working together.

Who are We Are Human Too?

We Are Human Too is a campaign group of self-advocates. The self-advocates are people with a learning disability and autistic people, from the North East of England.

We Are Human Too group came together in 2019 after hearing about the abuse that happened at Whorlton Hall, in County Durham. The group has self-advocates and colleagues from:

- Skills for People
- Speaking Up Together at Your Voice Counts, and
- Sunderland People First

The Group were angry and upset about the abuse that some people experience in Assessment and Treatment Units (sometimes called ATUs) and in secure hospitals.

The Group joined in with national campaigns including Stripped of Human Rights and Right to Home to challenge the abuse scandals that keep happening. The national group organised protests in Newcastle, Leeds and London.

We created a Government Petition to ask that an independent body led by people with lived experience should be created to work with the Care Quality Commission (CQC) to monitor secure settings such as hospitals and assessment and treatment units (ATUs), and hold them to account.

The We Are Human Too Group have continued to provide support to people when the programmes that show the abuse of autistic people and people with a learning disability are shown on TV or are in the press.

The group made a We Are Human Too video in 2020 to explain the campaign work that we all been doing. Click on this link to watch our video:

<https://www.youtube.com/watch?v=fbFRu6VRov0>

How the event happened



12 years since the abuse of people with a learning disability and autistic people was uncovered at Winterbourne View, we continue to hear about abuse scandals.



In 2023, over 2,000 autistic people & people with a learning disability are still being detained in inappropriate & often substandard inpatient care. The average length of stay for people within inpatient services is now 5.6 years.



We are tired of reports, recommendations and promises of change. But nothing happens. We want actions that are led by autistic people, people with a learning disability and families.



What would a good life look like for autistic people and people with learning disabilities isn't found in reports and reviews. This is about people's Human Rights. Take a moment to listen: <http://bit.ly/43gx8bF>



Members of the We Are Human Too group came together to support each other following a new Panorama Programme in September 2022 which showed the abuse of people at the Edenfield Centre, run by Greater Manchester Mental Health NHS Foundation Trust. Here is a link to the Panorama report: <http://bit.ly/3mkzKVf>



It was hard for self-advocates and families to know what to do after seeing yet more examples of abuse. We wrote to Managers and Commissioners from local Health Trusts and members of our North East and North Cumbria Integrated Care Board saying that this needed to stop, and things need to change.



Managers and Commissioners from across Health and Social care services responded to say that they wanted to work together to make changes happen. This was the start of building relationships and planning our event.

Planning



In October 2022, the We Are Human Too team suggested holding an event which would be organised and hosted by autistic people, people with a learning disability and families.

Our **aims for the event** were:



To have action led conversations to support wider change for people to have good lives.

To focus on the role of the voluntary and community sector in supporting this change.

To develop partnership actions and next steps.



It is important to say that from the beginning that we saw the event as an opportunity to bring people together to start a conversation and develop future plans together.



Supporting the voluntary and community sector to make changes happen is not a new idea. It has come up time and again in many reports since Winterbourne View.



There is a lot of evidence to show how the voluntary and community sector can prevent autistic people and people with a learning disability from going into inpatient services. We can also support people when they leave hospital and go back home.



We Are Human Too team set up a Steering Group of self-advocates and allies that support our work.



We wrote a plan for holding an event and asked the North East and North Cumbria Integrated Care Board for funding to organise and host this event. Funding was agreed in December 2022.



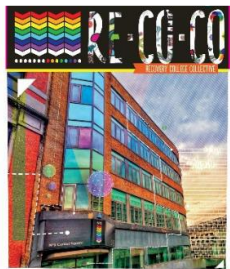
The We Are Human Too Steering group met monthly to plan the event and organise the venue and who should come.



We wanted to invite managers and commissioners from the voluntary and community sector, health and social care services. They have money and can make decisions about what can change. We made an invitation list with help from local Health Trusts and the NENC Integrated Care Board.



