



National Development Team **for inclusion**

**An Evaluation of the Experiences of
People with Learning Disabilities,
Family Carers and Professional
Advisors as Members of CQC
Inspection Teams within the Learning
Disability Review**

**Prepared for the Care Quality Commission by
the National Development Team for Inclusion
(NDTi)**

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1. Background

- 1.1 Following the Panorama programme exposing the abuse of people with learning disabilities at Winterbourne View, a private assessment and treatment unit in Bristol, CQC wrote to the Care Minister Paul Burstow proposing a programme of unannounced inspection of locations caring for people with learning disabilities and behaviour labelled as challenging. The Minister supported this proposal and a series of inspections of services was instigated to help assure people that similar problems did not exist elsewhere. As part of this, people with learning disabilities, family carers, and staff/managers who worked in learning disability services were recruited to form part of the inspection teams. Existing CQC methodologies were adapted for these inspections – in part learning from experience gained in an earlier joint Healthcare Commission, Commission for Social Care Inspection and Mental Health Commission series of inspections in learning disability services and more recent Dignity and Nutrition CQC inspections..
- 1.2 To help their learning about the effectiveness of this process, CQC are collecting data through a number of routes. One of these has been through commissioning the National Development Team for Inclusion (NDTi) to evaluate the process from the perspective of people with learning disabilities, family carers and service professionals involved in the inspection teams. Other initiatives are collecting data from other perspectives.
- 1.3 This report is the summary of the NDTi work and its findings. There is also an Executive Summary report that has been produced in easier to read format with graphics.
- 1.4 One element of wider contextual background should also be noted before describing the evaluation and its conclusions. The issues exposed on the Panorama programme, together with the public and political response demanded a rapid response from CQC. The inspection programme and processes around it thus had to be developed and implemented at a rapid pace that all concerned agreed was far from ideal. This speed necessarily had an impact on how things were done and we would observe that, in many ways, what was achieved within the available time was impressive. We note and acknowledge that some of the things our evaluation has identified could or should have been done differently quite possibly would have been done in alternative ways had a longer timescale been available.



2. About NDTi

- 2.1 The NDTi is a not for profit organisation that promotes equal and inclusive lives for people in their communities, particularly where ageing or disability are issues. The organisation does this by taking action at local and national levels: advising policy makers, encouraging public debate, carrying out research & evaluation, and providing change management support to local and national organisations to help them achieve better outcomes.
- 2.2 The team for this evaluation was led by Steve Strong, NDTi's Programme Lead for Learning Disabilities, and included Alison Macadam (who focused on family carers) and Philippa Chapman (who focused on professional advisors) - both are experienced evaluators. John Hersov helped to facilitate the review day with self-advocates. The work was overseen by Rob Greig, NDTi's Chief Executive.



3. A note on terminology

3.1 Various words have been used during the course of this work to describe the different stakeholder groups involved in the inspections. There has been a degree of confusion in use of the terminology and some disagreement about appropriateness of words. In particular (i) the term 'experts by experience' has been used to varyingly describe one or both of people with learning disabilities and family carers, and (ii) the term 'professional advisors' about people recruited from service roles caused some disquiet amongst some family carers and people with learning disabilities who felt it devalued their own expertise implying it was of a less professional nature.

3.2 For reasons of clarity, this report will use the terms:

- *Self-advocates* – to refer to people with learning disabilities
- *Family carers*
- *Professional advisors* (acknowledging concerns amongst the other two groups of people but also noting this term is best used for this report as it is in common usage within CQC).
- *The three stakeholder groups*, to refer to all three sets of people collectively



4. The Brief

- 4.1 In short, the brief was to capture the experiences and views of the self-advocates, family carers and professional advisors regarding their involvement in the CQC inspection process, including potential changes they may suggest to improve experiences and outcomes, and to report this to CQC in the context of whether their participation helped to achieve CQC's aims and aspirations in instigating their involvement.
- 4.2 It should be emphasised that our brief was not to evaluate the Inspection process itself and its design – but rather the experience of these three sets of stakeholders within it. This was sometimes a difficult boundary to manage, as the design of the process impacted upon the experiences of those involved. However, in this report, we have sought to limit our comments and conclusions to factors that are directly concerned with, or directly emerge from, the experiences of the stakeholders in question. Also, it was not our brief to evaluate and assess the performance of the two support agencies and so we have similarly sought to avoid direct comment on that.
- 4.3 It is also important to note that the delivery of this brief was significantly influenced by the available timescale for the work – a period of seven weeks from confirmation of the contract to delivery of the report. This had a number of implications such as limiting the extent to which we could engage with the full range of stakeholders. However, whilst this may have limited the depth and detail of our findings, we have no reason to believe that it has in any significant way impacted upon the thrust of the conclusions in this report.
- 4.4 In this context, we particularly want to acknowledge and thank people, particularly the three groups of stakeholders, for their willingness and cooperation in meeting and speaking with us at very short notice and with limited flexibility around dates and times. Almost without exception, people we spoke to and met with went out of their way to help provide us with the information we needed to undertake this evaluation, an indication of their commitment to the whole process.
- 4.5 Finally in introduction, it is worth noting that an evaluation of this nature that is commissioned 'after the event' cannot gain as much information nor provide as much added value as one that commences at the start of the process and collects

data as the work progresses. We would recommend that future evaluations should commence near or at the beginning of such programmes of work.



5. Methodology

- 5.1 The approach used for the evaluation drew on a number of different components and sources. The broad approaches included the concept of 'realistic evaluation' that involves understanding the causal factors that helped or hindered the achievement of the desired outcomes and the use of a 'logic model' to help track the intended ways of achieving the desired goal and how actions did or did not vary from that. These were then supported by the use of semi-structured individual interviews and group workshops and data gathering through questionnaire to either supplement or support the interview processes.
- 5.2 In more detail, the evaluation consisted of the following elements/stages:
- A review of documentation relevant to the issue, supplied by CQC
 - Preliminary interviews with a number of CQC officers to obtain contextual information
 - Separate semi-structured review days with self-advocates and a family carers (see Appendix 5) supplemented by the use of an easy read questionnaire provided to those present (see Appendix 6) – either to be returned immediately or through the post with pre-paid return envelopes. For family carers the additional option was provided of electronic return through the Support Agency.
 - A 'survey monkey'¹ based questionnaire for professional advisors, sent to them by email, alongside telephone interviews with a sample of people – chosen as far as possible² to reflect the varying job roles from which people came. Whilst covering essentially the same issues, the questionnaire for professionals was more detailed than that for self-advocates and families as there was no face-to-face inter-action with this group.

¹ Survey monkey is an on-line survey tool that allows for anonymity of participants if required and produces quantitative analysis of answers alongside the capacity for receiving and analysing qualitative observations

² People's availability within the given time constraints prevented this being a more scientific sample of the group

- An analysis of the data from these different sources to produce preliminary conclusions
- Further discussions with CQC staff to obtain additional information and data on issues arising from the preliminary analysis
- Production of this report and an easier to read Executive Summary document detailing the findings.

5.3 The review days for self-advocates and families were organised by the two support organisations - Choice Support and the Challenging Behaviour Foundation - – who we wish to thank for their assistance with this – along with CQC. The support organisations work with CQC to recruit, train, support and pay Experts by Experience from a range of backgrounds, and who have a range of experiences of using health and social care services. Invitations to participants went through those organisations. i.e. the sample was determined by availability through the support agency invitations. The perspectives of the two support agencies themselves are perhaps under-represented in the report as it did not prove possible to organise one to one interviews with their representatives. Their experiences were only obtained through a short group teleconference with them and CQC. The two support agencies and the lead CQC contact for them emphasised the strong collaborative partnership that the three lead individuals had developed. Also, we understand that both agencies have themselves been collating data on the experiences of the people involved. We have not had sight of that data and thus it is not included in our analysis.

