



Review of support for families with disabled children – Frequently Asked Questions

4th January 2011

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This document sets out the ‘Frequently Asked Questions’ about the review. It will be updated regularly and published on the review website:

<http://cqc.org.uk/reviewsandstudies/currentprogramme/supportforfamilieswithdisabledchildren.cfm>

If you have any further queries please contact reviews.studies@cqc.org.uk, including the phrase ‘support for families with disabled children’ in the subject line.

What is this review about and why is CQC conducting it?

Q What is a CQC special review?

Under the Health and Social Care Act (2008), CQC is responsible for a programme of special reviews and studies. A special review is an in-depth assessment of the performance of health and/or social care organisations, which focuses on particular services, pathways of care or groups of people. The main aims of the programme of special reviews are to provide assurance to people who use services and the public that services are meeting standards and are of high quality, and to help health and social care organisations to improve.

We carry out special reviews where an aspect of health or social care is of importance across the country and where there are opportunities for organisations to make substantial local improvements. A review will result in assessments of local health and social care services, which are usually published alongside a national overview report. These assessments may either be in the form of reports written by local inspectors or, as in the case of this review, assessments based on performance information collected from organisations.

Q Why is CQC carrying out this review?

The aim of this review is to promote improvement in the delivery and commissioning of support for families with disabled children by:

- Producing robust and objective local area-based assessments of specialist health support, along with supporting benchmarking information
- Ensuring appropriate action takes place in the areas where performance is weakest;
- Publishing a national report setting out recommendations for service providers, commissioners, local partners in children’s services and central Government.

The main output from the review will be the assessment of the quality of the local support provided to families with disabled children for each local area in England, as

defined by PCT geographical boundaries. This assessment will be structured using a framework based on the expectations set out in Aiming High for Disabled Children: Better Support for Families, and where no clear expectations exist, a consensus of key issues and 'reasonable' thresholds of performance derived from wide consultation with a range of national and local stakeholders, a review Advisory Group and an advisory group of Parents and Carers of disabled children.

Wherever possible the assessment for this review uses data from existing national sources: selected items and data submitted as part of Children's Services Mapping, National Transition Support Team local Self Assessment Questionnaires and the national survey used to inform the disabled children's services national indicator (NI54 and VSC 33), looking at parental experiences of services for disabled children and young people aged 0 to 19 across England.

Q Why does the review include local data collection?

Some local data collection will be necessary in order for the review to look at issues beyond the scope of national data collection systems and provide a robust and rounded assessment. The local data collection comprises:

- a form for completion by all PCTs,
- a form for completion by selected providers of NHS acute services (non-Foundation and Foundation acutes)

Through combining the national data with new local data, the review will derive a more rounded picture of how well the specialist health needs of disabled children and young people and their families are supported.

Q What is the framework for assessment?

The framework for assessment is structured around 4 themes:

1. access to key services and timely support
2. delivering pathways managed around the needs of families and disabled children
3. empowering families and disabled children
4. supporting the inclusion and equality of families and disabled children.

All data relate directly to these themes and address key components of local support, about which little or no evidence currently exists. These themes have been developed through consultation with a wide range of stakeholders, including parents and carers, disabled children, commissioners, service providers and professional bodies.

Q Why is this review important?

Some families may experience better quality support than others. Some families – and stakeholders working with them - suggest there is room for improvement in some areas and for some types of support. Much support is highly valued by families and some areas may provide excellent support.

A national benchmark of health support is important to enable local PCTs and their partners to understand how well their contributions support the agenda set out in Aiming High for disabled children: better support for families, to provide key information – for the first time - about a range of local support for families with disabled children and to give services an ‘evidence base’ of information to plan and move forward in a time of considerable change.

This CQC special review supports three of the five priorities set out in the Operating Framework for the NHS10/11:

- keeping adults and children well, improving their health and reducing health inequalities;
- Improving patient experience, and staff satisfaction and engagement;
- Improving access through achievement of the 18-week referral to treatment pledge.

The services assessed in this review have been identified as a priority for local change. This change has been supported through an extensive programme of policy, guidance and other resources for development, intended to transform the experiences of families with disabled children.

General guidance for answering questions in the review

Q What is the data period for the review?

In general questions should be answered:

- For ‘interval’ questions (e.g. “How many children were referred to this service...”) the period is generally 01/04/2010 – 30/09/2010.
- For ‘point in time’ questions (e.g. “For children with complex needs, are there arrangements in place through which...”) answers should be given in relation to the position as of 30/09/2010 (end of the half financial year, and close to the commencement date for our data collection).