Self-advocates from the team said that it was important that all information that we sent out was provided in **easy read**. This included proposals, minutes from meetings and flyers advertising the event.



Self-advocates also created an **All You Need to Know Guide** about the venue which included information about physical and sensory accessibility needs.



We are grateful to allies who helped us find out about venues that would be accessible and cost effective. We chose Newcastle Recovery College because this is a community venue.



We chose to organise a half-day event so that we could have focused conversations. People said that when they have attended full day events, people sometimes leave after lunch.

Speakers

We needed the event to be different so we contacted speakers who could bring something different to the event and to conversations

We thought about the following areas:

Encouraging managers and commissioners to think differently about how we support autistic people, people with a learning disability and families rather than within inpatient services.

Hearing personal stories about what has made a difference in the lives of autistic people and people with a learning disability.

Looking at examples of different ways of working that have worked well in other areas of the country or internationally.

Sharing evidence to show the importance of doing things differently.

Supporting a “We are all in this together” way of working, encouraging partnership working and opportunities to support change.

The Speakers that we contacted were known to self-advocates or were recommended by allies from our Steering Group. We were really pleased by the positive response from Speakers. People said that they were delighted to have been contacted and felt privileged to take part. This meant a lot to our team.

These are the Speakers that joined us for our event:

Members of the We Are Human Too team.



Gavin, Ann, Derek and Matthew gave a presentation about the background behind the We Are Human Too teams work and why we felt that it was important to host this event.



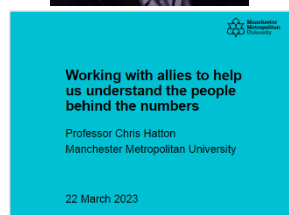
Neil Denton. Neil is a Community Mediator.



Neil's presentation looked at the importance of building relationships to make change happen. Neil used examples of his work as a community mediator to show that relationships are the most important area.



Chris Hatton. Chris is a Professor of Social Care at Manchester Metropolitan University.



Chris's presentation looked at information that is available about how many autistic people or people with a learning disability are in hospitals, and what happens to people before, during and after they are there?



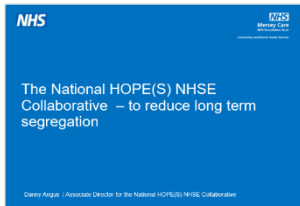
Tim Keilty. Tim is the Chief Executive Officer of New Prospects Association.



Tim shared his experiences of supporting people over 30 years, thinking about what's wrong and what needs to change. Tim shared his thoughts in a recent blog called Building the Right Support when Everything is broken...



Danny Angus. Danny is the Associate Director for National HOPE(S) NHSE Collaborative Mersey Care NHS Foundation Trust.



Danny talked about the HOPES model and how the team have supported people in long term segregation to move back to the community.



You can find out more about the work of the HOPES team by clicking on this link:

<https://www.centreforperfectcare.com/about-us/hope-s/>



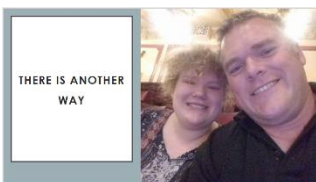
Jen Rhodes. Jen is a Consultant Clinical Psychologist working with autistic adults and adults with learning disabilities in Northumberland.



Jen talked about the Trieste model of mental health and how we could deliver mental health and learning disability services differently, to better meet the needs of the communities we serve.



Jeremy Harris. Jeremy is Bethany's dad.



Jeremy talked about how his daughter; Beth was locked in hospital cell for three years with no treatment. Jeremy shared "There is a better way. The right people doing the right thing in the right place. It's not complex."



Thank you to our Co-Chairs: Making sure that the event ran smoothly and keeping us all to time.

Stewart Chappell: Self-advocate and Project Worker from Skills for People.

Neil Denton: Community Mediator.

Our Agenda













We spent lots of time working on an agenda that would involve everyone in learning and sharing together.