5.4 Coverage achieved was as follows:

- 16 self-advocates (62% of those participating in the inspection) engaged in their review day and completed the additional questionnaire.
- 15 family carers (56% of those participating in the inspection) engaged in their review day and completed the additional questionnaire.
- 27 professional advisors (52% of those participating in the inspection) completed the questionnaire, with 15 people (29% of the total) being spoken to in telephone interviews.



6. Findings and Conclusions

6.1 Introduction

- 6.1.1 This section describes the main findings and conclusions from the evaluation. The brief was primarily to report the experiences of the three sets of stakeholders and this is what is done in this report. The methodology and the brief for this work did not enable or involve the evaluation team meeting the full range of stakeholders nor reviewing the resultant reports. There are thus some limitations on our conclusions in term of the extent to which it was possible to validate through 'triangulation' the impact of the three sets of stakeholders on the overall inspection process. As a result, where statements are made about findings they represent conclusions where there is a clear consensus from participants that this was the case and/or we were able to verify assertions from other sources (e.g. CQC staff).
- 6.1.2 Similarly, in order to illustrate the key points, quotes from individual people are sometimes used. These are in italics, with verbatim quotes being in quotation marks, those without such marks being our summaries of views expressed. It is emphasised that, in line with recognised practice in undertaking qualitative research, quotes are only used when they either (i) illustrate a position where there is corroborative evidence to support it through 'triangulating' the sources of information described in the methodology section, and/or (ii) they are an example of views expressed by a number of other people. In addition, comments are made that summarise views and experiences from a range of people. Comments are offered as the opinions and experiences of those involved. As such, they represent the reality as experienced by that person – even if others perceive otherwise. Comments are annotated as follows; self-advocate (SA), family carer (FC), professional advisor (PA).
- 6.1.3 Also, it should be noted that we have received a huge wealth of information and data, and it is simply not feasible in seeking to write a report of reasonable length to cover every issue raised by the three sets of stakeholders. We have therefore focused as far as possible on those where there was a clear breadth and evidence of opinion or experience and/or those issues that it appears most important to address.

6.2 Overall Conclusion

6.2.1 Prior to describing the detailed conclusions (as these will significantly comment upon how CQC might have (i) made the experience more positive for the three stakeholder groups and (ii) got more out of their contribution and the process), we wish to note the clear conclusions from the evaluation that:

- It was a positive experience for those involved. Everyone that completed the questionnaires said they would be willing to engage in such inspections again
- There is clear evidence that the three stakeholder groups felt that they individually and collectively had provided significant 'added value' to the process and resultant reports over and above that which CQC inspectors alone could have achieved. This was endorsed by the prevailing view amongst CQC inspectors
- The three stakeholder groups felt that they and their views had been taken seriously by CQC, in particular by the lead inspectors, and that the process had not been tokenistic
- There is early evidence of a wider benefit to individuals and services from their involvement beyond the direct issue of the inspection reports e.g. through participants using the additional knowledge they had gained about CQC standards to influence practice in their local area.

6.2.2 We therefore conclude that the decision to involve self-advocates, family carers and professionals in these inspections was a wise one and that both CQC and the wider health and social care community has derived benefit from it. Some of these specific benefits are outlined in more detail below.

6.2.3 However, we also conclude that had a number of elements of the involvement been done differently as described later in this report, significantly more benefit could have been derived and the experiences of those involved could have been still more positive. The ability to respond to these constraining elements (outlined in subsequent sections) will be significantly determined by two factors, namely (i) available resources and a decision that the benefits derived merit that resource commitment and (ii) the further embedding within CQC (through initiatives such as the current Acting Together Programme), of a culture of use of external 'experts' so that their involvement is not a somewhat rushed process in response to public demand for action following an occurrence such as the Panorama programme on Winterbourne View.

6.2.4 The three sets of stakeholders themselves were also clearly of the view that involvement of this type in inspections is something that had value and should continue:

'Now you've got us, don't shut the door' (FC)

'I think this is an excellent way to inspect services and many registered care homes would benefit from Inspections based on this team approach' (PA)

"It was nice to go in from the outside, using my own experience of using these sorts of services" (SA)

6.3 The Creation of Added Value

The evaluation identified a number of ways in which having the three stakeholders added value to the quality and content of the outputs from the Inspections.

6.3.1 The mixed team enabled more in-depth discussions to take place with people within services than might otherwise have happened. Family carers reported how families of people living in the service opened up to them once their family carer background was explained. Self-advocates and others described how the self-advocates were able to engage in conversations with people living in the services that a CQC inspector would not have been able to do:

"We could see things that they (professionals) miss. Pick up on how people are feeling, their body language". (SA)

"Families just opened up to us when we told them we were a family carer too" (FC)

One person disclosed abuse to the self-advocate member of the team – which we are informed was appropriately fed into the system and addressed.

6.3.2 The team membership enabled questions to be asked by the three stakeholder groups that were probably more challenging than those which CQC Inspectors would have been able to ask:

"The person with a learning disability on our team just asked 'Does anyone hit you here?'" (PA)

"I was acting dumb to get information" (FC)

"We have the ability to get into nooks and crannies and detect small details that would otherwise be overlooked" (FC)

6.3.3 The different stakeholders added a breadth of perspectives to the process and analysis that added depth to the understanding of issues. A key element to this was that all three sets of stakeholders believed and could give instances of where their experience of learning disability and learning disability services added understanding insight to situations where the lead inspectors either had less (recent) experience or else were 'generic' inspectors.

"The inspectors spend more time on paperwork than talking to people, so the experts role is very important" (SA)

6.3.4 A small number of family carers indicated that they felt the professional advisors did not fully respect and value their contribution. This contradicts the evidence we gathered as, without exception, the professional advisors were positive and complimentary about the role and contribution to the team of the family carers.

6.4 The Need to Incorporate More Added Value

Despite this, the three stakeholder groups identified a number of ways and places in which they felt that the potential for their contribution could have been greater and both CQC and the services concerned could have gained greater benefit from their participation.

6.4.1 The focus of the inspection on just two standards was frustrating to people, as they felt that they saw issues that were of importance to address, but beyond those standards and so the process did not allow them to explore and investigate them in more detail:

"They could have got so much more out of us but didn't because we had to focus on the two standards" (PA)

6.4.2 Professional advisors in particular found themselves facing issues where they could see staff struggling with how to respond to service situations or implementing poor practice where the team member knew what advice they could give to help and improve performance – but they were necessarily constrained by the process of assessing compliance. Nonetheless, some stated they found ways of providing feedback, for example through informal conversation with staff.

6.4.3 The structure for feedback and the format of the report was felt to be limiting in terms of people commenting on the breadth of issues that they felt they could contribute on.

6.5 Getting the Most Out Of Individuals

Linked to this, there were many examples given by the three sets of stakeholders about how more could have been got out of them, with greater quality outcomes, if elements of the process had been designed in different ways. Many of these are connected to one or both of:

- a) the timeframe within which the inspections had to be done, and
- b) the level of resources available for the inspections.

6.5.1 There was a clear feeling that greater attention could have been paid to getting the right team together for a particular service and matching the team skills to a specific visit. (We understand that geography and personal availability at short notice necessarily influenced team membership). This issue was particularly relevant for services with a greater degree of 'security' and/or for people presenting challenges to those services. Across all three sets of stakeholders there were varying degrees of experience of such services. For example, 27% of family carers and 31% of self-advocates had no direct contact with services of this particular type either at all or in recent years. Whilst all professional advisors reported recent work and/or interactions with these types of services, it is interesting to note that some CQC inspectors felt that they found working within the more restrictive environments/settings more difficult than some of the family carers. Some people directly expressed to us their anxiety and difficulty within these settings whilst some expressed concern for others on their teams. Other factors such as seeking to have team members with the right communication skills would have helped – though this would have required more pre-knowledge of people living in the services than it might be possible to obtain.

