

Special review

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Health care for disabled children and young people

A review of how the health care needs of disabled children and young people are met by the commissioners and providers of health care in England

March 2012

About the Care Quality Commission

The Care Quality Commission is the independent regulator of health care and adult social care services in England. We also protect the interests of people whose rights are restricted under the Mental Health Act.

Whether services are provided by the NHS, local authorities or by private or voluntary organisations, we focus on:

- Identifying risks to the quality and safety of people’s care.
- Acting swiftly to eliminate poor-quality care.
- Making sure care is centred on people’s needs and protects their rights.

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Introduction

The findings presented in this report were gathered in 2011 as part of the previous approach that CQC undertook for 'special reviews'.

This review looks at what organisations told us they were doing to support the health care needs of disabled children and young people (aged 0-18 years), and their families and carers. We also asked for the views of people who use these services to find out what their experience actually was. The aims of the review were to:

- Produce an overview of services for families in England, as reported by primary care trusts (PCTs) and acute hospitals.
- Provide information for a variety of organisations to influence and plan the future provision of services for disabled children and young people and their families and carers.
- Provide local, accessible, information for families and others when they deal with care providers and those that commission care (PCTs, General Practitioner consortia and clusters).

The review began in 2009, and focuses on a wide variety of information collected from disabled children and young people, parents, carers and groups who represent the interests of those who use services. It also draws on information collected from PCTs and hospitals for all or part of the period between 30 September 2009 and 30 September 2010, and national data already collected by other means. This report is broadly divided into:

- Comments and stories provided by those that have contact with services for disabled children and young people and their families and carers.
- Information about how PCTs, through providers of services and acute trusts, view the provision of services.

This report provides a unique data set that will be of use to those who influence, plan, provide and use services. However, the data highlights some inconsistencies, depending on its source. While on the whole, PCTs report high levels of access and user-centred care, those who use the services report a variable level of satisfaction.

Since 2010, the Department of Health has agreed that CQC should not carry out periodic reviews of primary care trusts or local authority adult social care departments. This change has had a significant impact on the way the data has been collected, analysed and reported, given that we are no longer assessing and reporting on the commissioning behaviours of the PCT.

The PCTs are still the legal entities responsible for commissioning. Although there have been some structural changes to their configuration, the findings of this report will be of interest to the PCT clusters and the community health service providers that have replaced the individual PCTs that were analysed in this review.

In trying to find out how well the services commissioned are set up to suit the needs of disabled young people and their families, we found that there was mixed provision across PCTs. Work is required across the range of services for disabled children and young people, covering the standard of, access to, co-ordination of and continuity of care. We therefore strongly recommend that commissioners use this report to take the

lead in establishing a real, local understanding of the needs of children with disabilities and their families, and respond by ensuring the most suitable provisions are in place.

The development and delivery of the review would not have been possible without the support and advice of a wide range of groups. CQC wishes to acknowledge this support and thank them.

Background

We consulted with our key stakeholders on undertaking this topic as part of our programme of 'special reviews and studies' for 2009/10 – Assessing and rating health and adult social care organisations (2009). The proposal by CQC for this review was based on the understanding that families with disabled children and young people need support to help manage their specialised health and other needs appropriately and should not experience any barriers to accessing that care. The review was informed by a number of reports and policy documents – particularly *Aiming high for disabled children: better support for families* (HM Treasury and Department for Education and Skills, 2007). It also reflects the recent green paper *Support and aspiration: A new approach to special educational needs and disability* (Department of Education, March 2011).

Aiming high clearly set out what good services for children and young people with a disability and their families should look like, including:

- Improved provision of information and greater transparency in decision making.
- Putting families in control of the design and delivery of their care package and services.
- Supporting disabled children and young people and their families and carers to shape services.
- Ensuring that services are responsive and provide timely support.
- Ensuring early intervention through good prioritisation of needs.
- Provision of good joined-up care across services.
- Provision of high-quality vital services for disabled children and young people – e.g. short breaks, wheel chairs and equipment.
- Ensuring that children, families and carers have a consistent experience, independent of the service they are using.

Aiming high also highlighted the 'next steps' required to improve services. These included:

- Improving the quality of data that is collected – e.g. all PCTs responding to all questions about the disabled children in their area, to be used by those who commission and provide services for disabled children and their families.
- Focusing more on earlier intervention.
- Improving multi-agency working.
- Developing local engagement through parents' forums.
- Engaging parents and children in the design of local services by local authorities, PCTs and schools.
- Developing good practice guidance for early intervention.

- Developing local transition support programmes.
- Improving the delivery of short breaks for families.
- Improving the provision of wheelchairs and other equipment.
- Developing the core competencies of staff in services for disabled children and their families, as well as better specialist services through mapping the needs for speech and language therapists etc.

Aiming high also had associated with it substantial funding to be used to improve the services required by disabled children and their families. This included £340 million investment (including £30 million for children's palliative care) over the three years from 2008/09 to 2010/11 to:

- Empower disabled children and their families through giving them a clear and transparent 'core offer'ⁱ, by piloting individual budgets and assigning £5 million to support best practice on engagement, such as parent forums.
- Encourage more responsive services, with disabled children prioritised at both a local and national level, and develop a national indicator on disabled children.
- Provide better coordinated support when disabled children and their families need it, with £19 million for a transition support programme.
- Improve key services with a grant of £280 million over the competitive spending review to boost the provision of short breaks, and a childcare accessibility project underpinned by £35 million of additional resource.

Aiming high, alongside the feedback we received from stakeholders, therefore provides a clear framework for what we should look for in organisations that commission and provide care for disabled children and young people.

Presentation of the results

The findings of this review are presented in this report in the following way:

Section one – describes the methodology and reports on what PCTs told us.

Section two – presents information collected from those that use and interact with services.

Appendix A – gives a full analysis of what people said about the services they use.

Appendix B – acute trusts describe how they would respond to three case studies.

ⁱ The core offer is made by the local authority and defines the types of interventions and activities that local disabled children can expect to receive.

1. Results from primary care trusts

Methodology

This review used a variety of methods to collect the views of those that use services and the quality of the services provided. These included:

- A series of interviews, group sessions and questionnaires with ‘SpeakOut’ groupsⁱⁱ.
- Meetings with a range of stakeholders to establish what we should ask commissioners and providers of services for disabled children and young people. We also worked with focus groups to explore issues raised by the analysis of the data.
- A questionnaire to PCTs about the provision of services to disabled children and young people in their area.
- A questionnaire to acute trusts which drew on a number of case studies of the care received by children and young people.

The questionnaire to PCTs focused on a range of topics, such as joint working and access to services, to reflect the *Aiming high* review and the views of stakeholders. The questionnaire to acute trusts also reflected *Aiming high*, with topics including delayed discharge, but we also asked for their response regarding the provision of care for three hypothetical case studies (see Appendix B).