The speakers that joined us were part of our planning team and helped make this event possible.





The 'We Are Human Too' team Welcomes you to our Build Community Capacity Now Event



	 9:00	Welcome and Registration
	 9:15	Co-chairs Introduction Neil Denton Community Mediator
	 9:20	Stewart Chappell Self-advocate and Project Worker from Skills for People
	 9:25	Introduction to the event Important information about the venue and keeping everyone safe.
	 9:25	We Are Human Too Introduction A campaign group of self-advocates made up of people with a learning disability, autistic people and families, from the North East of England.
	 9:40	Table Discussions: <ul style="list-style-type: none"> What have you heard? What is important to you? Please add your thoughts on the wall banner or use the chat box if you are joining virtually.
	 9:45	Neil Denton – Relationships: the first mile not the extra mile.

	 10:00	Table Discussions: <ul style="list-style-type: none"> What have you heard? What is important to you? Please add your thoughts on the wall banner or use the chat box if you are joining virtually.
	 10:05	Chris Hatton Professor of Social Care, Manchester Metropolitan University Working with allies to help us understand the people behind the numbers.
	 10:20	Table Discussions: <ul style="list-style-type: none"> What have you heard? What is important to you? Please add your thoughts.
	 10:25	Break: Please introduce yourself to someone from a different table.
	 10:40	Tim Keilty Building the Right Support...When Everything is Broken. Who's up for a challenge!
	 10:55	Table Discussions: <ul style="list-style-type: none"> What have you heard? What is important to you? Please add your thoughts.

		Danny Angus Associate Director for National HOPE(S) NHSE Collaborative Mersey Care NHS Foundation Trust Learning from HOPES.
		Table Discussions: <ul style="list-style-type: none">• What have you heard?• What is important to you? Please add your thoughts.
		Jen Rhodes Consultant Clinical Psychologist, Northumberland Looking at the Trieste model - how could we deliver mental health and learning disability services differently, to better meet the needs of the communities we serve?
		Table Discussions: <ul style="list-style-type: none">• What have you heard?• What is important to you? Please add your thoughts.
		Break:
		Jez Harris 'Bethany's Dad' "There is a better way. The right people doing the right thing in the right place. It's not complex".
		Table Discussions: <ul style="list-style-type: none">• What have you heard?• What is important to you? Please add your thoughts

		Table discussions – one important question <ul style="list-style-type: none">• Bringing our thoughts together with a facilitated graphic.• Our Working Together Pledge.
		End of event – postcards and next steps



We have included all presentations from Speakers as part of our report.



The We Are Human Too group used funding from our sponsors to pay for a film company to produce a video of our event.



We will share a video from Media Savvy as soon as possible. The video will include our speaker presentations and interviews with people that joined our event.

Having a safe place to learn and share together



Seventy-eight (78) people joined our event. People came from the voluntary and community sector and health and social care services from across the North East and North Cumbria.



We asked people to sit at tables from their own teams or with people from the same area of working. We felt that it was important that people discussed questions together.



We shared advice at the beginning of the meeting about how we could support each other to feel safe. There were break-out rooms where people could have some chill out time or talk to a member of the We Are Human Too team if needed.



We only had four (4) hours to learn and share together but what everyone achieved in this time made our team feel that this was the start of doing something different.



We made sure that we had time for people to share their own thoughts throughout the meeting. We asked two important questions.

What have you heard?

What is important to you?



We asked everyone to add their thoughts, comments and ideas to a wall banner so that we could record what people said.

What people shared within the meeting



4. Photo of post-it notes responses from people that attended the event answering two questions.



We recorded what everyone said when answering questions these questions.



The full list of things that people said can be seen in the **Extra information section** of our report on Page 22.



We think that everything that people shared is important. We have also looked at key themes or common things that people said when answering questions.



We have included key themes or common areas within our **Recommendation's and Next Steps** section.