There was some feeling of not being prepared for settings such as secure facilities, some occasions when personal safety guidelines within the context of the visit being undertaken were lacking and occasional occurrences of people feeling anxious for their personal safety. (FCs)

On one visit where several people using the services were on the autistic spectrum, it helped the team that one team member had knowledge about autism - but that was by chance rather than design.

"I was concerned that many really had little concept of secure services and as such this would come culturally as a shock to many" (PA)

6.5.2 Some people found themselves (very occasionally) visiting services that they could not understand why they were being inspected leading people to question why they were giving their time to the process. This appears to have arisen from a desire to

adhere to the original plan to inspect 150 assessment, treatment and rehabilitation services. It transpired that there were not 150 locations that meet this criteria and had not had a recent inspection. Therefore the scope of the programme was broadened to include some adult social care locations. CQC acknowledged that this change should have been communicated more clearly to the external team members.

“Some places I didn’t know why we were there, it was someone’s permanent home. It was not the type of service we should have been visiting” (PA)

“Some units didn’t seem to have people with learning difficulties in them” (FC)

- 6.5.3 Generally, people strongly believed that there could have been greater preparation for the individual visits, with the short notice for where they were visiting often meaning they felt unable to effectively brief and prepare themselves for the specific inspection. A pre-meeting happened on only one occasion that we were made aware of (because all parties had needed to travel to the location the day before) and this was considered by all to have had really added value. In this context, the support agencies particularly complemented the administrative support that had been provided through CQC to help the inspections take place.

For some people, doing the visits felt like ‘A bit of a shock’ (SA). “I could have done with greater validation before beginning in the role” (FC). For others, “I was happy to hit the ground running” (FC)

- 6.5.4 People stated how they felt more confident and knowledgeable as they undertook more inspection visits. There was also some indication of a growing trust and respect between some individual inspectors and some of the individual wider stakeholders as they began to do a number of visits together. Together, these imply a capacity to add greater value as a number of visits are completed.

6.6 The Effectiveness of Training

We found it difficult to obtain full clarity in relation to how people received and experienced the training provided prior to the visits. In terms of views obtained on its effectiveness, these varied – though on the whole the evidence is that it helped and was valued.

- 6.6.1 As with a number of other issues noted in this report, the capacity to deliver appropriate training was influenced by the timescales within which the Inspections were being carried out and the available resources. Whilst the balance is largely positive, the evidence on structure, content and process of the training was mixed. We understand that different people within each stakeholder group received slightly

varying forms of training input (for example, due to some people being involved in the pilot phase when training was different) and this might explain some of the variability. Appendix I summarises responses from the questionnaire on how well people felt the training prepared them. Only 35.7% of families and 38.4% of professional advisors believing it equipped them well or very well for the inspections, compared to 73.4% of self-advocates. Family carers were critical in our discussions with them of Day One of the training that directly involved CQC inspectors, but positive about Day Two. Others (including some family carers) valued Day One. The anonymous questionnaire from Family Carers was more negative about the training overall than their verbal discussions indicated. Some family carers and professional advisors commented on how it was their life or work experiences rather than the training that helped to equip them for the role. The involvement of the two support agencies in the training was welcomed. Comments from individuals were markedly different, both about how the training was organised and which parts were most valuable. For example:

“I think the training was well planned and executed” (PA)

“It was poorly organised” (PA)

“It gave people a chance to talk and ask questions and was clear about what was expected of us as experts” (SA)

“The second day, without CQC, was really crucial in helping me understand what to do’ (FC)

“Meeting the Inspector was the best training on the training day” (FC)

- 6.6.2 One issue that particularly generated comments was that of the appropriateness and effectiveness of separate or joint training between the three sets of stakeholders, with some people finding that the mix impacted on the ability of the training to help prepare them whilst others valued the diversity. We understand that the mix of people receiving training changed over the course of the work as a result of family carer requests, in particular about wishing to work alongside professional advisors rather than self-advocates.

“There was little time to discuss professional advisor roles and responsibilities as the day was regularly taken over by expert by experience carers’ feelings and discussions around their own concerns” (PA)

“Could usefully have had some (self advocate) experts by experience on the training” (PA)

“The day was a valuable opportunity to hear the perspectives of others taking part in the programme, especially the family carers” (PA)

Some families felt the use of easy read materials for their training (with self-advocates) was inappropriate for them.

- 6.6.3 The Inspection pack was widely complimented, felt to be helpful and well-structured. We understand that, as part of the coproduction approach to its development that involved self advocates, families and service professionals, CQC responded positively in the early stages of this work to amend it so that it was more 'user friendly'.
- 6.6.4 We would note that we received a number of positive comments about the contribution that both CBF and Choice Support made to the training process, in particular from family carers in relation to the CBF.

6.7 Effective Team Leadership

Team leadership by the CQC Inspector was a critical factor in determining both the positivity of the experience of the three sets of stakeholders and the extent to which they could provide added value.

- 6.7.1 The overall picture on this is positive, with almost everyone stating they were listened to and included by the Inspector (see Appendix IV) and some being highly positive about their approach and behaviour. Within this, there was naturally some variability, from which CQC can learn. For example, CQC Inspectors acknowledged that there was variability in how positively their colleagues felt about working with these three sets of stakeholders:

"I thought the Inspector was brilliant. He made me feel welcome and part of the team" (SA)

"Some inspectors did things above and beyond the call of duty" (PA)

"The Inspectors made me feel welcomed, comfortable and valued" (FC)

"The extent to which we could contribute, use our skills and be creative depended on the lead inspector" (PA)

6.8 The Importance of Team Building

There was a significant feeling that, despite the best endeavours of various people, on some occasions the Inspection teams found it difficult to gel as a cohesive team. People identified a number of contributory factors to this – most of which are again connected with matters of time and resources.

6.8.1 The splitting of the team over the two days was widely understood considered necessary but it was felt that the potential to overcome the problems created by this were largely lost (see section 6.9). At its most extreme, some people said they did not know who else was on their team. We understand that it was CQC's intention that the teams would be primarily 'virtual', with the Lead Inspector being the common thread. This was partly for reasons of time and resource, and partly arose from the decision to spread the inspections and team over two days so that people in services were not overwhelmed by the number of people from the inspection team. The first comment below neatly sums up the views of many people on the occasions that the team functioned well together:

"In spite of lack of group preparation beforehand the team worked well together on the day. CQC lead inspectors were well briefed: roles were allocated efficiently and there were useful team updates during the day, but overall the process was rather too spontaneous and random" (PA)

"On one occasion we all turned up together – it felt good" (SA)

"We didn't know what each team member was doing" (SA)

6.8.2 The two-day split also created some other unexpected problems, leading on some occasions to people working the second day feeling that they were less important member of the team

"Key decisions on the service had already been reached in day one....." (FC)

"A nurse in the hospital challenged why I was there as I hadn't be there on day one" (FC)

6.8.3 The lack of a pre-meeting restricted the capacity to develop a common approach to a specific visit (though it is worth noting that all three stakeholder groups generally felt that the team were adopting a similar approach/value set as described in Appendix II)

"Resources played a part in not being able to have pre and post visit team meetings" (CQC Officer)

6.8.4 Within the overall positive experiences about lead Inspectors, there were occasions when people felt that the approach to team leadership affected how people were seen and understood as part of the team. For example, professional advisors sometimes feeling they were seen as an extension to the CQC Inspector, doing paperwork reviews rather than using what they saw as their wider skills, and some family carers feeling their contribution was subject to restrictive boundaries

6.9 Clarity and consistency of process

Across the whole range of processes that involved the three sets of stakeholders, there were examples where a lack of clarity and consistency around processes being used created difficulties for team members. Perhaps paradoxically, it was this lack of clarity that enabled some lead inspectors to be flexible in how they interpreted the processes and it was on these occasions of flexibility that Inspectors were 'awarded' the greatest praise.