All PCTs in England (151) and 158 acute trusts returned questionnaires to us during January and February 2011. In addition, five PCTs completed the acute questionnaire as they also provided services to children and young people in addition to commissioning services from providers. PCTs and acute trusts then ratified their data in May and June 2011. Most of the data collected was self-reported.

While we have provided an analysis of the key themes and findings for this report, there is other data from this review that we have not included, but are making available on our website as part of open access to information requirements. This can be found at the review’s webpage: www.cqc.org.uk/public/reports-surveys-and-reviews/reviews-and-studies/support-families-disabled-children

Results: Planning of services

There are 770,000 disabled children under the age of 16 in the UK which equates to 1 child in 20.ⁱⁱⁱ We asked PCTs how many disabled children and young people were in their area, based upon their most recent Joint Strategic Needs Assessment or Annual Public Health report. We were guided on the definition of what constituted a disabled child or young person from two sources – the Disability Discrimination Act (DDA) (1995) and the National Service Framework for Children, Young People and Maternity

ii SpeakOut is a network of community groups supported by CQC and the University of Central Lancashire.

iii Contact a Family – www.cafamily.org.uk/professionals/research/statistics.html

Standards standard 8 for disabled children, young people and those with complex health needs.

Most PCTs told us that they do estimate the number of disabled children and young people in their catchment area, with an average number per PCT of around 5,000 children and young people. Excluding the five PCTs that told us they had no disabled children or young people, the range of population was between 200 and 36,173.

We asked PCTs a range of questions about the services provided for disabled children and young people in their area. The rest of this section is dedicated to highlighting our key findings.

Health action plans

We asked PCTs to comment on the provision of health action plans (HAP), which describe what young people should expect from their care as well as advise them on how to stay healthy.

PCTs were asked to indicate what percentage of disabled young people have a HAP (figure 1), and whether they were developed with young people (table 1).

Figure 1: What percentage of disabled children have a HAP in place in each PCT?

Number of PCTs

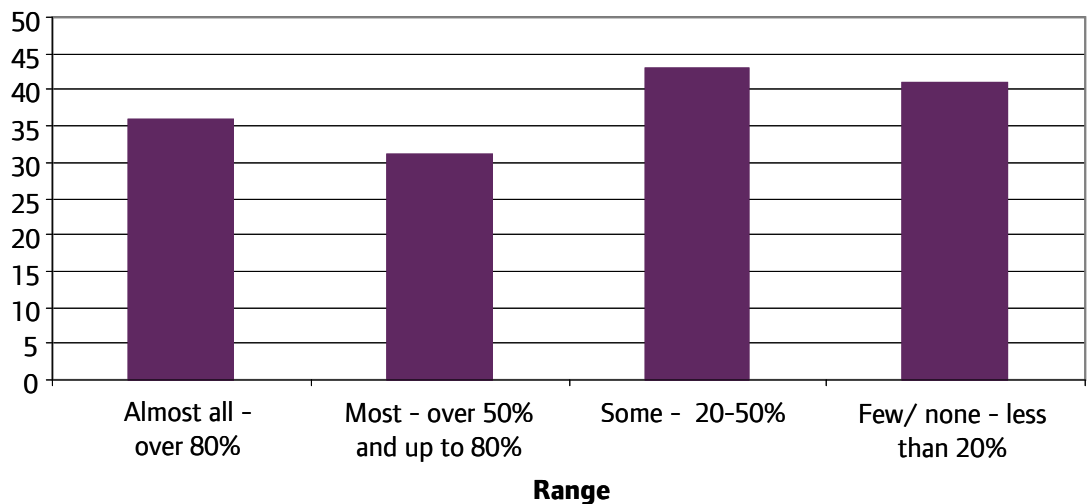


Table 1:

Is the HAP developed with young people?	Number of PCTs
Yes	127
No	24

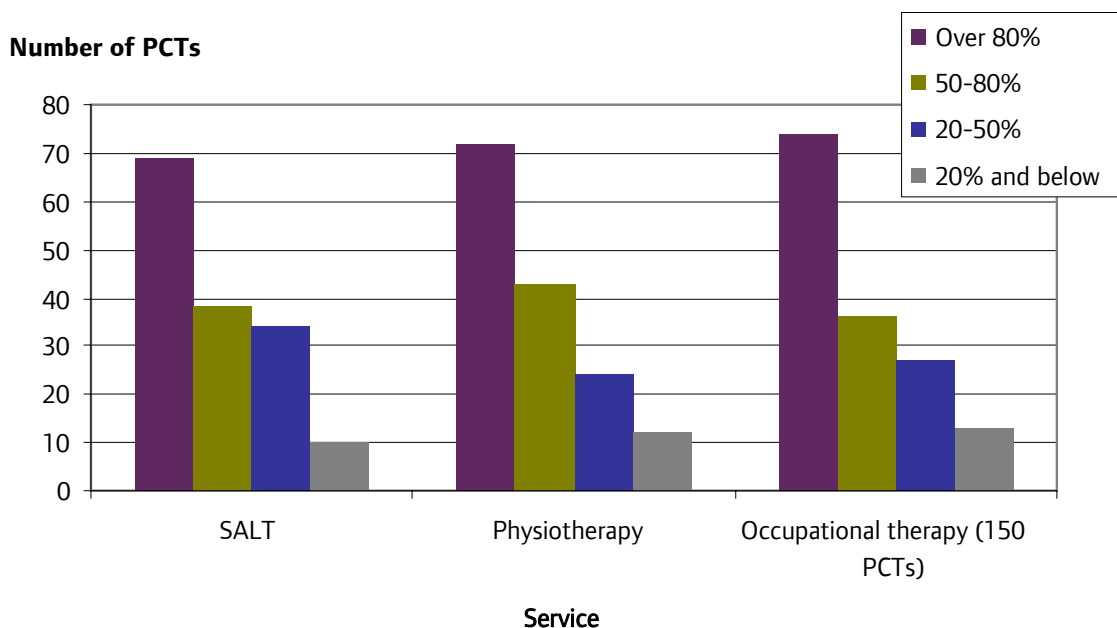
Therefore, while the majority of PCTs indicated that HAPs are developed with disabled people and young people, there is wide variation in the proportion of disabled children and young people that have HAPs in place.

Specialist support

Specialist services should be well coordinated with other services to provide the best experience for people interacting with services and enhance capacity. We asked PCTs whether their speech and language therapy (SALT), occupational therapy and physiotherapy services were coordinated with other services. One PCT declared that they did not directly commission specialist occupational therapy services; therefore the total of number of PCTs recorded in this data set is 150.

