

Checking Quality Together

Taking part in Care and Treatment Reviews



NHS
England

WINTERBOURNE VIEW – TIME FOR CHANGE

Transforming the commissioning
of services for people with learning
disabilities and/or autism

NHS
England

CARE & TREATMENT REVIEWS



Expert Adviser Training

December 2014 - March 2015



is part of



advocacy services in staffordshire

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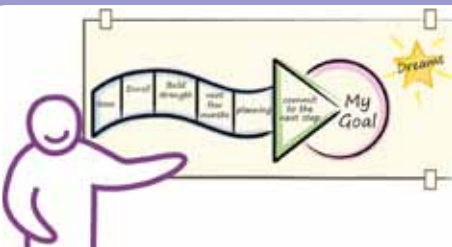
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About this report

DEC



Reach were invited to take part in the Care and Treatment Reviews (CTR's) both locally and regionally.

MAR



Between December 2014 and March 2015 Reach experts and a carer took part in the NHS England Care and Treatment Reviews.



Reach experts and carers joined the review teams in their role as expert by experience. They spoke up and took part using their lived experiences.

The team visited people with learning disabilities, autism and mental health issues in hospitals and secure units to find out about people's care and support.



The team also checked if each person was ready to move on or if they needed to stay there.

The views, ideas and experiences of Reach experts and the carer have been used to write this report. This will help us with our Quality Monitoring work.



CARE & TREATMENT REVIEWS



Expert Adviser Training

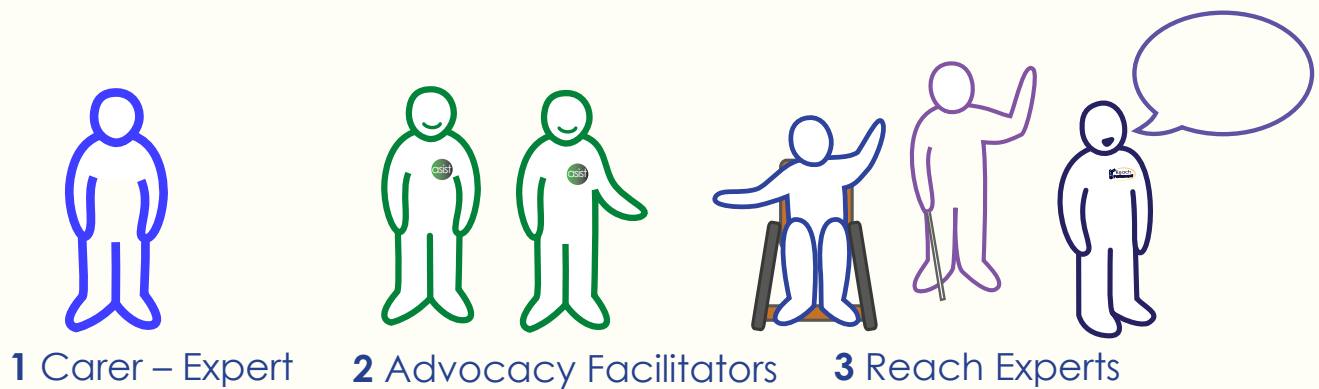


About this report

Reach were asked by NHS England, and Clinical Commissioning Groups (CCGs) to take part in **10** Care and Treatment Reviews (CTRs).

We took part in **9**, as **1** was cancelled because the person's care was already agreed.

People who took part in the CTRs:



We worked together with 4 CCGs:



7 reviews for Stoke CCG

1 review for Shropshire CCG

1 review for Vale Royal CCG

1 review for Wirral CCG

We are continuing to work with CCGs on Care and Treatment Reviews.

About Reach



Reach is a speaking up advocacy project for people with learning disabilities in Stoke-on-Trent and Staffordshire.

We support people to take part and speak up. Reach is part of Asist Advocacy services.

Reach members live with the issues that affect people with learning disabilities.