6.9.1 The recruitment process was not included in our brief as this is covered in the Acting Together contracts for self-advocates and family carers and is evaluated through this. However we did ask an opening question to all three sets of stakeholders to help understand the context through which people became engaged in the work. A number of people did comment on recruitment issues, often describing a process that had been lacking structure – most notably professional advisors. In particular, some people were not clear about when they had been recruited to be part of the Inspection teams. Boundaries between the recruitment process and the training were unclear with some thinking that they were still being judged and recruited at the training days. Some people said that the first they knew they had been accepted was when they got a request to go on a visit.

6.9.2 There was generally variability between the three sets of stakeholders as to whether they were clear what was expected of them. The self-advocates were generally clear and happy that they focused mainly on inter-acting with people living in the service. For family carers, there were differing views, with some families feeling that the focus on families that they were asked to take was in some ways limiting. For professional advisors, the issue tended to be that they started out being clear about their role but then felt that how they were used on the inspections did not always reflect their understanding and/or skills.

"I feel the role of professional advisors needs to be looked at again in terms of how their specialist knowledge and experience can be maximised" (PA)

"My role was to give an overview of the day from the point of view of an experienced family carer" (FC)

"The role wasn't too clear – I said what I saw on the day and the Inspector listened to me" (FC)

6.9.3 There was a general feeling that the processes on the day would benefit from greater consistency and clarity. Some elements were widely felt to be beneficial – such as a short 'get together' at the start, 'checking in' every hour or so to compare notes, learning and re-group in terms of the next steps, and the end of day de-brief.

These things did not always happen, it appearing to depend significantly upon the lead inspector.

- 6.9.4 On occasions, it appeared that the briefing to the provider service had been inadequate in terms of what was to happen, who was involved and people's roles. Also, some things were considered 'off limits' that could have added important further understanding – such as the team being shut out of 'difficult situations' that arose with individual people using the service.

“At one place people thought I was looking around with a view to moving in” (SA)

“Someone (a provider staff member) asked me what qualifications I had to do the inspections – I found this really annoying” (FC)

- 6.9.5 The structure provided for gathering information was generally felt to have worked well, with a recognition and appreciation that the questions were a framework rather than a rigid approach to be followed in detail. Self-advocates described how they found it worked to essentially have a conversation with people – often whilst their supporter took notes and helped with completing the questions framework. Family carers similarly used flexibility to achieve the best out of discussions with relatives. However, both self-advocates and family carers generally felt they would have liked to spend more time with people to gain a full picture of issues.

- 6.9.6 The arrangements for speaking with family carers were often experienced as difficult and limiting. Part of this was practical (having to make phone calls from a car because a lack of facilities or speaking with a parent when they were on a bus). Some felt that greater flexibility around the process would have helped. For example being allowed to phone in the evening or even the following day with the findings being immediately sent to the Inspector. Also, family carers felt that some understanding of (and prior meeting with) the family member in the establishment would have added greater context and understanding to the discussion with the family member. There was also a concern about the family carers being selected for interview by the provider, at least in part this was a consequence of visits being unannounced so the CQC Team had limited capacity to review and propose families to speak with. However, some families expressed concern that this could mean it was not a representative view being received – though as one family carer said:

“If that was a positive parent I hate to think what a negative one would have said” (FC)

- 6.9.7 The process for end of day feedback was also experienced in different ways. On the occasions that a detailed verbal discussion did not take place, people generally felt they had not been able to fully contribute to the 'analysis'. The written format for

reports was felt to be constraining and it was welcomed when some inspectors accepted hand written notes in lieu of the formal forms.

- 6.9.8 Sometimes professional advisors and family carers were involved in the final feedback meeting with the service. (We assume self-advocates were not as they generally were not present on day two). The sets of stakeholders valued this, feeling they were able to provide added value to that process as well as it validating their input, but it only happened with some lead inspectors.

In one situation, a lead inspector was concerned about giving difficult feedback to the service. The professional advisor offered to accompany them and was able to quote from their detailed notes to support the points being made.

- 6.9.9 It was considered by a number of people to be inappropriate that they were required to return their paperwork rapidly after the end of the visit, only for there to then be a long delay, often of several weeks, before receiving a draft report for comments - on which they were again sometimes given very short deadlines to comment. If nothing else, for people doing several visits, this time-lag made it difficult for them to focus on one service - having perhaps visited several others in the meantime. Some families and self-advocates also said they did not always get to see the final report.

6.10 The End Report

The reports were generally felt to be representative of the views of the inspection team, though people were concerned about the limited scope of issues covered and processes for taking findings forward.

- 6.10.1 Appendix III shows the extent to which people felt the report was a fair reflection of the service they had visited. Generally, it was felt that it was a fair reflection, though with family carers giving a lower number of top two ratings (21.4%) than self-advocates (73.3%) and professional advisors (76%). No family carer said that reports gave a totally true picture of the service inspected i.e. there were factors beyond the scope of the two standards being covered by the Inspection that were felt to be important to a full picture of the service. Some commented that they felt the language used in the reports was 'bland' and that they would have appreciated more 'plain speaking'. There was a feeling from many people that the reports would be helpful to the services concerned.

- 6.10.2 It was generally felt that Inspectors listened to requests for changes and, if not taking them on board, at least explained why they had not. However, there were some issues about 'ownership' of the report and whether the whole team 'owned' it

or it was primarily a report from the CQC inspector though CQC officers were clear that CQC's 'ownership' had been clear from the outset. On occasions this resulted in some team members feeling that they were "second class citizens".

"One Inspector told us – your part of the report made the report" (SA)

"I felt everything was added into the report that I wanted to have in it" (SA)

"It did feel that the person from CQC was listening, but it was made clear they had the final say" (FC)

"At the end of the day the report was mine. I was very conscious that the report would be seen by the media ...be in the public eye"" (CQC inspector)

Though this perhaps did not recognise similar concerns from others:

"What if I'm part of an inspection, then next week it is on Panorama?" (FC)

6.10.3 There was concern from all three groups of stakeholders that the inspection's focus on two standards meant that other issues they observed, which raised concerns, were not explored and reported on. Most notable was a major concern from a significant proportion of people that they were part of reporting services as being fully compliant when people had lived there for several years, on the face of it inappropriately, without apparent plans for them to move to more appropriate settings. It should also be noted that some professional advisors commented that the focus on two standards did helpfully allow an in depth exploration of those issues.

"I felt we were giving OK status when there were things going wrong" (SA)

"The outcomes of inspections don't identify communications and cultures within the settings" (FC)

"I am concerned that the process does not pay sufficient attention to possible problems in the service. It seemed more concerned with saying that the service met standards" (PA)

6.10.4 Some people commented that the report did not allow the space to report and praise good practice they observed

"You see examples of good practice but have no-one to tell about it" (FC)

6.10.5 The reports were felt to be overly structured, with CQC's approach to reports sometimes losing the true sense of the team's conclusions

"It's difficult putting my words from the inspection into a report style document" (SA)

“Reports were fairly comprehensive, though characterised by standard CQC phraseology and not always bringing the establishment to ‘life’”(PA)

6.11 Next Steps

There was a widespread concern from all three sets of stakeholders as to whether their work would lead to any long term change or improvement in services.