The definition of community nursing was left to local interpretation by the PCT. The majority of PCTs told us that all three services were coordinated for disabled children and young people in over 80% cases. However, a substantial number said that in 50% or under of services there was no coordination (figure 2).

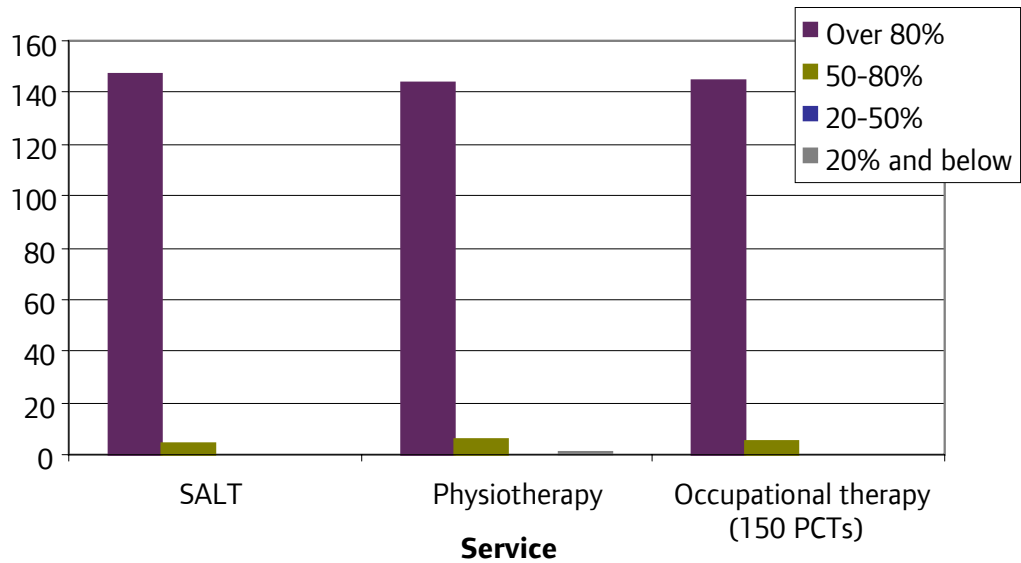
Figure 2: Numbers of PCTs that make coordinated appointments for children and young people. PCT responses have been separated out into percentages of appointments which are coordinated.



PCTs were also asked whether the findings of speech and language therapy (SALT), physiotherapy and occupational therapy assessments were shared with families (in the case of their primary provider):

Figure 3: Numbers of PCTs that share proportions of specialist assessment findings with families

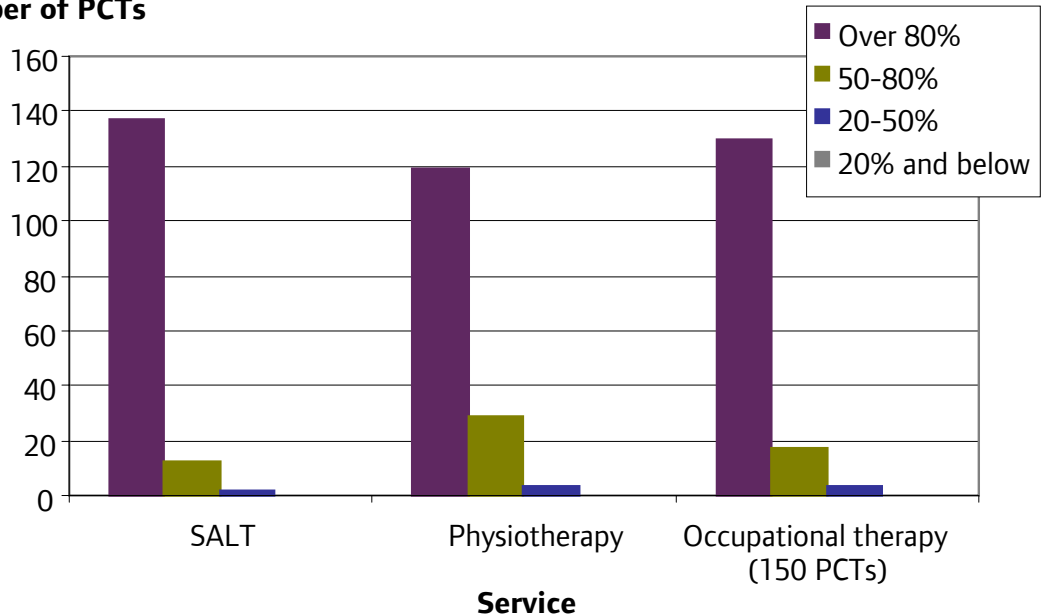
Number of PCTs



Figures 3 and 4 show that most PCTs told us that they share findings with families and other services that children and young people use in over 80% of cases. It should be noted that services share a higher proportion with families than they do with other services the disabled child or young person is in contact with.

Figure 4: Numbers of PCTs that share proportions of assessment findings with other services^{iv} the child is in contact with

Number of PCTs



^{iv} 'Other services' include health services, multi-agency support teams and education staff.

The Common Assessment Framework

The Common Assessment Framework (CAF) is designed to be used by different disciplines to plan an individual's needs and to make sure they don't have to answer the same question many times. It relies on one professional trusting another – say a social worker trusting a nurse – to get the assessment right. The main benefit is to avoid duplication and to have a single record, so that all professionals have the same information and can identify problems that the first professional can't. It therefore supports consistency and good decision making.

We asked PCTs a range of questions about the CAF, two of which are shown below, showing that while the majority of PCTs said that staff were trained in the use of the CAF, follow up on its use was not as consistent (figures 5 and 6).

Figure 5: Number of PCTs that check that the CAF is being used for initial assessment of disabled children

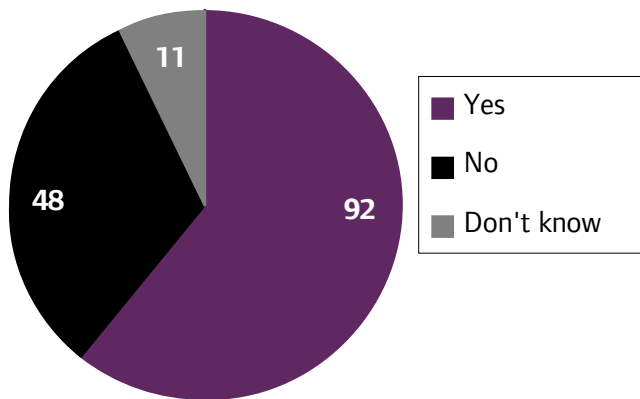
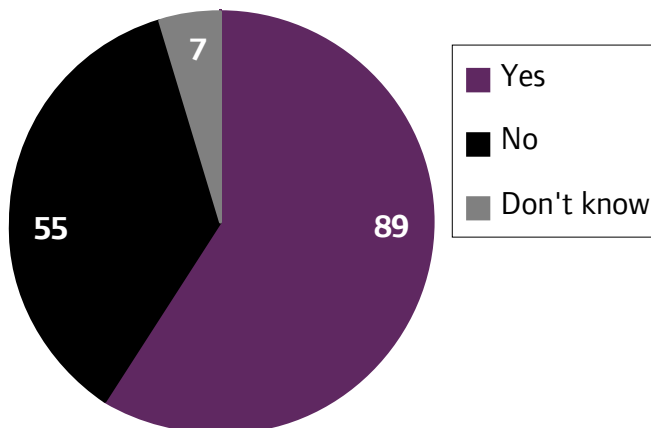