We work with health and social care organisations by sharing views and ideas (planning), sharing stories and experiences (informing) and finding out if services work for people with learning disabilities (checking).

NHS England and local Clinical Commissioning Groups (CCGs) are working with individuals and organisations like Reach across the country to find and support experts by experience.

Reach experts work as part of a team and take part in the reviews based on their own personal experiences.

The team speak to:

- the person the review is about
- their advocate
- their family and carers

The team learn more about the person and whether their care and treatments are right for them. Reach experts help to find out what is working, not working, and how things can be made better for the future.



Winterbourne View



In May 2011, a BBC Panorama documentary showed people with learning disabilities and autism being abused at a private hospital in South Gloucestershire, England called Winterbourne View.

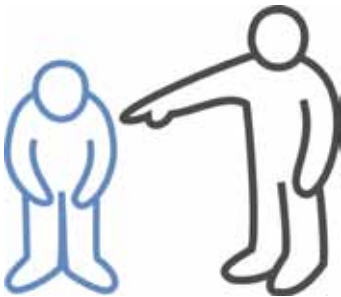


Some of the hospital staff at Winterbourne View committed physical and emotional abuse as they:

- hit patients and pulled their hair
- shouted at them
- held them down under chairs
- gave them cold showers
- force fed medication to patients
- made fun of and mocked people.



Police investigated and some hospital staff were arrested and sent to prison.



The Panorama programme showed:

- people were not in the right place for their needs, and stayed there too long
- services failed to see the 'warning signs'
- there were poor standards of care/management
- there was too much physical holding (restraint)

It's important to find out when people's care is not working so Winterbourne View does not happen again.

Sir Stephen Bubb's Main Recommendations

NHS England asked Sir Stephen Bubb, a government advisor and an expert on charities and healthcare to review what happened at Winterbourne. Sir Stephen made some suggestions to improve things and to stop this happening again.

Strengthening Rights

Closing Institutions

Better Commissioning

Holding people to account

Stronger Community



Closing Institutions - Ending services that are not right for people's own needs.

Holding people to account - Plans should be made public for everyone, and people should have to explain why things have gone wrong.

Strengthening Rights - Create a charter of rights for people with learning disabilities and/or autism, and support people to challenge/review their care.

Better Commissioning - Spending money on services by working together and planning, to improve the lives of people with learning disabilities and/or autism.

Stronger Community - High quality services with better training and leadership, and money to help people to live in the community if they can.

NHS England - Transforming Care



Transforming Care is about improving the health and care system for people with learning disabilities, mental health issues and autism.

It is about helping people to live the best lives possible, in the right place for them with good quality care.

It is important to check the quality of life for people with learning disabilities and stop hospitals from becoming their homes.



People should have the support to lead fulfilling safe lives in their community with less need for hospital stays. The NHS England Transforming Care Programme focuses on:

- **Empowering individuals** - Giving people and their families more choice and say in their care.
- **Right care in the right place** - Making sure that Care and Treatment Reviews help people to get the right care in their community if possible.
- **Regulation and inspection** - More checking of the care providers to improve the quality of care and close down poor quality places.
- **Workforce** - Developing the skills of the staff to make sure high quality care and standards are provided.
- **Data and information** - Making sure that people have the right information when they need it and are told about any progress.

What is a Care and Treatment Review?



After the abuse at Winterbourne View, and as part of Transforming Care, NHS England are leading a programme of Care and Treatment Reviews (CTRs).

Patients in hospitals and secure units will have their care reviewed if they have learning disabilities, autism or mental health issues.



A Care and Treatment Review checks:

- is the patient receiving the right care?
- is the patient in the right place for their needs?
- what does the patient want to happen?



People with learning disabilities have been involved as part of the teams reviewing people.

The reviewing team:

- learn about the patient's history
- think of new ideas to improve their care
- listen to the professionals involved in their care
- try to give the patient and family a voice
- talk about the help a patient may need if they go to live in the community.



The team see a lot of information, and they all agree to keep everything private and confidential.