Q How should answers be estimated for questions regarding percentages (e.g. What percentage of disabled young people have...?)

A number of multiple-choice questions use the options below (or similar). For these questions answers should be estimated using the following general principles:

- all/almost all = over 80%
- most = over 50% and up to 80%
- some = over 20% and up to 50%
- few/none = 20% and below.

Q How should answers be provided for questions about length of waits?

For average and longest waits answers should be given as accurately as possible. Decimal places are permitted to denote partial weeks. Please provide the mean wait as your average.

Q In the acute tool, how should answers be provided for statements where the statement is a yes/ no to a negative statement?

For example: We do not use family members as interpreters, unless in an emergency situation and only until an appropriate interpreter can be found. Answer yes, no or don't know.

Due to technical constraints, we need to ask the question in this way. We are sorry if this causes any confusion on your part. It may help you decide how to respond if you consider:

- If the given statement applies to you/ is 'true' for your support: Yes
- If the given statement does not apply to you/ is 'false' for your support: No
- If you don't know or can't decide: don't know

Q What age range of children should we include?

We are aware that support varies greatly between and even within PCT areas. Through consultation and testing, we understand the majority of support includes an age range of at least between 3 and 16 years of age.

For this assessment, questions which require numbers of children and young people referred during a period (waiting, and so on), will assume that data for your services includes children and young people at least between 3rd and 16th birthday. We know many local services, and hence data, will extend beyond this range – for example may include those from 1 year or up to 19 years of age. You should use your locally agreed and existing information and do not need to amend your answers to reflect this.

Exceptional cases

There will be a text box for you to provide age ranges where these are exceptionally different and you feel the data you submit may otherwise misrepresent the local position. For example, where support is for early years only, or for all ages and includes children/ young people and adults – possibly equipment support is via an all-ages service in your area. Or some may not have local data systems that differentiate. In exceptional cases where you need to specify a data extract, you should include children and young people between their 3rd up to their 16th birthday at the point of referral.

Q How do you define ‘disabled children’?

It is not appropriate for us to provide prescriptive definitions (or ICD-10/ ICF) coding for disabled children.

The Disability Discrimination Act (DDA) sets out a measure and local organisations should have a sound understanding of the needs and population of disabled children. We are aware that local understanding (and arrangements around) the population of disabled children may vary. For the purposes of this assessment, you should consider the measure set out in the Disability Discrimination Act, your own experience and practice and arrangements you have with your PCTs and other local partners to support disabled children.

In the supporting materials for this review we set out the broad range of needs that this review seeks to assess, and the support that is not included within scope. We hope you find these helpful.

You should also take in to consideration the National Service Framework for Children, Young People, and Maternity Services, standard 8 for disabled children, young people and those with complex health needs. Page 4 of standard 8 provides a note on terminology (paragraph 1.5):

"This standard relates to children and young people who are disabled and/or those with complex health needs, including children and young people with learning disabilities, autistic spectrum disorders, sensory impairments, physical impairments and emotional/behavioural disorders..."

Regarding our questions around delayed discharge and transfer or care, consultation and piloting suggests that on the given date, each provider will identify relatively few children with complex health needs who's discharge or transfer of care is delayed. We hope that you will be able to identify these individuals with reasonable effort and confidence and enable us to generate important new national data. However, we seek to minimise the work involved to meet our requests and you will have noted that this question is voluntary.

Q For acute trusts, how should scenario questions be answered?

For acute trusts, three scenarios have been developed using the hypothetical young people Naseem, Sarah, and Chris. Their needs and situations are based on real experiences. For each child, a small number of questions are asked about what would happen in your service. Answers should be based on the actual experiences of children and families with similar needs to Naseem, Sarah, and Chris, who have visited your service over the last year. You should use your knowledge of the organisation, including its resources and policies to come to a judgement about what you would expect to happen in each scenario.

Form compilers may need to involve colleagues to get a range of evidence and reach a fair and agreed view. It may be useful to bring the questions to a meeting where you can consider the answers together.

Unless you signify otherwise, we will assume answers apply regardless of the child's PCT. If any of the answers would vary because of specific arrangements with a particular PCT, you are asked to signify which PCT(s) are different, and select the appropriate answer which would apply for children/ young people from that PCT. You may have different arrangements with more than 1 PCT, in which case you will need to provide an answer for each PCT where this is the case.

Organisations required to submit local data

Q Which types of organisation are being asked to submit local data?