Figure 6: Number of PCTs that monitor needs and actions identified in CAFs and follow them through in care planning



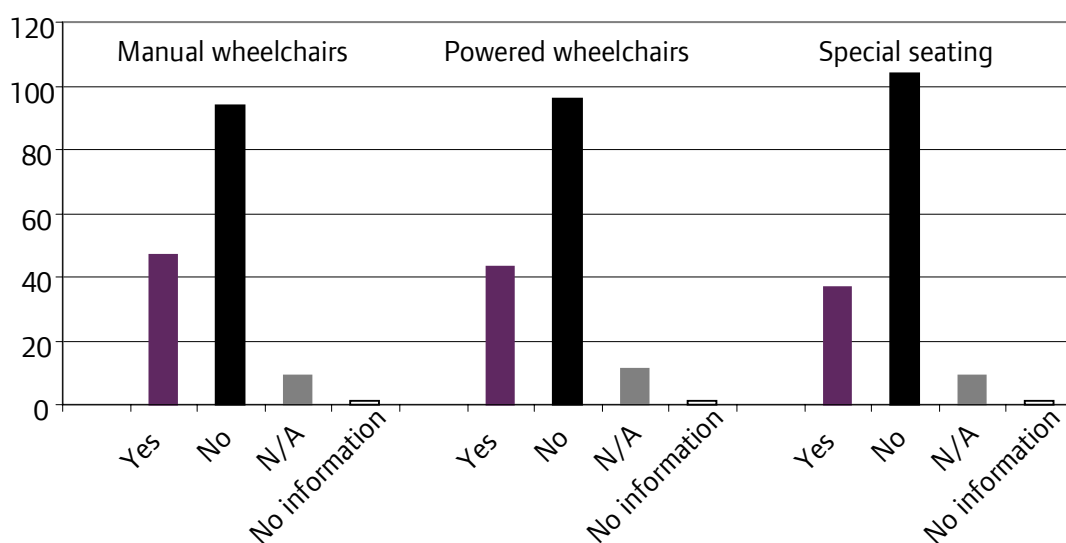
Eligibility criteria for wheelchairs and other equipment

Eligibility criteria are important as they provide a framework to enable PCTs to stratify need for support in a way that is fair, proportionate and transparent.

We asked PCTs whether eligibility criteria for wheelchairs, community aids and community equipment specify an upper and lower age limit. Figure 7 shows the situation for manual and powered wheelchairs, and special seating.

Figure 7: Are upper and lower age limits set for eligibility criteria for manual and powered wheelchairs and special seating?

Number of PCTs



The range of lower age limits was 0-5 years and the upper limit ranged from 17 to 19 years. The majority of PCTs said that there is no upper or lower age limit for any of the four types of specialised aids, however around a third of PCTs indicated that they do have criteria.

Children with complex needs

To establish whether PCTs ensure that the care for children with complex needs is joined up, we asked a number of questions (table 2).

Table 2:

Are there arrangements in place through which community providers share information with acute services to support planned admissions?	Number of PCTs
Yes	145
No	4
Don't know	1
No information	1
Are there arrangements in place through which community services share information with acute providers in an emergency about individual children/young people's needs and care plans?	Number of PCTs
Yes	137
No	6
Don't know	7
No information	1
Are there arrangements in place through which community-based staff are involved in planning discharge from acute care?	Number of PCTs
Yes	147
No	2
Don't know	1
No information	1

As can be seen from the table above, the vast majority of PCTs indicated that information is shared in both routine and emergency situations.

Results: Delivery of services

We also asked PCTs to give us information about the top five providers they commission for each of the following services:

- Specialist or targeted community nursing support.
- Continuing care.
- Community speech and language therapy for disabled children and young people.
- Community physiotherapy for disabled children and young people.
- Community occupational therapy for disabled children and young people.
- Short breaks for disabled children and young people.
- Wheelchairs, aids and equipment for disabled children and young people.

The information shown in this section of the report is generally for the top two providers used by PCTs.

Specialist or targeted community nursing support

The largest number of PCTs used community nursing services from only one or two providers, for which they had a named contact.

PCTs told us about the accessibility of advice and support from community nursing services in non-emergency situations, which was mainly in office hours (figure 8), and the availability of visits by community nurses (figure 9).

Figure 8: What access is provided for community nursing services for advice and support in non-emergency situations?