What is a Care and Treatment Review?

The review teams are:

- Reach and carer experts by experience
- An advocate
- Expert clinicians
- NHS commissioner
- A local authority commissioner



4 **big** things the team need to find out are:

1. Is the person safe?

2. Is the person getting good care now?

3. What are the person's plans for the future?

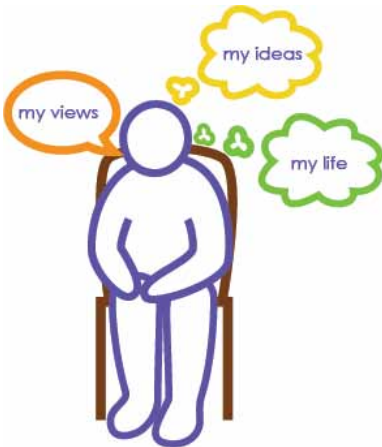
4. Does the person need to be in a hospital, or can their care and treatment needs be met in the community?



“Good to check that people are not forgotten and to check they are treated well”



What happens at a review?

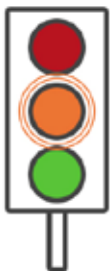
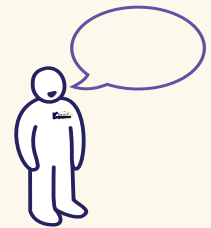


The team try and meet the patient whose care is being reviewed. The team also meet doctors, and other professionals involved in the person's care. These might be advocates or social workers.

The team also read the person's records. This helps the team to find out about the person, their care, why they are in hospital, and what can change for the future.

The team use questions and checklists about:

- ✓ managing risks and keeping people safe
- ✓ does the patient need to be in hospital
- ✓ communicating the patient's needs and behaviour
- ✓ thinking about independence and risk
- ✓ voice of family and carers
- ✓ patient's individual involvement
- ✓ patient's rights and freedoms



The team use traffic light colours to help them talk about the patient's care. The team decide whether something is good (green), something is bad (red), or something needs improving (amber).

The team are led by the commissioner who listens to everyone and this helps the review. A decision is made by the team about the person remaining in hospital or moving into the community. A report is then written.

After a few months the team get together again to see what has happened since the review.

How were Reach experts prepared?



Reach experts were contacted by telephone, told a little bit about the Care and Treatment Reviews and were asked if they would like to take part.

People who wanted to be involved were invited into Reach to talk about it further, where we had an awareness session.



Reach experts taking part in the reviews were also prepared by having training and preparation sessions using the NHS England 'Expert Adviser Training.'

Reach experts went through each of the main aims and questions with an Advocacy Facilitator.



This was a chance to talk about any worries. Any concerns raised were answered and talked through.

We talked about what to expect, getting used to the paperwork and about the places that they were going to visit.



Reach experts were given a file with clear information about the review, the place and the team members involved in the review and a copy of the review questions.

Anyone who wanted further support and guidance were encouraged to get in touch and arrange another meeting.

How were Reach experts supported?



An Advocacy Facilitator from Asist supported Reach experts to take part in the Care and Treatment reviews.

The Advocacy Facilitators supported Reach experts with any issues or worries throughout this work.



The Advocacy Facilitator met up with the Reach expert beforehand to help build trust and to answer any questions.

The Advocacy Facilitator organised transport and taxi arrangements with each person for all the reviews.



The Advocacy Facilitator supported experts:

- before when arrangements were made
- during the the reviews (checking they were happy and comfortable with everything)
- and afterwards to reflect on the information



Reach experts shared their views and opinions about the Care and Treatment Reviews.

Reach experts were supported to fill in a feedback form about taking part in the Care and Treatment Reviews and to send their feedback to NHS England.

What worked well about the reviews?