What have you heard? Key themes



We don't need any more reports to make changes happen.

No more reports. We have lost our anger. Nothing has changed in 10 years or the preceding decades. How do we build our relationships with people and other organisations? More funding in the right areas. So, what are we going to do? There is not enough resistance!



People and their families need to have choice about care and treatment.



Inpatient settings and mental health hospitals can make things worse for people and families.

This is not ok; people continue to be abused and traumatised.
Trauma, Abuse, Unsafe Care.



We need to support people and families who are in crisis in a different way as its not working

We need places that feel 'normal' or 'natural' for people to gather + belong + access help if they need it.



We need to build a Connected Community to support each other.

Connected Community = Stronger communities. Good partner relationships. Improved mental health. Physical health benefits. Goals and strong Bridges.



We need to work together. Stop blaming each other and make sure that everyone is a partner in conversations going forward.

Stop focusing on blame culture. No longer meeting needs of the person in our care.



Look at how we support staff to have open and honest conversations without fear of blame?

Blame us for everything. No level of responsibility / accountable. Pushed too far for too long. We need a definite change NOW + answers not maybe.



The things that we have shared are the same for everybody.

The ideas in learning disabilities + autism is the same as ideas in other 'groups' e.g., mental health – Hubs community etc We are all Human.



The words and how we say it matters. We need to stop using language and abbreviations that make people feel less valued.

People are being diagnosed with a LD + / ur, asd while on a m.h ward. Term Ld = Dehumanise.



People with a learning disability, autistic people and families must be involved in making changes happen by being involved in planning and commissioning.

That change happens effectively with the voices of people with learning disabilities and autism leading this change- Action led.



We need to focus on building relationships.

Staff + People relationships are important, so they don't break down.



Change is needed but we need to support each other with change.

Change is scary but so is the status quo...Who is responsible? All of us.

Extra information.



People were asked to write their answers on post it notes and add them to the wall banner. This is a record of what everyone shared.

What have you heard?

“Too many reports, not enough action.”

“We know what needs to happen”

“Reports are a smokescreen for change.”

“Good relationships are fundamental.”

“Love is not always considered in the system.”

“Systems are reactive not proactive.”

“We all know what good looks like but there is no collaboration to recognise skills and strengths and difference.”

“No more reports. We have lost our anger. Nothing has changed in 10 years or the preceding decades. How do we build our relationships with people and other organisations? More funding in the right areas. So, what are we going to do? There is not enough Resistance!”

“How many people are in hospital for years- high statistic.”

“Campaigns + protests”

“We are human too. Change. Lots of reports/no change.”

“Relational working requires vulnerability.”

“People with Learning Disabilities / Autism want to be heard and be included within decision making and change.”

“Too many reports, we hear all the words, but nothing comes out of it.”

“Term Ld= Dehumanise.”

“If Dehumanise= can do what you want.”

“Anger! We are still having conversation”.

“Too many reports not enough action.”

“Frustration” “Scandals”

What have you heard?

"People with learning disabilities/ difficulties are given no choice with their treatments."

"How much is spent or should be spent on family expenses i.e., travel out of area?"

"Type 2 diabetes very high in hospitals."

"Obesity + lack of exercise."

"Focus on blame rather than actual change."

"Remember Ministry of Justice Patients."

"So, what! What about other people in Society.i.e., elderly."

"This is not ok; people continue to be abused + traumatised."

"Trauma, Abuse, Unsafe Care."

"Regardless of what happens there are still significant challenges for people in services."

"Transforming care worked?"

"Sad Despair."

"Breakdown in relations leads to De-Humanisation."

"Mutual + Enabling."

"We need places that feel 'normal' or 'natural' for people to gather + belong + access help if they need it."

"Getting in the way of system goals, People should shape system goals."

"Hospitals still in crisis."

"We need a regionally national campaign, Let's get angry!"

"HOPES should be on every ward. Why are so many people in long term segregation in a hospital setting?"