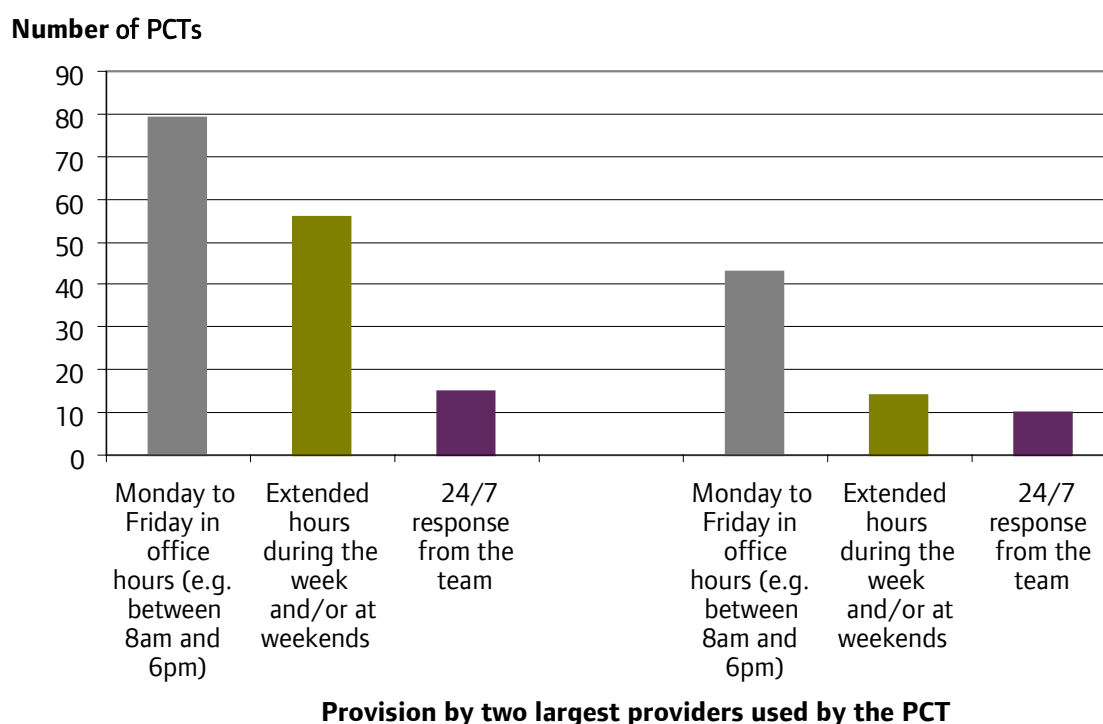
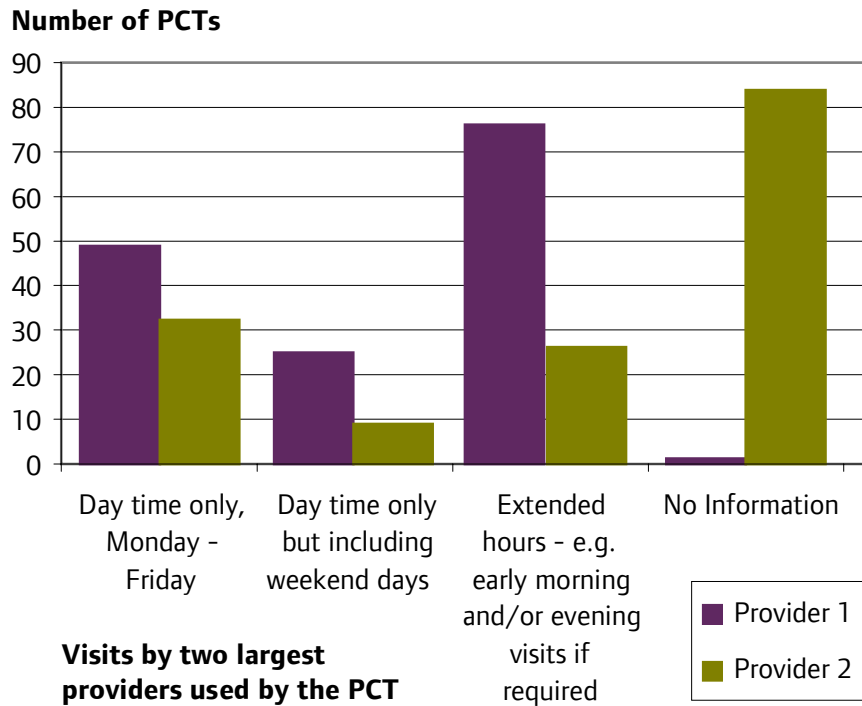


Figure 9: What times are offered for community nurses to make visits to suit the needs of disabled young people and their families?



We also asked PCTs whether the providers they commissioned community nursing from could support the needs of children and young people with autism and autistic spectrum disorder (figure 10 and table 3).

Figure 10: Do your community nursing providers support the needs of children with autism and autistic spectrum disorder?

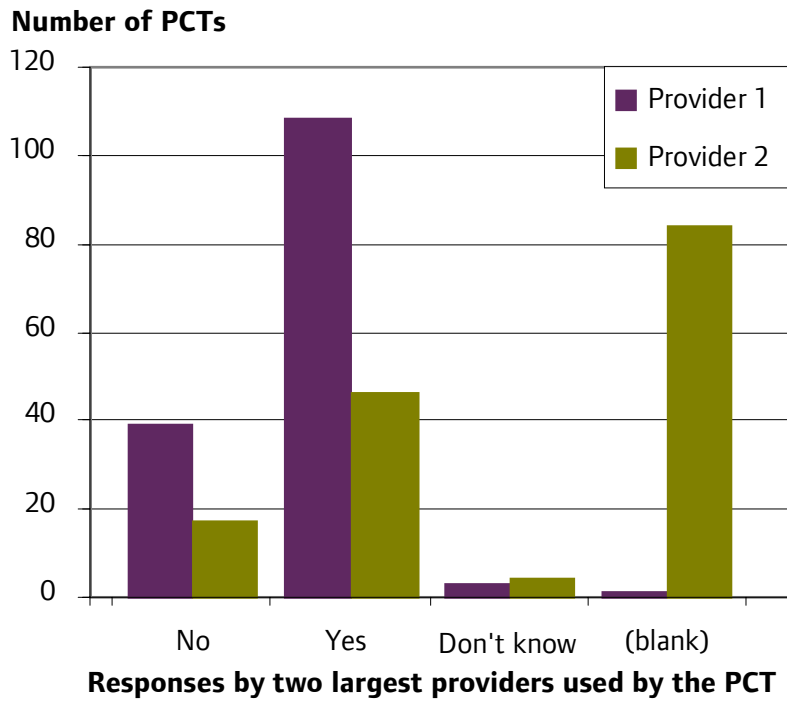


Table 3: Numbers of PCTs that commission community nursing to support the needs of children and young people with autism and autistic spectrum disorder

For all disabled children and young people needing community nursing, do you support:	Provider 1	Provider 2
Those with behavioural needs^v?		
No	41	17
Yes	106	47
Don't know	3	3
No information	1	84
Those who are technology dependent?		
No	5	11
Yes	144	55
Don't know	1	1
No information	1	84
Those who are in transition into adult support?		
No	2	2
Yes	148	64
Don't know	0	1
No information	1	84

Continuing care

We asked PCTs a number of questions about how involved disabled children and young people were in the recruitment and assessment of staff who deliver their care packages (table 4).

^v Additional support needs of a social, emotional and/or behavioural nature

Table 4:

Do you involve disabled children and young people and their families in interviews or assessment processes of people delivering their care packages?	Provider 1	Provider 2
No	87	38
Yes	47	25
Don't know	7	9
No response	10	79

This shows that 87 PCTs (nearly 60%) indicated that their primary provider does not involve disabled children or young people in interviews or assessments of those that deliver care packages. However, table 5 demonstrates that there was more involvement in induction and training of staff.

Table 5:

Do you involve disabled children and young people and their families in induction and/or training of people delivering their care package?	Provider 1	Provider 2
No	35	18
Yes	93	43
Don't know	13	11
No response	10	79

A higher number of PCTs answered 'yes' to involving disabled children and young people and their families in performance evaluation, but with consistently high numbers of PCTs saying that there was no involvement (table 6).