6.11.1 One of the most consistent concerns expressed by all three sets of stakeholders was that of whether there would be follow-up on the issues identified through their work. At its most fundamental this was a concern that their work should not have been in vain and did not become ‘window dressing’ as part of a response to Winterbourne View. Many of the participants had strong views about what should be done with the services above and beyond the content of the reports. Two particular concerns were:

- Some people expressed concerns that they were part of a process that might be primarily about managing the current pressures on CQC rather than being part of an ongoing programme of service improvement
- That the follow up work after the reports is understood to be coming under the responsibility of regional CQC offices and thus, on the whole, people who had not been involved in these inspections. There was a concern that the knowledge and learning and the commitment to the inclusion of the three sets of stakeholders would not be continued into the future

6.11.2 In this context, there was a specific request from a number of professional advisors for CQC to organise a day for them to (i) share the experience with other professional advisors and (ii) hear from CQC how their work is being used and the next stages in this work.

(about the inspection report) “This is fine as far as it goes – but what happens next?” (PA)

“People at CQC have put their heads up about this – but what is to stop them putting them down again soon?” (PA)

6.12 Modelling Behaviour

6.12.1 The involvement of these three sets of stakeholders modelled a way of working that sent important messages to services about the involvement of (in particular) self-advocates and family carers. For example, the fact that one NHS Trust had

objected to the presence of a self-advocate on the team on the grounds that their judgement could not be trusted, and that CQC had responded to this in a supportive way to this process, was considered to be sending out positive messages about how services should behave and operate themselves. CQC reported to us that providers welcomed the involvement of self-advocates and families, though our evidence from those people is that this was not always the case. The separate evaluation commissioned by CQC of provider experiences should add more to understanding this question.

6.12.2 Similarly, we were informed by some CQC officials that this process constructively challenged some internal thinking and attitudes within CQC that will help, in the long run, to further embed a culture of involving people and families in inspections.

6.13 Personal Impact

Finally, the evaluation has indicated that a side-benefit of the involvement of these three sets of stakeholders has been the knock on effect for them both personally and in their (if appropriate) work setting. There are, however, some concerns from a small number of people that CQC could have done more to assist them in dealing with some of the emotional challenges in doing this work.

6.13.1 A small number of people, mainly self-advocates and family carers, did find the experience difficult from a personal perspective. Sometimes this was connected with people's motivation to be part of the team in the first instance, in others through occurrences during the inspections. It should be emphasised that this feedback came from a small proportion of people, and may relate to recruitment issues, but it does imply a need to be conscious of supporting people from outside when undertaking what could be emotionally charged work.

"In one situation we found ourselves in an isolated and scary place and asked for, and were given, personal alarms" (SA)

"I was upset because some people had to be moved from the wards, places they lived because of bullying or because they did not like it. I handled this by talking to my supporter" (SA)

"CQC had a duty of care to me. They should have asked me to tell my story, allowed me to 'ventilate' at the start of this" (FC)

"If I'd had access to a coach, I would have taken people away with me" (FC)

6.13.2 The motivation behind people offering to be involved in the inspections was almost comprehensively a desire to contribute to improved lives for people – particularly

following the Panorama programme about Winterbourne View. In addition to people feeling a sense that they had contributed to this, a wide range of other benefits were identified, including:

- Increasing personal knowledge to CQC standards and thus enabling them to challenge poor quality services they are involved with locally
- Gaining reinforcement through working with people who shared similar aspirations for services
- Reporting back, in general terms, about the work to other people working in services and so sharing a national perspective on the state of learning disability services

“It made me feel better about my relative, that I had them at home with me”

“The power and passion in this room is more than I have seen anywhere in more than 20 years (FC – during the NDTi’s evaluation day with family carers)

“Gaining kudos” through being part of a CQC inspection team and so having a stronger voice to influence case for their own relatives (FC)

I would dearly like to carry on this work and join the CQC on a full time basis”(FC)

“I value my peers. I became involved because I didn’t want them to be forgotten” (SA)



7. Summary and Recommendations

- 7.1 Before summarising our conclusions and recommendations, we wish to note that throughout our work some people (particularly those involved in the inspections) have been seeking to encourage us to provide answers to a wider question of whether the involvement of these three sets of stakeholders qualitatively added value to the reports and other outcomes from the inspection process. Whilst we have touched on this, our evaluation can only contribute to an understanding of that question. To answer it fully would have required wider interviews and evaluative processes (such as reviewing the content of final reports) that were beyond our brief. We are aware that other work is contributing some of this, such as an evaluation the experience from the perspective of the Inspectors and the Providers.
- 7.2 It is interesting to note that, against all of the quantified questionnaire ratings other than about training, the family carers were less positive than either the self-advocates or the professional advisors – on team coherence of purpose, end report validity and being listened to. (On training, the professional advisors were slightly less positive). The timescale and scope of our work did not enable us to explore why this was the case, but we can hypothesise a number of explanations, such as families having higher standards or expectations, some things about the design working less well for families or the impact of the ‘social construct’ of family experiences with services and related bodies.
- 7.3 From the material described in this report, which summarises the wider data gathered and the analysis undertaken, there are a number of conclusions that can be drawn and recommendations that arise from these³.
- a) The decision to involve self-advocates, family carers and professionals in these inspections was a wise decision. Both CQC and the wider health and social care

³ In undertaking this evaluation we were aware that OPM had undertaken a not dissimilar but much wider evaluation into the learning disability inspections that were undertaken a few years ago by the Healthcare Commission, Commission for Social Care Inspection and Mental Health Act Commission. We intentionally did not review that report until after the completion of our analysis in order not to risk skewing our findings. On reading that report, we have been struck by the similarity between their findings and ours – suggesting there is a degree of consistency of the issues arising and the potential actions that could and should be undertaken by the CQC.

community appear to have derived benefit from it. We are aware that CQC is already developing the involvement of external members of inspection teams through the Acting Together programme and we recommend that based on this evaluation it would seem wise to expand and develop this approach to CQC's work, including beyond the learning disability field. However, we recommend that this should be accompanied by consideration of the recommendations below (some of which have resource implications) and a continuing evaluation of its impact as involvement expands.

- b) The extent of the success of the involvement of these three groups of stakeholders was, in our opinion, significantly affected by (i) the short timeframe within which, for political and other reasons, the inspections needed to be undertaken and (ii) the amount of resources available to the initiative. CQC will need to consider whether the investment of the necessary additional resources that would be needed to address some of the findings of this report will be justified in terms of the improved inspection outcomes that should be delivered as a result.
- c) The mix of the three different types of external stakeholders had a positive impact and should be continued
- d) The focus on just two standards created tensions for some of the three sets of stakeholders and possibly resulted in some 'added value' from their involvement being missed. It may be appropriate to review the breadth of coverage of standards for future inspections or identify ways in which this potential added value could still be obtained.
- e) With a greater lead-in time to Inspections, consideration should be given to seeking to match the specific experiences of the three sets of stakeholders to the nature of the specific service being inspected.
- f) There would be benefit from greater preparation of teams prior to a visit, in terms of (i) information about the service to be visited and (ii) a pre-meeting for the team members with the lead inspector
- g) There will be benefits from developing a core of external members of inspection teams from these three sets of stakeholders who can develop skills and relationships with CQC and thus be increasingly effective members of the inspection teams
- h) The pre-inspection training was helpful but had mixed reviews and would benefit from a thorough review that in particular should consider clarifying what training people should receive and how to group people together when receiving it