Felt included
part of the team
and listened too

Actually saw the
person - and feel
this is important

It was
person-
centred

Feel it is very
important to review
every individual
case

Well organised,
felt included,
asked questions
and given
answers

Communication
passport
was good, what
liked doing and
not liked doing

All panel
members were
supportive

Helps the panel to
pick up on things
like safeguarding,
check records and
stop things getting
missed



“ Care and Treatment
Reviews are vital, as they
are planning someone's
future ”

The session
beforehand was good
and would be good
for future meetings

What worked well about the reviews?

It's good that people with learning disabilities are a part, giving their experiences and views – I feel this is important

Happy that took part and asked the questions I felt were important

Valued the preparation and support before and after the review

Good to see the person and the parents, that's what the review is about

Good preparation

Good that people with different expertise are reviewing the individual cases

They explained terms, medical conditions, investigations in a way all could understand

“ Important to get it right, as peoples lives are affected by the decision ”



What didn't work so well about the reviews?

Some information could have been more accessible for the expert by experience e.g. words and pictures

Not being able to talk to the patient, family, friends and others

Some gaps in people's information was not explained

Didn't see the person

I had difficulty reading some handwriting



Having a communication passport would have been good, as this person didn't have one

Would have liked to have seen the communication passport before seeing the person to get to know likes and dislikes



“Communication between professionals needs tightening up so nothing is missed”

Some information goes over your head

What didn't work so well about the reviews?

Could have had more people's input like social workers, advocate, family and support workers

I felt that they were a bit hurried, and was not enough time

More notice needs to be given for everyone to attend

I felt that it was a problem as I did not see either person face to face



Should we be hearing personal information without people's consent? – I was worried that the person had not given consent – confidentiality important

I found it difficult to talk about the person until I had seen the person or saw a photo of the person

Some information was horrible, like face down restraints



“Seen this sort of thing on the tele, but felt ok and it has not played on my mind”




What can improve the reviews for the future?

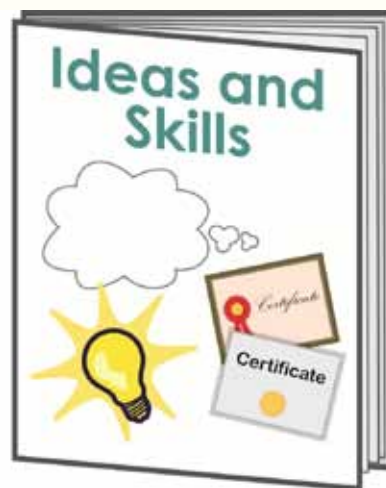
Seeing the person. It is very important to see the person

Maybe more time to review each case due to the amount of information

If no one there like parents, family friends contact them by phone or involve people by letter so can send views in



I thought a question could have been asked on dignity and respect



Have a separate room for the person away from the panel as they may feel upset, scared and worried

Training to do the reviews is needed, think they should

Would have preferred a break in between in the middle



“ I would like an easy-read version of the 43 questions ”

Need more notice so family and others can be involved, and the person can be prepared

What can improve the reviews for the future?

Need to know why old places didn't work, so doesn't happen again

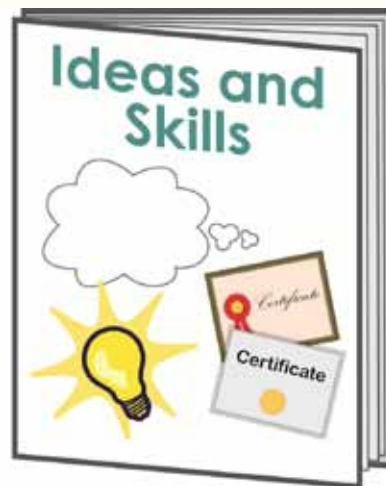
Don't use technical words, put it in a way everyone understands

More time for everyone to prepare, preparation time

More notice for people so can ensure that they can be there

Could see person on another day

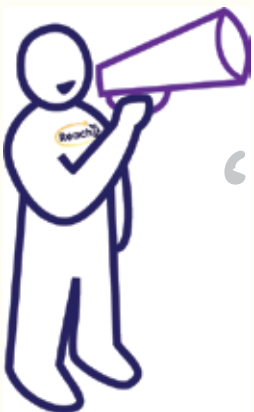
More effort to see the person, maybe on different days