Table 6:

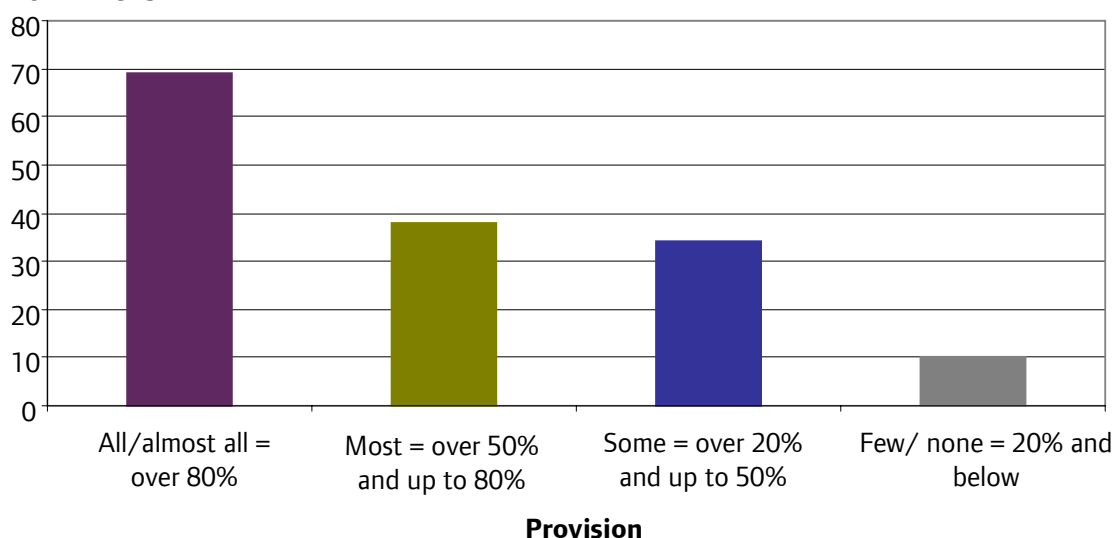
Do you involve disabled children and young people and their families in performance evaluation and review of people that deliver their care packages?	Provider 1	Provider 2
No	49	21
Yes	86	39
Don't know	6	12
No response	10	79

Community speech and language therapy for disabled children and young people

The majority (84%) of PCTs told us that they commissioned community speech and language therapy (SALT) services from one provider (the 'primary provider'). We asked PCTs a range of questions about the provision of SALT services. As reported in the previous section, PCTs were asked how well SALT appointments are coordinated with other services (figure 11).

Figure 11: Are SALT appointments coordinated with other support that families may be receiving (primary provider)

Number of PCTs



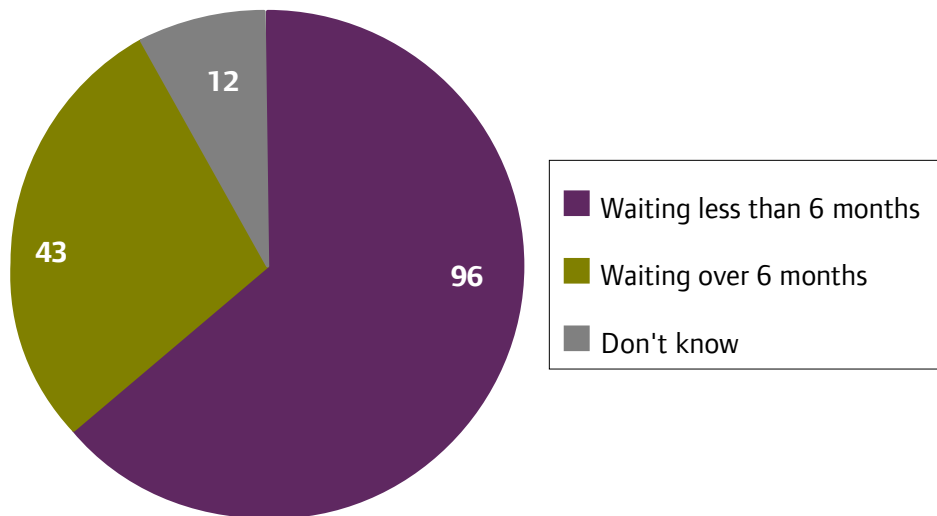
The majority of PCTs (97.4%) also indicated that they always or almost always (over 80% of cases) shared SALT assessments with families.

All PCTs said that their providers were able to provide SALT services to disabled children and young people with autism and autistic spectrum disorder.

We also asked PCTs about the numbers of children and young people referred to SALT services (for their most significant provider) and the time it took to get a referral.

- PCTs said that the average wait for a referral (between 1 April and 30 September 2010) to see a SALT specialist was 12.7 weeks (range 0-311 weeks).
- Ninety-six PCTs said that they had nobody waiting more than 6 months, while 12 PCTs (8%) said that they didn't know (figure 12).
- Of those children referred from 1 April and still waiting to start treatment on 30 September 2010, on average, 21 children and young people had been waiting 6 months for a referral to see a SALT specialist.

Figure 12: Waiting times for SALT referrals for disabled children and young people (by number of PCTs)



We also asked PCTs how many complaints regarding SALT services they had received about the primary provider between 1 April 2010 and 30 September 2010. The average number of complaints per PCT was 2 (range was 0-7).

Community physiotherapy for disabled children and young people

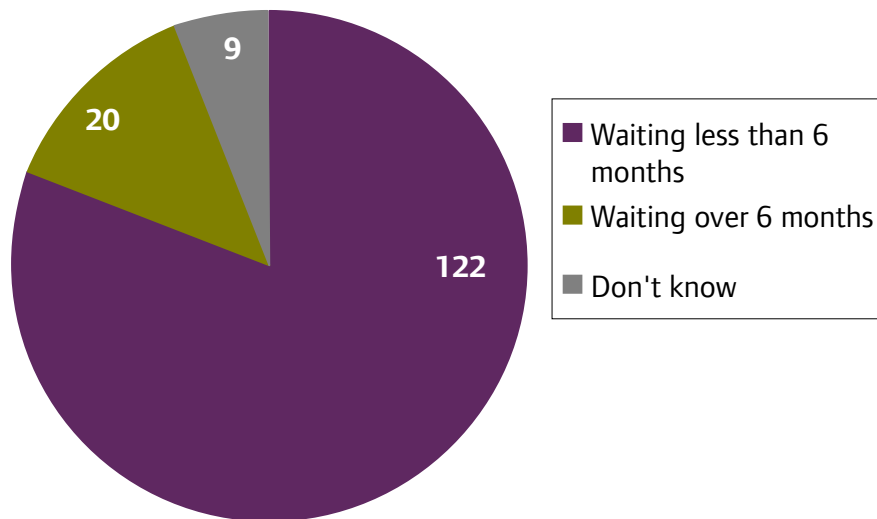
The information below is for the primary provider of the community physiotherapy services, since the majority of PCTs (77.5%) use only one provider. When asked whether PCTs ensured appointments were joined up and findings shared with families, 48% of PCTs said that appointments for children and young people are coordinated with other support families may be receiving in all or almost all cases (80 – 100%).

