Looking at the Experiences of People with Learning Disabilities, Family Carers and Professional Advisors as Members of CQC Inspection Teams on the Learning Disability Review

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Background

The Panorama programme showed that people with learning disabilities were being treated badly at Winterbourne View.

The Care Quality Commission (CQC) decided to check other care services around the country to make sure that the same thing was not happening in other places.

They decided to work in a different way to do this. People with learning disabilities (who we shall call self-advocates in this report), family carers and people who work with people with learning disabilities were all involved with the checks.

In this report, these three groups of people will be called the stakeholder group.

The CQC asked the National Development Team for Inclusion (NDTi) to find out how the stakeholder group felt about this work.
This is their report, prepared with the help of People First, Bath & North East Somerset. We have used pictures from Photo Symbols.

This report is about what the NDTi found.
About The National Development Team For Inclusion

The National Development Team for Inclusion (NDTi) works to make life better for people who need support to live their lives.

We want to make sure that everyone has an equal chance to live the kind of life they want to and take part fully in their own community.

We work with people who use services, families, staff and managers to help services and support to be better. This includes work on:

- where people live
- what they do in the day
- how people get choice and control
- better access to healthcare

We help people to plan and guide how people are supported

We train people about how to:

- be part of the community
- be a better manager
- get real jobs
- plan services
- be person centred.
What We Were Asked To Do

We were asked to find out from the stakeholder group what they thought about the checks, and what could have been done better.

We would like to thank the stakeholder groups, CQC staff and the people who supported the stakeholder groups for their help.

To find out what people thought, we used:

- Interviews with CQC staff.
- Workshops with the self advocates and family carers.
- Surveys with the stakeholder group.

Thank you to Choice Support and the Challenging Behaviour Foundation, who helped us to organise these events.
We also looked at a lot of CQC paperwork.

We brought all this information together.
The Main Things We Found Out

The stakeholder group thought that this was a good way of working and that it should carry on.

Everyone said that it was better because self advocates, family carers and professional advisors were involved.

The stakeholder group found the experience useful in other areas of their lives.

The stakeholder group felt that the CQC staff really listened to them.
Everyone thought that people who lived in the services were more likely to say what they were really thinking to self-advocates and families.

"We could see things that the professionals miss and pick up on how people were feeling, their body language."
What Else Worked Well

The way information was collected was seen as working well.

The CQC staff listened very carefully to the stakeholder groups and made an Inspection Pack to help do the checks.

Everyone thought that the pack was very helpful and well set out.

Self advocates would usually talk to people while their supporters took notes.

The main feedback was positive - almost everyone felt that they were listened to and included by the CQC Inspector.

Some lead Inspectors involved the professional advisors and family carers in giving feedback at the end of the visits.
As the teams made more visits, they grew more confident about the work and each other.

Everyone felt that the reports usually showed all the views that people had put forward, and that the reports would be useful for the services visited.

The way the CQC Inspector led the teams was a really important part of how the stakeholder group felt about their work. People said most of the Inspectors were really good.

Inspectors listened to peoples’ views and if they did not put them in the final report, they would explain why not.
What Could Have Been Better

The stakeholder group thought that:

- they should have been able to look at all of the quality standards that are usually checked, not just the two standards which were looked at in this review

- it would be good to suggest ideas about making services better rather than just pointing out the things that are not good

- the way that reports were written sometimes made it difficult to put ideas in.

The report needs to be more flexible.

- Both self advocates and family carers felt that they did not have as much time as they would have liked during the visits.
Everyone had training before they did the work. Some people thought the training was very good but others were not happy with it.

Some family carers and self advocates said that it took a long time for the report to be published.

Some people said that they did not always see the final report.

Some thought that the reports could have been more 'plain speaking'.

The inspection was arranged very quickly so it was sometimes difficult to get the right people to help.

Some of the places visited were very different from anything people had experienced before.
Family carers were often less positive about the work than self advocates and professional advisors.
Everyone worked hard, but sometimes the teams did not really feel like they were a team.

Some reasons for this were:

- teams did not always do the visit together

- not being able to meet together before a visit meant that the team could not share ideas about how to work together

- sometimes lead Inspectors did not make all 3 stakeholder groups feel that they were working in the right way.

Sometimes Inspectors worked in different ways - which was a problem for some of the stakeholder groups.

The feedback showed that the best inspectors were the most flexible ones that changed how things were done to help people get involved.
How To Make Visits Better

These were some of the ideas about how to make visits better:

- having a short meeting before the visit started

- 'checking in' with each other every hour or so to see how things were going

- having a short meeting at the end of the day to check how things had gone.

The service providers need to have more information before the inspection so they know who is in the team.

One self advocate said –

"At one place people thought I was looking around with a view to moving in."
The stakeholder group was worried about whether their work would make a difference.

They have asked CQC to come and talk to them about what will happen next.

Having self-advocates and family carers on the visits showed service providers a good example of how to involve people.
Using What We Have Learned

The NDTi has made some suggestions to CQC on how they might learn from this work.

Involving the stakeholder group worked well. This way of working can be used for all of CQC’s checks, not just learning disability services.

Having a mix of self advocates, professional advisors and family carers worked well.
It would be good to look at all standards when visiting, not just a few.

To make this work well will need more resources.

This means things like money and staff time.
It would be good to match the skills and experience of the stakeholder group to the service being inspected.

It would be good to have a ‘core’ group from the stakeholder group so CQC has people to work with in the future who are experienced at going on inspections.

The role of the professional advisors needs to be explained clearly.

Some people found the visits upsetting. This might be something to think about in future training.
To make inspections work better CQC could make sure there is:

- more information about the service being inspected
- a meeting of the team before, during and after the visit
- clear information about what training people were going to get
- changes to the ways that contacting the family carers of people living in the services was done
- more talk about how the way the final report is produced.
Some more thinking about how the team should work together as a team.

Self-advocates, family carers and professional staff all got involved with this work because they were really interested and concerned about making services better.

It would be a good idea for CQC to give people feedback on what changes have happened because of their work.

One of the family carers said

“Now that you have got us, don’t shut the door.”
Summary

We were pleased to do this work for the CQC. This review of learning disability services was carried out quickly. Perhaps in the future it would be good to plan how to do the review before the inspections started.

The feedback that NDTi got was that people felt good about the way they had been involved and listened to – but that some things could have been done better.

The stakeholder group felt that they had been able to put a lot in.

They felt their views had been treated with respect and used by CQC in their reports.

CQC will now think about what we have found out in this report to help them decide how to involve people in the future.