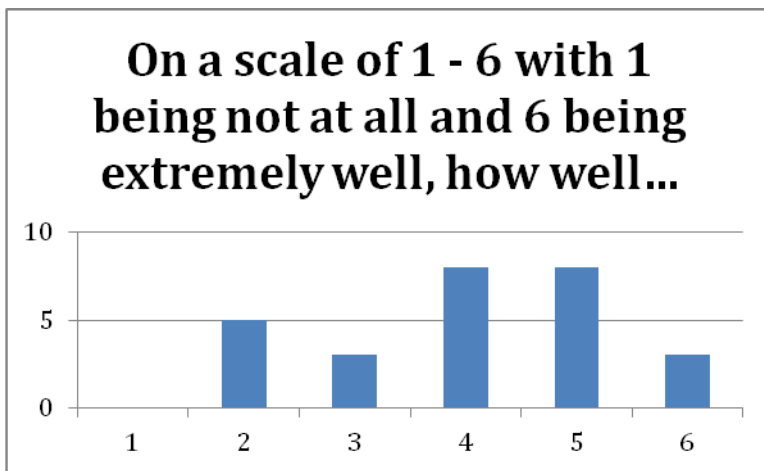
- i) The inspection pack developed to support the external team members was a helpful resource
- j) Team leadership from lead inspectors was good, in some cases exceptional, though would benefit from a greater degree of consistency, applying the approaches from the most positively viewed team leaders
- k) Teams generally worked together fairly well, but greater attention could have been paid to team building and the processes that might affect that such as how to handle the split of the team across a two day visit.
- l) The recruitment process for professional advisors could be structured to create a greater degree of clarity and communication about stages within that process and when people are approved as potential team members and allocated to teams. (Recommendations for other stakeholder recruitment are beyond this report's brief).
- m) The role of the professional advisor on the team, their added value and the tasks best allocated to them on an inspection would benefit from a review and greater clarification
- n) There would be benefit from greater consistency around elements of process on the day that people found most helpful including (i) a pre-meeting (ii) regular check-ins throughout the day (iii) clear engagement of all team members at the end of each day
- o) Whilst adhering to agreed best practice in structure for the inspection days, the flexibility which several lead inspectors utilised should be continued in ways that reflect the different ways in which team members are best able to contribute to the process.
- p) The arrangements for contacting and speaking with family carers did not always work well and would benefit from a review
- q) The process/timescales around producing the final report would benefit from (i) more recognition of the difficulties faced by the three sets of stakeholders in contributing to it, (ii) more communication about the progress on report production, and (iii) a review of the language used to achieve greater clarity and engagement of stakeholders.
- r) The reports were generally considered to be a reasonable reflection of the services inspected but there was a significant concern that the focus on two standards missed key issues in a number of services

- s) Lead Inspectors respected and listened to the views of the wider team and generally incorporated their views into the report. There would be benefit of greater clarity and explanation from the outset as to 'ownership' of the final report.
- t) The three sets of stakeholders are concerned to know that there will be continued follow-up to the issues identified by them in the report. CQC could consider how to maintain communication over the coming months with people in order to keep them up to date with the impact of their work.
- u) The involvement of the three sets of stakeholders, particularly self-advocates and families, succeeded in sending messages to people across the system about how people can be involved as equal partners.
- v) Some people found the process quite difficult personally, and it may be beneficial to consider this, on an individualised basis, at the recruitment stage
- w) There are early indications of 'knock-on' benefits in wider service settings from the involvement of the three sets of stakeholders in this process. This additional benefit should be considered when decisions are being taken on further investment in this process.
- x) An end of process review meeting for professional advisors would be appreciated by them. (We understand that self-advocates and family carers have had this opportunity through meetings as part of the wider work delivered by the Support Agencies).

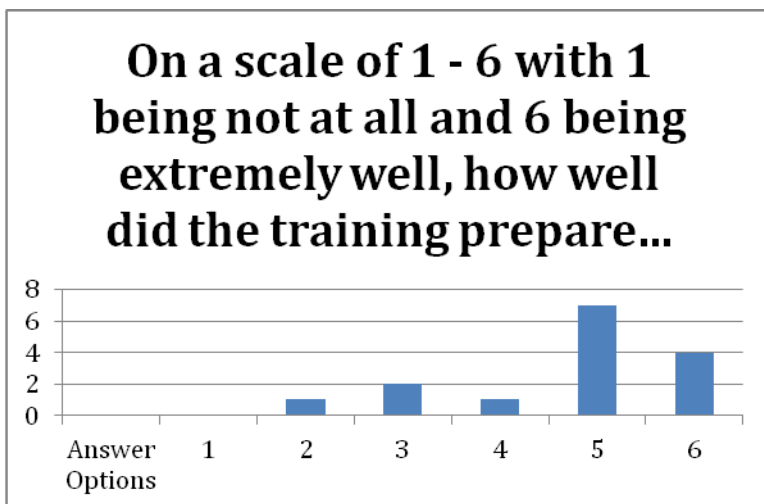


Appendix I

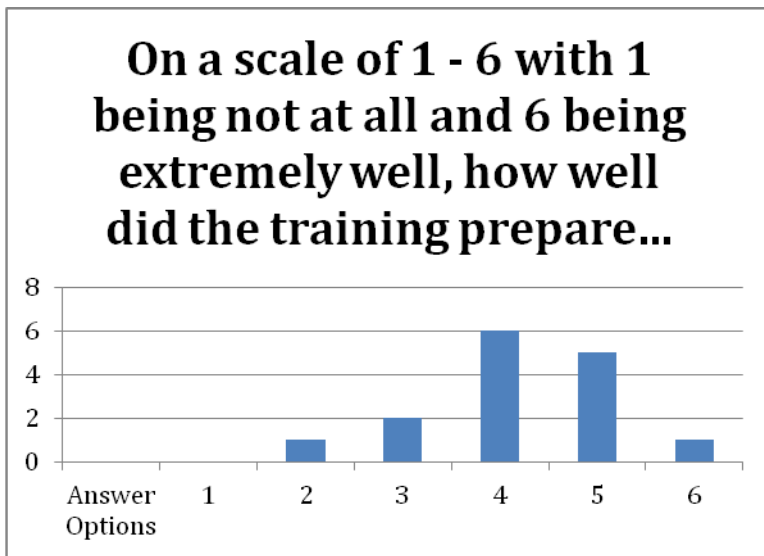
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Self-Advocates:



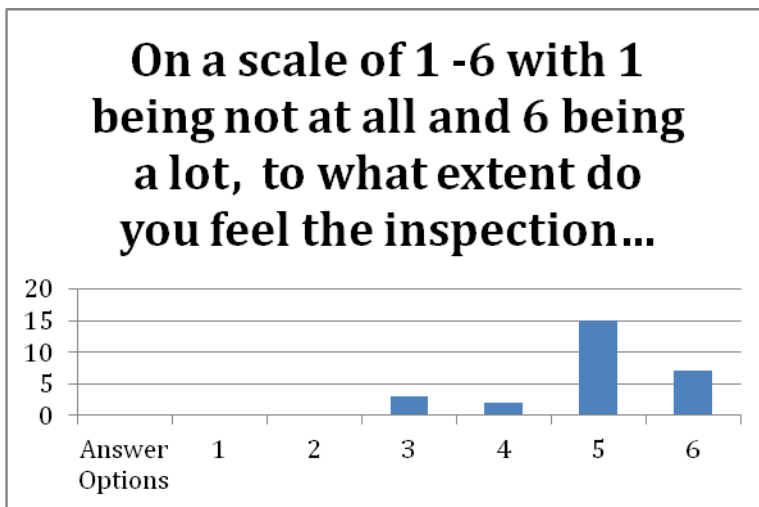
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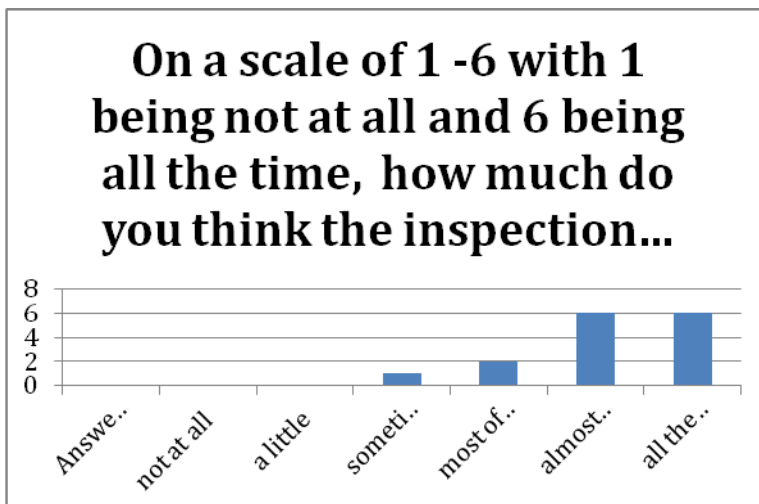