For specific needs, 77% of PCTs told us that their primary provider of community physiotherapy had the skills to support children with autism and autistic spectrum disorder.

We also asked PCTs about the numbers of children and young people referred to community physiotherapy services (for their most significant provider) and the time it took to get a referral.

- PCTs said that the average wait for a referral (between 1 April 2010 and 30 September 2010) to see a community physiotherapist was 6.9 weeks (range 1.2 – 23 weeks).
- Eleven PCTs said that they did not know what the length of waiting times was.
- Of those children referred from 1 April and still waiting to start treatment on 30 September 2010, on average, 21 children and young people had been waiting for a referral to see a community physiotherapist.
- 122 PCTs said that they had nobody waiting more than 6 months while 9 PCTs didn't know (figure 13).

Figure 13: Waiting times for community physiotherapy referrals for disabled children and young people (by number of PCTs)



In addition, we asked PCTs how many complaints about community physiotherapy services they had received about the primary provider between 1 April 2010 and 30 September 2010. The average number of complaints per PCT was 1 (range 0 - 3).

Community occupational therapy for disabled children and young people

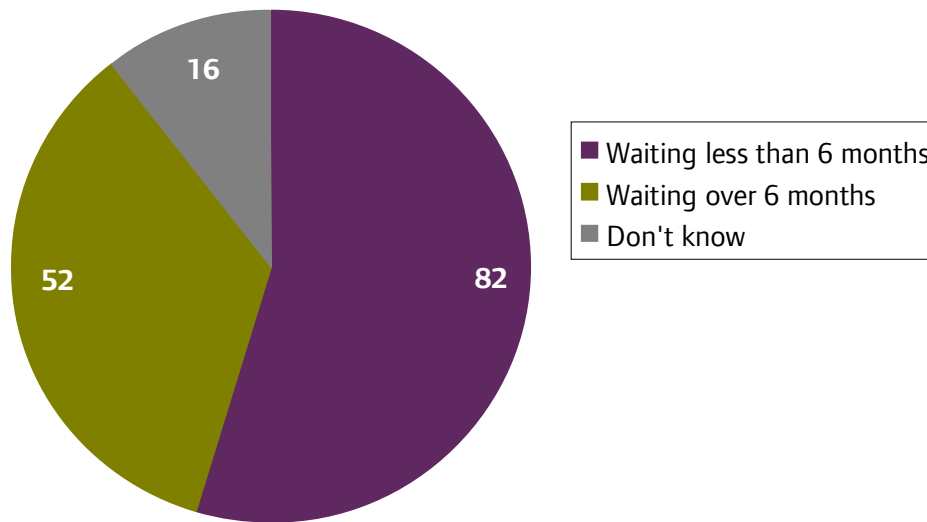
The information below about community occupational therapy services is for the primary provider, as the majority of PCTs use only one provider. When we asked whether PCTs ensured appointments were joined up and findings shared with families, 49% of PCTs said that appointments for children and young people are coordinated with other support families may be receiving in all or almost all cases (80 - 100%).

For specific needs, 92% of PCTs said that their primary provider of community occupational therapy had the skills to support children with autism and autistic spectrum disorder.

PCTs told us about the numbers of children and young people referred to community occupational therapy services and the time it took to get a referral.

- PCTs said that the average wait for a referral (between 1 April 2010 and 30 September 2010) to see a community occupational therapist was 14.6 weeks (range 1.6 - 94 weeks).
- Of those children referred from 1 April and still waiting to start treatment on 30 September 2010, on average, 28 children and young people had been waiting six months for a referral to see a SALT specialist.
- 82 PCTs said that they had nobody waiting more than six months while 16 PCTs said that they didn't know (figure 14).

Figure 14: Waiting times for community occupational therapy referrals for disabled children and young people (by number of PCTs)

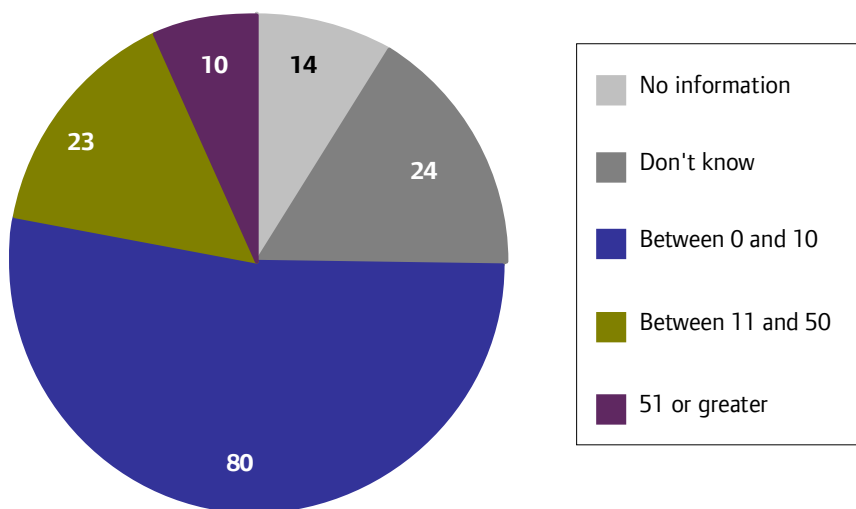


In addition, we asked PCTs about how many complaints about community occupational therapy services they had received about the primary provider between 1 April 2010 and 30 September 2010. The average number of complaints per PCT was 2 (range 1–9). Eight PCTs did not know how many complaints had been made.

Short breaks for disabled children and young people

We also asked PCTs to provide us with information about their most significant provider of short breaks (15 PCTs [10%] said they do not provide this service). This included the numbers of children and young people referred for a short break – 24 PCTs said that they did not know (figure 15).

Figure 15: Number of children and young people referred for a short break between 1 April and 30 September 2010 (by number of PCTs)



Of those children or young people referred for a short break, on average, one short break per PCT was provided for the same period (range 0-18). Twenty PCTs said that they did not know.

We also asked PCTs how many complaints and appeals about short breaks they had received about their most significant provider between 1 April 2010 and 30 September 2010. Eleven PCTs indicated that they had received a complaint (range 0-5).

Wheelchairs, aids and equipment for disabled children and young people

PCTs provided information about the volume and types of equipment supplied to children and young people by their primary provider. The total number of referrals for equipment for children and young people between 1 April 2010 and 30 September 2010 for lightweight manual wheelchairs and powered wheelchairs for PCTs who commissioned these services is shown in figures 16 and 17 (approximately 44% of PCTs said that they did not know and approximately 16% indicated that no referrals had been made).