"Need to change no more reports- action."

"No more reports inclusive working listens to advocates."

"People are being diagnosed with a LD + / ur, asd while on a m.h ward."

What have you heard?

"Always feel your wrong. Failure can be overwhelming when you have been fighting for so long, but still craved support and pushback is received – not right support now."

"ARE you listening."

"We deliver coverage not connection – need to flip this."

"Young People- how many on at risk register- Dynamic support Register?"

"Connected Community = Stronger communities. Good partner relationships. Improved MH. Physical health benefits. Goals and strong Bridges."

"Out of sight."

"30 years of saying NO Reports! - Action now."

"Homes not Hospitals."

"No more Reports, People want Action and see change."

"Have CNTW thought about moving to Trieste Model?"

"We are all squashed by legislation."

"The System Dehumanises"

"Broken Record"

"Lots of reports, little action"

"Fixing Processes"

"Accessible data is vastly under reflective of ACTUAL numbers. "

"CQC Lanchester Road, Durham, Bankfield Court Middlesbrough, (not great reviews)."

"Nothing has happened- we talk but don't do enough!!"

"Nothing has changed: Why not? Building Relationships: Why not?"

"No Significant change"

"Strong Bridges, Friends + Support became family."

"Paperwork is driving our care- ticked boxes doesn't mean good care."

"Change attitude, we are all doing our best- receive the blame."

What have you heard?

“Focus on what we do want, not what we don’t want.”

“Staff + People relationships are important, so they don’t break down.”

“The ideas in learning disabilities + Autism is the same as ideas in other ‘groups’ e.g., mental health – Hubs community etc We are all Human.”

“Time to get Angry!”

“Flip narrative restraint, PRN, Seclusion= failure in care.”

“Shared goals, Shared objectives, Satisfaction- job/life.”

“ICB, think they know everything- treated as equal on level playing field between bosses + people in hospitals everyone around them in-between.”

“Redesign not Repair.”

“Blame us for everything. No level of responsibility / accountable. Pushed too far for too long. We need a definite change NOW + answers not maybe.”

“Dehumanisation, Staff Fatigue, looking for someone to blame.”

“Mean, Reasons, Opportunities.”

“Start conversation with How can I help?”

“Safe fail not fail safe.”

“Nothing to look forward to- deprived every right/privilege- Person chooses own support + own agency + support as may have only received insufficient support so far.”

“Where does the existing NENC PBS programme fit with national H.O.P.E.”

“This is not very accessible DATA.”

“Continue to fight until you get answers you need/want/deserve. Never take no for an answer. Never back down no matter what or long it takes.”

“Peer Support in Hospitals and in organisations.”

“Sometimes patients are more mature than the system/ staff/ governors. Experienced staff + trained – not just degree staff with no care or experience.”

“It's about matching models.”

“Save trees, Save people.”

What have you heard?

"Small changes can be a big difference= right support, genuine care, experience+ funding."

"In my role to hopefully reduce hospital commissions."

"Someone needs to make brave decisions. Let's stop doing the usual."

"Emotional connectivity improves care!"

"How do you keep connectivity in segregated services?"

"How can Hospitals be part of communities? How do we bridge the gap between them?"

"Collaboration builds good foundations together. Good relationships "Not us + them".

"Good relationship= better care, Reduce dehumanising. What does good look like?"

"The importance of relationships, and how positive relationships lead to better outcomes (shared decisions making)"

"Who cares?"

"Do you care enough?"

"No more reports, Action now"

"We have so many measures but still don't know what the size of the problem is"

"Safe wards! Create right environment for bridging gaps."

"No more reports, Action now"

"10years- no change. People still experience abuse. Advocates + Families want change now"

"Advocates + Families want to be deciding how, what, where they get care."

"Inpatient Services= CQC not good ratings knowledge is power accountability."

"Nobody wants to take responsibility for bad stuff but boasts about good stuff which is unfair."