More accessible information

Need more notice so that the person can be prepared

Need more time



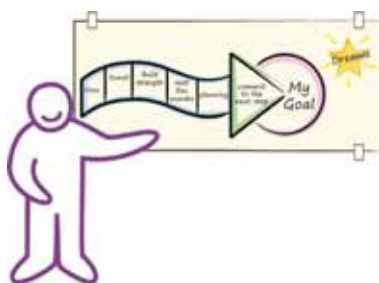
“ I would like to know how the person is getting on after the review ”

Could review people over different days, so all can be involved

Conclusions



- The reviews were carried out both locally and regionally and done in different ways. Some took a whole day and others took several hours.
- Everyone who took part in the Care and Treatment Reviews felt that it was a good thing that they were taking place, and felt that more should be done.



- Experts by experience all felt included, listened to and part of the team. Everyone felt respected, supported and valued, and when they asked questions they were given answers.



- The reviews were person-centred and focused on the person's needs not the needs of the services.

- The questions asked also kept the reviews focused on the person being reviewed.

- It is really important to listen to a person to find out what they want but the team were not always able to meet the person at their review.

- Everyone felt that it was important that people worked together as a team.

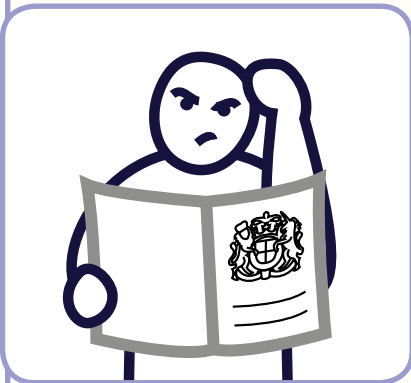
- Each team member has new ideas, separate views and different experiences which come together to keep the review about the person.



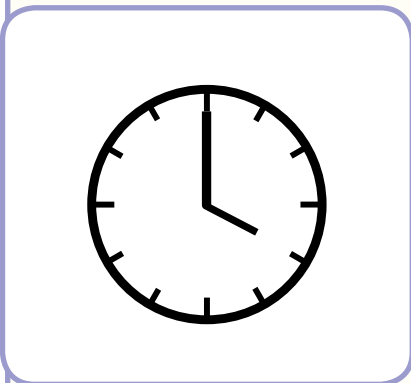
Conclusions



- It is important that people with lived experiences can take part in reviews, using their understanding of the issues facing people to help the review.
- Most meetings were well organised and not too formal this helped people to take part and speak up equally regardless of their positions of power.



- People said there wasn't enough accessible information and it is really important so that people can understand and really take part in the reviews.

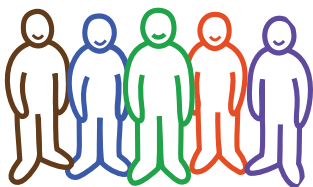


- People said more notice for the reviews should be given, so that all involved in a person's care could attend and share information.
- People felt that some reviews were hurried whilst other reviews were given the time they needed.



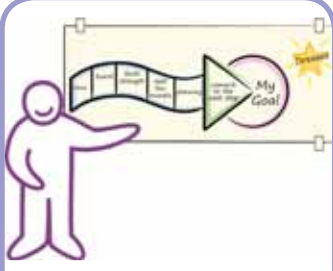
- Some people had a communication passport which helped the team to find out about the person and was useful if the person did not attend their review.
- People said training, preparation and support was very important for them and it helped them to fully understand their role and take part in the reviews.

