Whorlton Hall

What next?
Recap – what has happened so far?

We watched the horrendous tv programme
Two consultation meetings were held in Newcastle at Skills for People. These meetings were well attended by people with learning disabilities, autistic people, family carers and health and social care staff members, and self advocacy organisations (Skills for People, Sunderland People First and Your Voice Counts).
The Cumbria and North East Transforming Care Confirm and Challenge group had an extra meeting.

A report from this meeting was sent to the Transforming Care Board and the Transforming Care Executive Strategy Group.
A small planning team organised the protest at the Monument on 26th June, and joined it up with national protests.

We produced placards, handed out 300 leaflets which focused on need for community care – and asked people to sign the NAS petition.

About 200 attended. We got press coverage on several TV programmes, including Look North and Tyne Tees news, and newspapers. Several self advocates and family carers spoke passionately in the media.
Response from services

• Nic Bailey who chairs the Transforming Care Board and the Transforming Care Executive Strategy Group attended the Confirm and Challenge Group in July.

• She answered some of the group’s questions
Challenge back to commissioners

• The Confirm and Challenge Group came up with a set of questions that they asked each of the 3 Transforming Care Commissioning Hubs to answer.

• They want representatives from each Hub to come to their meeting to answer them.
Confirm and Challenge Group Questions

What are you going to do differently with regards to inspections of all services you commission both now and in the future? For example hospital, residential services, community services such as GP, community teams etc.

What are your plans to include people with lived experience in quality assurance of all services?

How many people with lived experience and family carers will be recruited to do these quality assurance inspections?
Confirm and Challenge Group Questions

What are your plans for the next 2 years? What are your plans for the next 5 years, and how will these fit in with the NHS 10 year plan?

Autism- autistic people die too early. Are they going to extend the LeDeR programme to people with Autism?

What is being done to address the rising numbers of suicides of autistic people?
Skills For People and Sunderland People First presented at the NTW Board away day – our focus was co-production, role of peer support, voluntary sector working with health partners, and together with Board members we came up with some ideas for future collaboration.
There is some work going on by Skills For People and Sunderland People First about recognising abuse – as those in Whorlton Hall reportedly did not realise they were being abused.
Other people-led ideas

There is lots of interest in current co-produced work like

• Mindfulness for Life
• parents teaching Positive Behavioural Support to parents
• the We are all Citizens workbook
• and self advocates to work with professionals on changing culture in services
What have other groups done in the UK?

National Autistic Society did a petition. These are their demands.

We are calling on the Government to:

- Declare that autistic people and people with a learning disability are #HumanToo and must have their human rights safeguarded
- Immediately commit to make money available to set up the right community services for autistic people and people with a learning disability - and that this is ring-fenced
- Change the wording of the definition of ‘mental disorder’ in the Mental Health Act, which currently includes autism and learning disability – whilst legally safeguarding ‘at risk’ individuals access to Care & Treatment Reviews
- Establish accountability right across Government to make sure this happens
• After the abuse at Whorlton Hall bemix created 6 big questions to ask Transforming Care Boards to make sure people in their area are safe.

• 61 people gave feedback on the questions.

• They have now put them into a Powerpoint for people to use.
6 Big Questions for Transforming Care Partnerships after abuse at Whorlton Hall
Whorlton Hall had a care rating of ‘good’ but people there were abused.

How can we know people in our area are safe?

What are you doing to make sure abuse cannot be hidden?
How many people are being treated in hospitals outside our area?
How can we know they are safe?
How are their families supported to see them?
How and when will they be cared for in or near their home?
How much longer than necessary are people staying in hospital?

What is stopping people living in the community as soon as they are ready?
How close are we to people being treated in or near their own homes, not hospitals?
What is being done to improve community services?
Because providers of secure care are with people all day and night, they have too much power over people. This is a reason people in Whorlton Hall were at risk of abuse.

Continued on next slide ➔
Do you agree?
How are families, advocates, professionals and you as commissioners involved with people, checking they are safe and getting better?
Winterbourne View and Whorlton Hall were owned by companies making a profit. We think some are good. But some do it mainly to make a profit.

Continued on next slide ➔
Which companies are providing secure care in our area?

How can we know they are putting people before profit?
Rightful Lives 8 point plan

• Rightful Lives came up with an 8 point plan
• 140 people commented on it
• You can find the Easy Read version here
  • https://bit.ly/2ZbEVKj
• You can watch a video of it here (it’s not very accessible)
  • https://vimeo.com/353200697
Rightful Lives
8 point plan

1) A plan for everyone who is in an in-patient hospital to get community support within 12 months or sooner, including making Care and Treatment Reviews better

2) The government must make sure that organisations are protecting people’s rights and that organisations are doing the things that the law tells them that they should be doing

3) The government should set up an independent group led by people with learning disabilities, autistic people, families, lawyers and representatives of key stakeholder organisations, to monitor what organisations are doing and to make they are doing what they should be doing

4) More money for community services, early support and for getting people home from inpatient hospitals, including money for specialist teams to help stop people being detained under the Mental Health Act
8 point plan

5) Families’ and friends’ rights to support somebody in hospital must be protected, including their right to talk publicly about some things

6) We need more information about local area and national plans for people with learning disabilities and autistic people so that we can check on what organisations are doing;

7) STOMP (Stop over medicating people) to be part of all NHS and private health care practice;

8) In the longer-term, we think that the law must be changed to strengthen the right of people with learning disabilities and autistic people to live ordinary lives in their communities
Other work that is happening

Work has been going on around citizenship.
This is about rights.
It is about people having a good life, not just having services or support.

You can find all the We Are All Citizens Workbook materials here

So what next?
We need to include

- People with a learning disability and autistic people
- Family carers
- Children and young people with a learning disability and autistic young people
- Parent carers
We need to have a voice at every level in health and social care

We need to understand the system as it is now:

- Integrated Care System/Integrated Care Partnerships
- Regional commissioning
- Local commissioning
- Special programmes
This is how we understood things a few years ago. We need to update this so we all understand.
It needs to be led by all of us working together
We all have to do the work

We have to agree to work together and not compete against each other for bits of work.
What can people with a learning disability, autistic people and family carers do to have a real voice in making things better for everyone?

Over to you - group discussion activity
You might want to think about...

• What we did in the past that worked well

• What is working well that we want to continue?

• New ideas that we haven’t tried before

Send all your replies to Karen at Inclusion North by 23rd September karen@inclusionnorth.org
What next? Actions from this meeting

**ACTIONS**

1. Chase 3 Hubs to go to the Confirm and Challenge Group
2. Send the bemix 6 questions to the Transforming Care Board and ask for answers
3. Monthly meetings of this group through 2019
4. Include areas who aren’t here today
5. Pull all the information together in one accessible document

**WHO/WHEN?**

1. Lisa Clark. Expect everyone to attend either the September or October meetings
2. Lisa Clark. Send questions to meeting of ESG on 20 September with answers back by 26th September Confirm and Challenge Group
3. Stephen, Skills for People, by 6th September
4. Karen, Inclusion North by 30 August
5. Karen, Inclusion North by 6th September