"Good support= good progress= good quality of life= increased chance of recovery + getting back community and staying there."

What have you heard?

"Collaboration needs to happen. Include everyone more inclusive- no blame."

"People need something positive to help them get through tough times."

"Good relationships understand why something happened!"

"Dehumanisation and transactional thinking replaced by relational thinking building communities."

"Connected communities= better health and happiness."

"Humanity in the system."

"Competition= Conflict, what are the aims not what do we want to prevent?
Building the right support."

"Freedom is therapeutic."

"Lessons learned turn into regulation, Affects humanity."

"Just try Honesty + Trust."

"Could do better."

"Bad Apple, Bad Barrel."

"How do we address institutionality."

"We don't really know who's where."

"Conservative measures have not changed things!"

"Many more people are in hospital. People are in hospital for too long. Far too many restraints are being used. Need better data in this area."

"People ignored + families? Or police involved and sectioned?"

"Information about hospital admissions/provision/ improvement is difficult to easily find- how should this be shared with people with learning disabilities and Autism/ what should be shared by ICB."

"Ensuring relationships are central."

"This is a human disaster."

"Relationships are lost in the system."

"Stop focusing on what we don't want blame culture. No longer meeting needs of the person in our care."

What have you heard?

“The language we use matters-it influences relationships + power.
Dehumanisation->Disaster.”

“There’s more talk about Autism + learning disability's but it's not leading to change.”

“All reports, no change.”

“Transforming care has failed.”

“Transforming care has taken integration backwards.”

“Interesting option of voluntary beds + use of crisis beds and “one” door approach (Trieste)”

“Too much current doubt, fear, rejection being unsure- people unwilling, unmotivated to make a difference.”

“Does the local Authority believe they have any responsibility to support discharge.”

“No wrong door model- children use something similar for adults coming out of hospital- include P.B.S and D.P.S.”

“No schedule flexibility or time alone or support to choose own schedule prepare + expect for the worst, increases mental health.”

What is important?

“Children + young people not really mentioned. What works for them? Do we have examples of good practice?”

“How do we ensure children + young people don’t become the next group of adults in hospitals.”

“That change happens effectively with the voices of people with learning disabilities and autism leading this change- Action led.”

“The power of lived experience- learning from others, how they made changes, have they got out of the system they were trapped in. How should care be changed for people with Autism that actually works? It can be done without restraint, LTS seeing the person at the centre.”

“Staff- ‘care’ staff, need to care.”

“Location of moving people from the local area where they have their families.”

“Quality of Life.”

“Equality, treating everyone with respect.”

“Where is the adequate support in the community? Hard to get support workers. This can delay discharge.”

“Accountability, are right people in the room?”

“Powerless but not helpless, things do not change but WE do.”

“Can do. Humanity + bravery + courage.”

“Listen to people with LDA in hospitals and community. Kindness. Nobody listens or cares.”

“Who is responsible? All of us.”

“See the person, don’t be afraid of disagreements.”

“We don’t talk about love.”

“Policy= reduce hospital admission. Action= build new hospitals.”

“VCSE - helps keep people well- mental health... gets no NHS recurrent £ + little bit of £ from LA. Health + LA disjointed.”

“Too much... it’s not us this thinking leads to disaster.”

“We need to value people in society.”

What is important?

“Doing with, not doing to.”

“Services reading available”

“Listen + Do!”

“To have resources. To meet needs. And support people to live lives they choose.”

“Build relationships.”

“We don’t need all the information to start making changes.”

“Change is scary but so is the status quo.”

“Community capacity is not on the agenda, (even when we are around the table).”

“Policy says ABCDEF....are priorities, system measures. The rest is in effect ignored.”

“Regular staff, parent, client meetings- everyone taking responsibility.”

“Let’s have courage to change.”

“Be open to Yes! Act, reduce long term segregation, FREEDOM, Humanity + understanding, Listening, speaking out, CHANGE!”