Appendix II

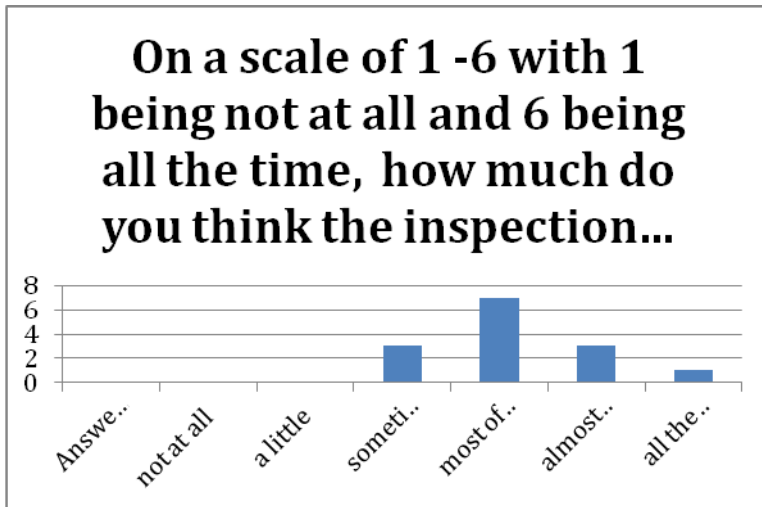
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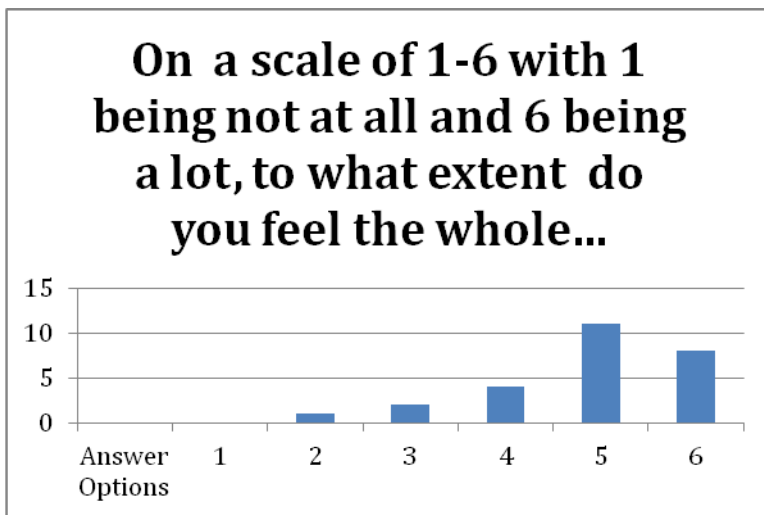
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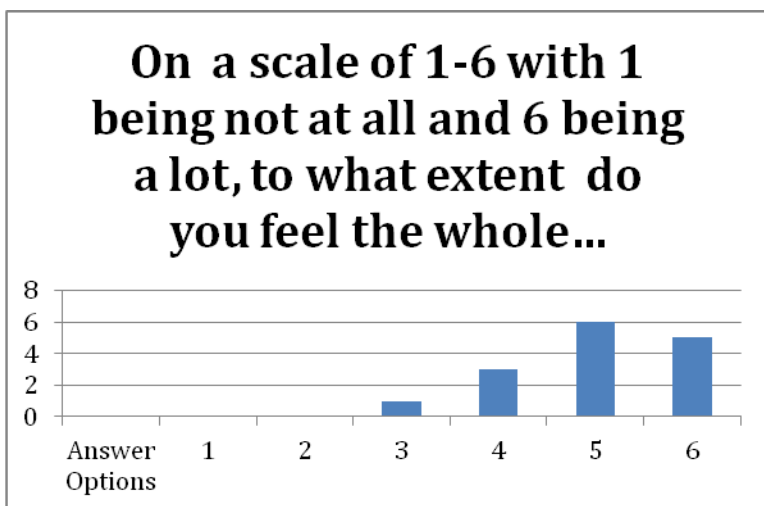


Appendix III

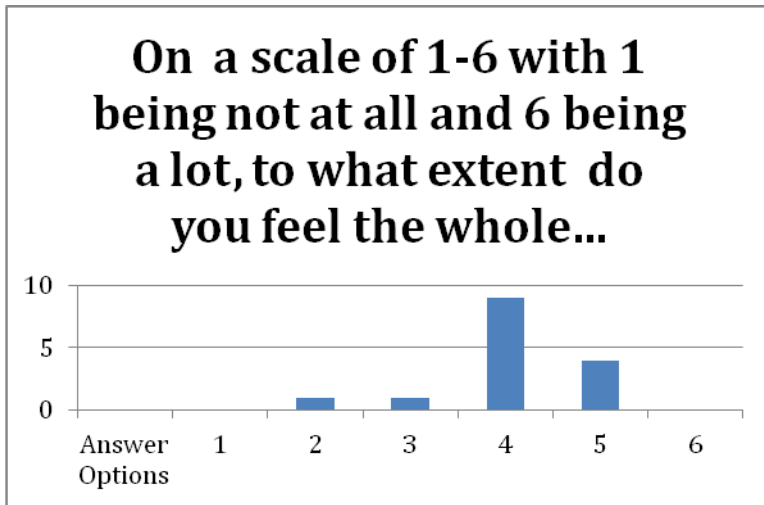
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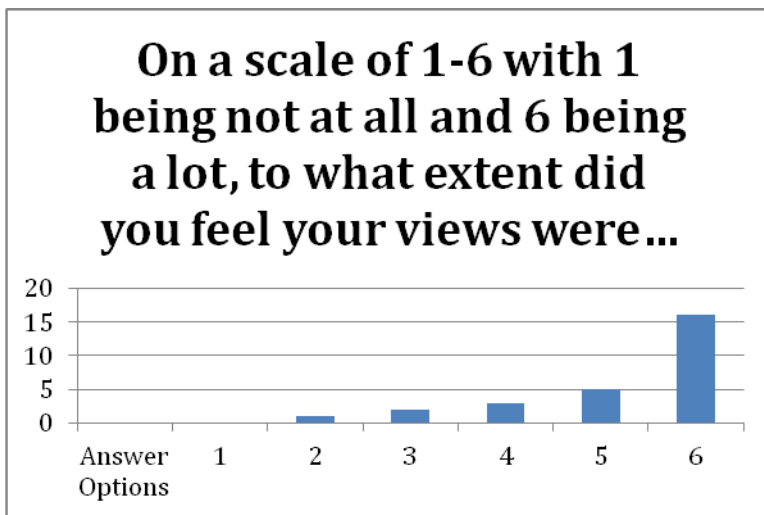
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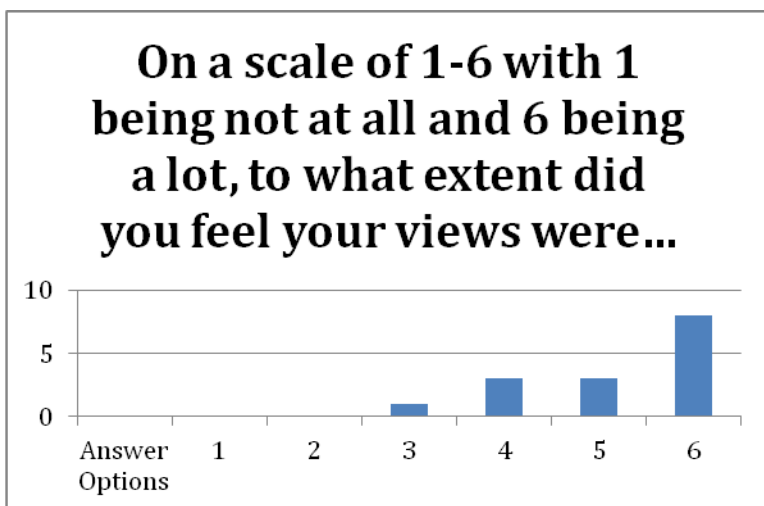