We are asking all PCTs and some acute trusts to submit data. We recognise that PCTs may not currently hold all the data we are requesting, but think that any such data should be available to them from partner and provider organisations. In particular PCTs may need to involve their community service providers in data collection. After careful consultation and piloting, it was decided not to go direct to providers due the wide range of local arrangements in place and the need to clearly identify which support contributes to which PCT. PCTs are best placed to collate the important information we are requesting and we are asking them only about services they commission.

Q We are a “commissioning only” PCT, do we still have to submit data?

Yes, as this review aims to promote improvement in commissioning of specialist health support for families with disabled children, as well as the delivery of that support. PCTs are accountable for the quality of the care that they commission, and are expected to have processes in place to enable them to appropriately monitor and manage the services and care they commission regardless of where the patient receives their treatment or consultation.

Q Our services are provided through a Section 75 agreement. Are the requirements of this review different for us?

No. We know there is much variation in local arrangements and the review has been developed - and piloted - with this in mind.

Nominations: As for every other PCT area, the PCT needs to decide who is best placed to respond about the services commissioned for your population, using your funds - however you arrange yourselves locally.

It is for you to decide who is best placed to collate the data we're asking for and who has the authority to sign this off it on behalf of the PCT.

Whatever you decide/ whoever you choose to nominate, the PCT will need to assure itself that the submission is accurate and pertaining to the level of the PCT area, as we will use the submission for our assessment.

Data collection: All questions, guidance and pick-list options aim to allow for most arrangements used by PCTs, but we can not cover all possible variations. If a term requires further interpretation in order to answer a question, focus on what local arrangements or policies do (outcomes) and how these work for families with disabled children.

We are aware that for some or all services for disabled children, PCTs may commission support through joint arrangements with other partners/ one PCT may take the lead on behalf of others. Each PCT in this case is contributing their funding for their population and the support commissioned through these arrangements should be included, where the questions apply. We require a submission from each PCT and each PCT needs to assure itself that the data they submit is accurate for that PCT. We understand that for some PCTs, some of their data may be best possible estimates.

When services are available to the local population because they are commissioned or funded by other agencies, for example some short breaks, or some equipment for disabled children, but the PCT does not contribute to this directly, PCTs should not include this support. This assessment does not include support if the PCT is not directly involved/ contributes.

Q Our processes are based on people's needs, not the condition that might give rise to those needs, so we cannot separately identify children with disabilities. Why are we being asked to provide information specifically about disabled children?

We acknowledge that information systems do not usually allow you to separately identify children with disabilities. Therefore questions are often phrased to include all

people who have a specific type of need, including (but not exclusively) children with disabilities. Other questions ask specifically about processes for children with disabilities, where we think trusts could reasonably be expected to have these in place.

Q Is it mandatory for my organisation to complete the data collection form?

Participation in the review is mandatory under the Health and Social Care Act (2008) and therefore organisations asked to complete the data collection forms must do so. CQC is applying for ROCR (Review of Central Returns) approval for the data collection.

We recognise that participation in the review will involve a certain amount of extra work for PCTs and acute trusts. However, we hope and expect that the results will be useful in identifying improvements that can be made, to the eventual benefit of disabled children and their families.

One section of the data collection for acute services – about delayed discharge and transfer of care – is not mandatory. We will not use this data in our scored assessment. However, we would like services to provide this information. Stakeholders believe it is important and worthwhile, and we will use the information for national reporting.

Q What national data is being used, and how will organisations be able to agree this data?

To minimise the size of our request we are using as much existing national data as possible in this review. To save you time, we have already filled in some questions with data for your area.

For PCTs we will be pre-populating data collection forms with existing national data submitted as part of:

- Children's Services Mapping (CSM):

We understand that this data has been provided by your PCT as part of the most recent national CSM exercise. The questions we have selected for our assessment have exactly the same wording and definitions as used in that exercise. They refer to the data collection consensus of 30th November 2009.

Please check the data and make necessary changes, reflecting the same period up to November 30th 2009 for Questions A2 and A5a.1. The data period for questions A7a and A7b is from April 2008 – March 2009.

- National Transition Support Team (NTST) Self Assessment Questionnaires:

We understand this data has been returned by your local authority partners in the national NTST self assessment questionnaire for your area, submitted in December 2009. The questions we have selected for our assessment have exactly the same wording and definitions as used in that exercise. Please check the data and make

necessary changes reflecting the position for your PCT area as of December 2009. You may wish to confer with contacts in the Local Authority Children's Services which relate to your PCT area.

These questions are clearly marked on the data collection form, and links are provided to web-pages for the original collection processes.

For each pre-populated question, PCTs are asked to either:

- change their response for the purposes of this assessment
- provide a response where no existing data was available, or
- leave the pre-populated data unchanged as their agreed response for the purposes of this assessment.