Conclusions



- Support from the Advocacy Facilitator helped people to understand the Care and Treatment Reviews and speak up about any concerns or worries.
- Some experts by experience worried about confidentiality and whether people had given consent for their information to be shared.
- People said no matter what the positives and negatives, they were not barred from the information and were valued members of the team.
- Some experts by experience were concerned and upset when they heard about safeguarding issues in a person's life, but knew this was relevant information that helped the team reach a decision.
- People involved in the person's life (social workers, advocates, family, key workers and others) need to share information with the team to help the review.
- More needed to be done to get all the people involved in a person's care to attend and take part in reviews because some people didn't attend.
- Experts by experience also felt that they had invested in a person by taking part, and would like an update about how the person is getting on.

Recommendations



1. Person-Centred

- It is important to keep working together to keep the person at the centre of their review.
- If the person cannot attend their review a communication passport should be provided, as this paints a picture about a person and their life.
- Consent forms should be used to show that a patient has agreed to their information being shared if they are able to understand this.
- Independent advocacy should be available so the patient has support, knows what to expect and is kept up to date.
- It is important that the experts by experience meet the patient to see where they live, their room, the gardens, to get a better understanding about the person and their life.
- Experts by experience could meet the patient separately as the patient may feel more comfortable talking to the experts away from the team.
- The expert by experience could also meet the patient on a different day and share the patient's views and wishes with the team at the review.
- Information about the patient could be available for the experts by experience before they meet the patient.
- Information about each team member could also be given to the patient and their family before the review meeting.

Recommendations



2. Working Together and Co-production

- An update from the review (without confidential information) should be given to the expert by experience as they want to know how the person is getting on now.
- Keep reviewing and checking on the decision made and where possible involve the same panel members for consistency.
- People with personal lived experience and knowledge should continue to be involved, as they are the experts.
- Continue working together as people have different skills, expertise, and experiences to help review the person's care and treatment.



3. Accessible information and communication

- For people to be fully involved everything needs to be in an accessible format that is right for them.
- Make feedback clear for everyone to understand.
- Be mindful of the language and terms used during the review, explain jargon so that everyone can understand.
- Use photographs, everyday language, clear font, short sentences to meet the communication needs of everyone.

Recommendations



4. Planning and Preparation

- Make time for experts by experience to meet the team before a review so that they know who to expect.
- Confidentiality and consent agreements should also be completed by the patient before the review.
- Risk assessments should be completed before reviews to safeguard the expert by experience, team and the patient being reviewed.
- Have a clear plan if something happens like illness, seizures, alarms and unexpected events so that everyone at the review can be kept safe.
- Make sure new experts have support with preparation, training and awareness and learn from experts who have already taken part.
- Continue training in an accessible way and keep it updated to meet the needs of the experts, the team and the patient.
- Plan regular breaks so that experts can have time out and the opportunity to talk to the supporting advocate about any concerns.
- Inform experts early on about the type of review the meeting will be whether it is an initial or a follow up review.
- More notice is needed so that people can be there and the patient can be prepared and supported to attend their review.
- More notice for experts and advocacy facilitators to prepare, and make sure advocacy support can be allocated to experts by experience.

Recommendations



5. Inviting People and Involving Others

- Experts by experience could see the patient at a separate time or on a different day and feed back to the review team.
- Have a timetabled plan organising reviews as far in advance as possible.
- Attendance could be encouraged by people having more notice and time to make arrangements either to attend or contribute information.
- Contact people and request their views and comments by phone, letter, and then feed the response back to the team so all views can be considered in the decision making process.
- Encourage social workers, advocates, family, carers and all involved in a patient's care to attend, contribute and be involved as their attendance has been low in the Care and Treatment Reviews so far.
- Include the Care and Treatment Review in the patient's CPA (Care Programme Approach) if they have one, as all those involved in a person's CPA meeting can inform the patient's care and treatment plan.

Thank You!

We would like to thank the experts by experience (both the carer and people with learning disabilities) who took part in the Care and Treatment Reviews.

Everyone gave their time freely, and without their feedback this report would not have been possible. We would also like to thank the Advocacy Facilitators and all those on the CTR teams.

Pictogram images used in this report were made by



Some of the images used



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This clear communication report was made by Reach