Appendix IV

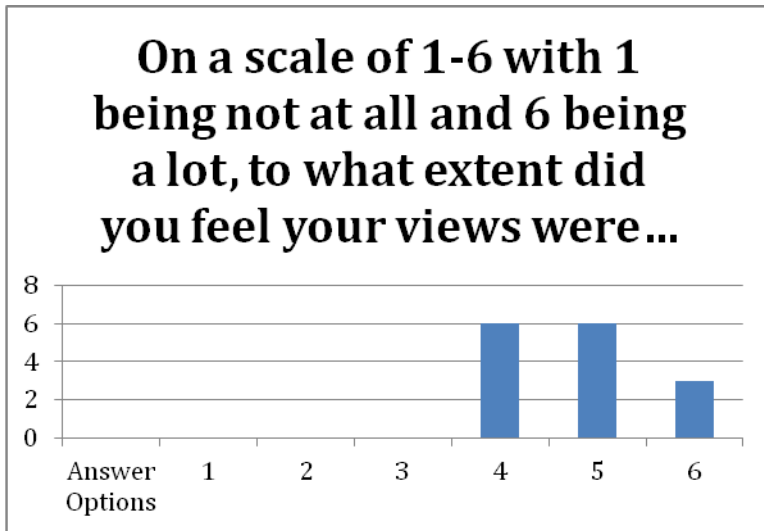
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Self-Advocates:



Family Carers:





Appendix V

Questions for Experts by Experience Group Workshops on 12th and 13th April 2012

(n.b. The following questions were a framework for a conversation used by the NDTi facilitators and not a rigid list of questions that were followed in a formal structure)



Part 1:

“How we got involved with this work”

- How did you hear about this work?
- Why did you want to take part?
- How were you chosen to take part?
- How well did that process work?



Part 2:

“The Training and Preparation that we had”

- What training did you feel you needed to take part in this work? What training did you get?
- Did it give you what you wanted?
- Were the training materials easy to understand?

- How well did the CQC explain why this work was important?
- Did you have any ideas about how the training could be improved? If so, what were they?
- Did you tell the CQC about these ideas?
If so, do you think they listened to what you said?

- Did you feel that you had the right experience for the hospitals you visited?
- Did you talk to anyone at the CQC about this before you went on a visit?
- Did you get enough help to prepare for the visits?
If not, what else would have been helpful?
- Were you clear about what your job was during the visits, and also what the other members of the team were doing?



Part 3:

“Going on Visits, as a member of the Inspection Team”

- How many visits did you go on?
- If you went on more than 1 visit, what were the main differences between the places you went to?
- Did you all go in together as a team on the visits?
- Was your job clear to the people you met there?
- Were you able to do your job well in the way you wanted to?
- Do you think that as an expert self-advocate you could do things, ask questions and see things that other people on the team could not?
- Did you feel or experience anything which upset you or you found difficult during your visit?

If so, how was it handled and were you able to get good support to deal with this?

- What do you think worked well about the visits?
- How else could the visits have been planned to help you make a better contribution?
- How did you find filling in the report template?
- Could you say everything you wanted to in it? If not, were you able to give your views in other ways?



Part 4:

“What we have learned from the work?”

- Were your views listened to by the CQC inspector when you talked together after the visits?
- Were they then included in the first draft of the report?
- Did you feel that the final report gave a good picture of the hospitals you visited?
- If you hadn't taken part in this work, what do you feel would have been missing?
- Did you think that the visits gave information that would make a difference to people's lives?

- What was the most important thing that you learnt from the work?
- Have you given your feedback to the CQC already?
If so, can you remember what you said?
- Would you like to go on more visits like this in the future?
- Is there anything else you would like to tell us?




Appendix VI

Questions for Experts by Experience Group Workshops on 12th and 13th
April 2012

CARE QUALITY COMMISSION INSPECTIONS



FAMILY CARERS & PROFESSIONAL STAFF FEEDBACK



How many inspection visits did you do?

Your name:

This is just for our records, we won't tell anyone what you have written on this form



What experience did you have of the type of services you were visiting before you did the inspections?

	In the last 5 years	More than 5 years ago
I have lived in one of these services	<input type="checkbox"/>	<input type="checkbox"/>
I have a family member living in one of these services	<input type="checkbox"/>	<input type="checkbox"/>
I have visited family or a friend in one of these services	<input type="checkbox"/>	<input type="checkbox"/>
I have worked in one of these services	<input type="checkbox"/>	<input type="checkbox"/>
I have managed one of these services	<input type="checkbox"/>	<input type="checkbox"/>
I have worked as a consultant for one of these services	<input type="checkbox"/>	<input type="checkbox"/>
I have not had any experience of any of these services	<input type="checkbox"/>	<input type="checkbox"/>

Please let us know about any other experience you may have about one of these services



On a scale of 1 – 6 with 1 being not at all prepared, and 6 being very well prepared, how well do you think the training prepared you for the inspections?

1 - not at all prepared	<input type="checkbox"/>
2 - helped a bit but I didn't understand some things	<input type="checkbox"/>
3 - just OK	<input type="checkbox"/>
4 - quite well prepared	<input type="checkbox"/>
5 - well prepared	<input type="checkbox"/>
6 - very well prepared	<input type="checkbox"/>



On a scale of 1 – 6 with 1 being not at all, and 6 being all the time, how much do you think the inspection team had the same ideas about what makes a good service?

1 - not at all	<input type="checkbox"/>
2 - a little	<input type="checkbox"/>
3 - sometimes	<input type="checkbox"/>
4 - most of the time	<input type="checkbox"/>
5 - almost all the time	<input type="checkbox"/>
6 - all the time	<input type="checkbox"/>



On a scale of 1 – 6 with 1 being not at all, and 6 being all the time, how much do you think your views and opinions were listened to and respected during the visits by the rest of the inspection team?

1 - not at all	<input type="checkbox"/>
2 - a little	<input type="checkbox"/>
3 - sometimes	<input type="checkbox"/>
4 - most of the time	<input type="checkbox"/>
5 - almost all the time	<input type="checkbox"/>
6 - all the time	<input type="checkbox"/>



On a scale of 1 – 6 with 1 being not at all, and 6 being totally, how much do you think this work has helped you and the rest of the team to give a true picture of the services?

1 - not at all	<input type="checkbox"/>
2 - a little	<input type="checkbox"/>
3 - OK	<input type="checkbox"/>
4 - fairly good	<input type="checkbox"/>
5 - very good	<input type="checkbox"/>
6 - totally	<input type="checkbox"/>



Would you be happy to help with another inspection in the future?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Not sure	<input type="checkbox"/>

Thank you



You can send this form by post to:

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Montreux House

18a James Street West

Bath BA1 2BT

OR

By email to:

admin@ndti.org.uk