The questions will form part of the scored assessment for PCTs and therefore are mandatory. If answers to these questions are left blank they will generally be treated as if the lowest scoring relevant value had been given.

For acute trusts there is no existing national data used to inform this review.

(See also the Q, "What if I am unable to answer a mandatory question?")

For PCTs: Provider information and involvement

Q What is meant by 'provider' for the purposes of this assessment?

Using ventilators as an example; for the purposes of this assessment the provider is the service that monitors children in the community who are ventilated, as opposed to the company that supplies the ventilators.

Q We have many services supporting disabled children in our area. Why do the questions focus on some and not others?

We know that the configuration of local support may be complex and that many different arrangements are in place. It is acknowledged that other agencies also commission important support for disabled children & young people and their families.

This review aims to understand the contribution and quality of health support for disabled children & young people and their families commissioned by PCTs, across their geographical area. This is important. There is little robust evidence but it may be that families in some areas may receive better support than others.

For some questions on the PCT data collection form, we ask for information about the providers of key services. We know that these are not the only health services which support disabled children, but have been careful to minimise our request to PCTs and

also make the review process manageable. We have selected these services on the basis of consultation with a range of stakeholders, to ensure our framework for this review is well-rounded and addresses issues that really matter to families.

Q We commission a particular service from more than one provider. How can we reflect this in the data collection?

PCTs may include up to 5 providers for each of the service areas we ask questions about, making sure they have included at least 80% of the total provision for each relevant service they commission. We understand that some of this data is likely to be an estimate.

PCTs will need to decide how to provide this information as accurately as possible for your PCT area. You may base your estimates on the relative size of your population each provider supports, the proportion of the budget they receive from you for this service, or other local variables best known to yourselves.

Q How will providers be involved?

We will request that PCTs give us the name and email address of an individual within each of these organisations to be a contact point for CQC communication with regard to this review. This information needs to be provided via the webform by **24th January 2011**.

We will advise provider contacts that, should they provide regulated activity and be registered with CQC in accordance with the Health and Social Care Act 2008, we may use data obtained through this review to inform our regulatory systems for registration and ongoing compliance with essential standards of quality and safety.

Q How do we enter this information in Section 10?

Section 10 asks questions about a number of different services/pieces of equipment. Therefore, you will be required to enter contact details at more than one point during that section of the form. If you do not yet have the data about particular services, but do have the contact details you should input any valid figure to progress through the form. However you must ensure that you submit the correct data for these questions before the final deadline of **14th February 2011**.

Q The PCT does not hold all of the information you request. Can we approach our providers for this information and, if we wish, give providers access to their data?

We anticipate that some PCTs may not have systems in place to provide all of the mandatory data we require. PCTs may wish to involve their providers of some key services in data collection and give them sight of relevant data prior to sign-off. If they

wish, PCTs may allow providers of key services direct access to the data collection form to provide their responses. However, PCTs must feel comfortable with this and will still hold responsibility for checking and submitting the completed PCT form. You will be able to download PDFs of each section of the form and circulate these to relevant providers.

Q Why are a small number of PCTs also required to complete the acute services data collection?

We are asking some important questions about NHS acute support for disabled children, young people and their families. These have been developed through consultation and piloting with a wide range of stakeholders. We have used HES and other data to select acute trusts to include in this review, based on their levels of activity with children and young people. Only very few have been excluded. This activity data identified some PCTs as providers of acute support too and these organisations are also required to participate, as applicable.

About the ‘lead contact’ role

Q What are the responsibilities of the organisation’s “lead contact”?

The lead contact will be CQC’s main point of contact at your organisation on all aspects of this review. It is their responsibility to ensure that all mandatory questions are answered and data submitted by the deadline. They will need to ensure that timely requests are made for information needed to complete the form, and that the information submitted by the organisation is comprehensive, fair, and accurate.

Q What sort of person should we consider appointing as “lead contact”?

It is likely that the lead contact will need to collect data to from different parts of their organisation and from partner organisations. Therefore, the lead contact needs to be someone who knows who to ask, and be of sufficient seniority to ensure that colleagues respond to such requests in a timely fashion. Trusts may want to consider assigning this role to either someone who leads in the organisation on children and young people, or someone from the performance management function.

Q Can someone else in our organisation access the data collection webform and help with the administration of filling it in?

Yes. When we ask you to nominate your lead contact, we will also ask you to nominate someone as “form compiler”. This person can fill in the data collection form but cannot submit it. You may nominate the same person as lead contact and form compiler if you wish.

Q Can we change our lead contact (or form compiler)?