“If we always do what we always do, we will always get what we always get.”

“There is a latency that is not acceptable- this is people’s lives- we are causing harm.”

“Close all-in patient Hospitals.”

“Flip the narrative. See the person not the risk.”

“Redesign, redesign, redesign.”

“Peer support is important.”

“Remirroring the privilege, meet sensory NEEDS.”

“I want to be happy.”

“Mental health services in community able to effectively support autistic people.”

“Do no harm + Nothing illegal.”

“Relational Thinking.”

“We need to build and value bridges and not feel threatened.”

What is important?

"Need cultural change, more open hospitals."

'We need to think + do radically."

"Freedom is therapeutic."

"Are we focussed on the right information."

"We are driven by reports- we should be driven by action."

"Honesty, regular communication + progress. Chance to have privileges- human rights. Love, respect, indignity, chance to prove ourselves."

"Involve people as much as possible- people know rights, consistency is key."

"Need good clear, understandable data."

"People with a learning Disabilities + Autism should not have to go back to hospital."

"We need to change the public narrative. People see people with learning disabilities + Autism as too difficult and challenging. Flip the narrative."

"Staff training? Management?"

"We need the kind of buy in and whole- system approach that Scotland achieved with trauma informed care."

"Easy to find information (Resource centre)."

"More support in the community."

"Meet real need, work together not do our bit."

"Need better data in this area. Building the right support. National + local accountability."

"Value a good relationship- avoid dehumanisation!"

"Families need to be heard. Are parents seen as an enemy? If so, how do we change this. What does need happen. How many others in Beth's situation?"

'See the person not the risk."

"Involvement."

"Support change."

"Need to be able to make people seen- wee need to know accurate numbers."

'People reduced to a risk score/ rating."

What is important?

"How can we answer children + young people + families are not failed. What training do staff require to understand people? Avoid admission avoid repeated trauma +harm."

"I wish people with Learning disabilities + Autism could work with the boss to influence, improving care in future for everyone. Improving quality for in hardest times."

"Systems to support different opinions."

"Build Kelation ships- Inclusive no more reports."

"There is urgency. People are being harmed."

"Get away from blame + finger pointing."

"Stop the- tick the box-> reports this doesn't improve care."

"Change, Action."

"Need action."

"That everyone is equal- no one is less. It's shameful that people must tell us they are human."

"Be open to YES!"

"Communication + genuine care is vital. People get locked up in hospitals for no reason + stay longer than necessary- not enough funding."

"Relationships are really important."

"Important that these things happen."

"Worried how many people in CNTW understand what needs to change."

"I intend to wear those big girl pants!"

"More campaigns. Rights!"

"Getting things done! Solidarity. Less empty promises leaders. Lack of bringing things to completion."

"We need to work from the ground up- the view of difference within the community, fear, political landscape, media, the "not our problem" mentality."

"We over focus on risk."

What is important?

“Everyone to be given a good quality of life.”

“The language of the system- Dehumanises.”

“How many we make reasonable, adjustments, everybody’s responsibility.”

“The churn of people = breaks relationships.”

“NHS reorganisations chasing tails= reactive not proactive.”

“Rehumansation- language, stigma, fear of difference. Working and budget protection. A way of bringing everyone together regularly from across agencies.”

“Move from, to people, with people, led by people.”

“How many people are forgotten with no oversight?”

“Relational thinking, enabling, trust and inclusive communication.”

“Valued families, good care + treatment.”

“Good bonding, co-production, better lives “An ordinary life”.”

“Systemic change is possible with strategies like the hopes national model. We need to look outside for other ideas ways of thinking- Trieste- risk management use of hospital admissions, mental act use of restraint.

“Rights based approach be less risk averse more person centred in our care approach.”

“Lived experience- self advocates at the heart of change ‘Hope model’.”

“Redesign and repair are needed.”

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5. Photo of the We Are Human Too planning team.