Yes, we expect some organisations will need to do this due to changing job roles etc. While the nomination period is still open these can be resubmitted by the online nomination form. Alternatively the current lead contact can send an email specifying the change to us at reviews.studies@cqc.org.uk with “disabled children re-nomination” in the subject line.

Overview of the data collection process

Q What is the background for this assessment?

Questions in this data collection are designed to be consistent with existing national guidance as far as possible. They draw on a number of priorities set out in Aiming High for Disabled Children: Better Support for Families (2007), the National Service Framework for children, young people and maternity services (2004), and other key policies and supporting resources. Other questions have been designed to look at outcomes for families and children, around which clear guidance does not exist. These have been formulated following consultation with a range of stakeholder groups. Our data collection forms, associated guidance and framework for this review should NOT be interpreted as giving new national guidance.

Q How many forms will there be?

There are two forms for the data collection, one for PCTs and one for selected acute trusts.

Draft versions of the forms are available on the review [webpage](#) in Excel format. These have been sent to ROCR for approval, and are thus subject to change. When the data collection period goes live, we will update the webpage with final versions in Excel format. However, your submission to CQC **must be made by entering data onto the webforms**, and we can not accept data sent to us on the Excel versions.

Q Our PCT has a joint management structure with a neighbouring PCT. Can we make a joint response?

No. You may nominate the same people as lead contact and form compiler for more than one PCT, but we need distinct data for each PCT. You will also need to make separate nominations for each PCT, even if the same people are being nominated.

Q Do I need to send CQC evidence to support the answers I put on the form?

Not generally, although we will carry out spot checks and in those cases we may ask to see supporting evidence. Organisations should retain supporting evidence for this.

Q What if I am unable to answer a mandatory question?

In the first instance check the guidance and FAQs to ensure that you are interpreting the question correctly. It is our aim that all questions, guidance, and pick list options allow for most arrangements used by PCTs, however it is likely that we have been unable to cover all possible variations. If a question requires further interpretation than in the guidance or FAQs, focus on what local arrangements or policies do (outcomes) and how these work for families with disabled children. We have consulted widely and only included questions where there is a consensus that comparative data will be valuable for a balanced assessment, for improvement or for informing people who use services. Mandatory questions which are not answered will generally result in the lowest score being assigned for that question. If you are still having difficulties answering a mandatory or concerns about interpretation please contact the team at reviews.studies@cqc.org.uk.

Most questions will form part of the scored assessment and hence are mandatory. If answers to these questions are left blank, or where the answer is 'Don't know/ after discussion with colleagues we cannot reach consensus' they will generally be treated as if the lowest scoring relevant value had been given.

Q What if I find I am unable to meet the closing date for data collection form submission?

It is very important that organisations meet the data collection deadline. Organisations cannot make changes to their data after the deadline because that would be unfair to those that met the deadline. Any incorrect or missing data that is included in scored assessment will be given the lowest score. Should exceptional circumstances (e.g. IT failures) prevent data being submitted please refer to CQC's "extenuating circumstances and extension to data submission" operational policy.

[Reviews and studies: policies relating to extenuating circumstances, extension to data submission deadlines, and ratification of data](#)

We may be able to grant extensions to the data collection where problems with the web-based data collection system have caused organisations particular problems. But it should be noted that any applications for an extension to the data collection period must be submitted on the relevant form before the deadline for the relevant collection.

After the form is completed and data submitted

Q How will responses of “don’t know” be assessed?

Such responses will generally be given the same score in the assessment as the least favourable response. The same applies for responses of “not available” or “not recorded”.

Q Will scored assessments and/or data be published?

Yes, the main output of this review will be local assessments of quality of the local health support provided to families with disabled children for each area in England, as defined by PCT boundaries. It will also produce some benchmarking information and a national report will be published that sets out recommendations for service providers, commissioners, other partners in local services and central Government.

Q What will happen if our area is assessed as performing poorly?

Organisations in areas that are assessed as performing poorly, either overall or in some aspects of services, will want to consider what action they can take (themselves or in partnership) to bring about improvement. CQC regional operations staff will commence work with organisations in selected areas that have been identified as poorly performing in the review to discuss their plans for improvement.

Q What will happen if our area is assessed as performing very well?

You should celebrate your success and try to maintain good practices whilst challenge yourselves to make services even better. We may contact areas which demonstrate examples of especially good care to discuss possible dissemination of good practice, including via our national report.

Q When will the report be published?

We hope to be able to publish local and national results in the winter of 2010/11.

If you have any further queries please contact email reviews.studies@cqc.org.uk.