Figure 16: Referrals for manual wheelchairs between 1 April and 30 September 2010 (by number of PCTs)

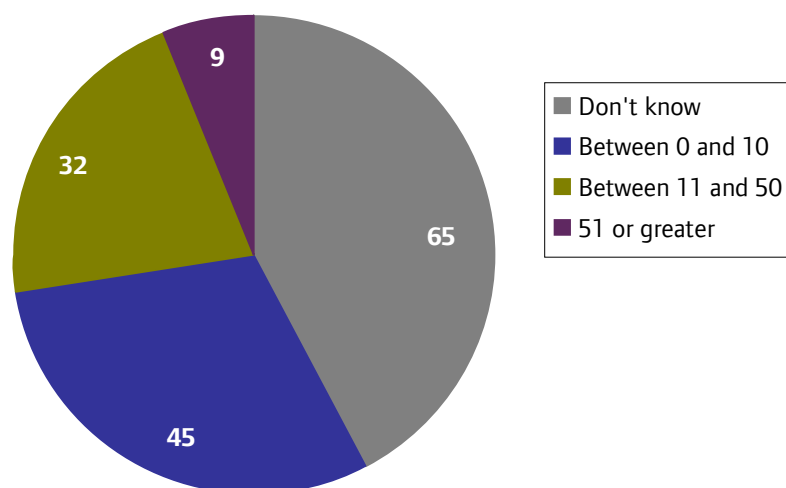
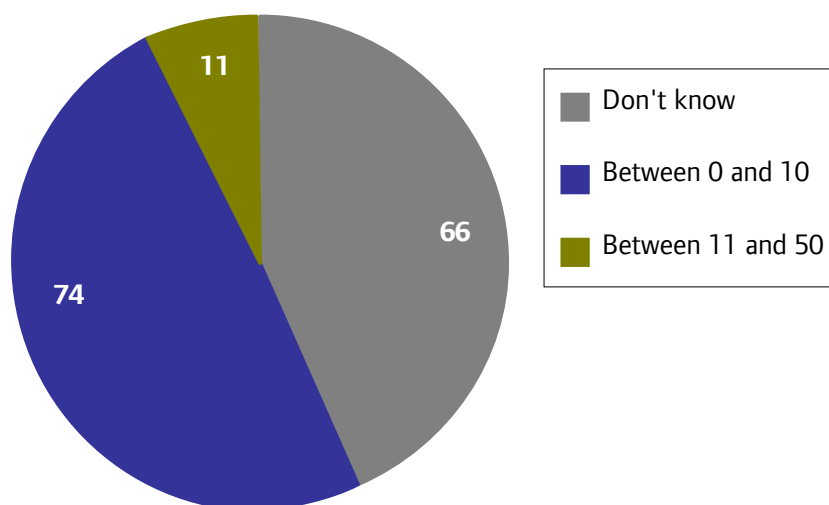


Figure 17: Referrals for powered wheelchairs between 1 April and 30 September 2010 (by number of PCTs)



PCTs also told us how many weeks children and young people wait, on average, between receipt of referral to the service and receipt of their wheelchair or special seating?

The national averages for waits for manual and powered wheelchairs were 9 and 12 weeks respectively (between 1 April 2010 and 30 September 2010). Some PCTs indicated that there were no referrals, while about 40% of PCTs indicated that they did not know (figures 18 and 19).

Figure 18: Number of weeks children and young people wait for a manual wheelchair between 1 April and 30 September 2010 (by number of PCTs)

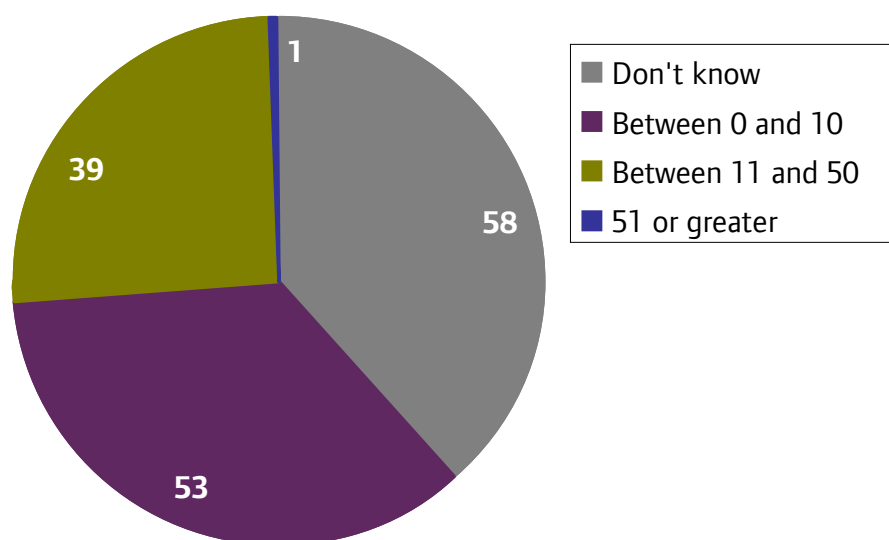
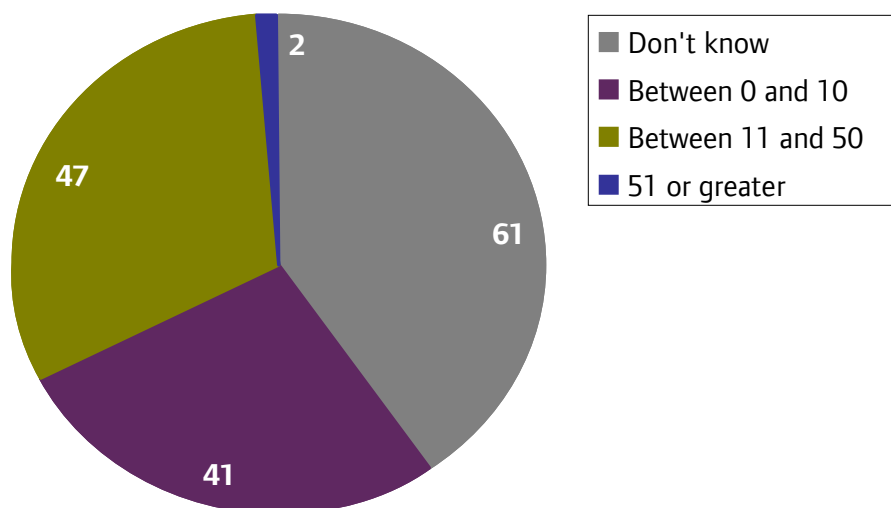


Figure 19: Number of weeks children and young people wait for a powered wheelchair between 1 April and 30 September 2010 (by number of PCTs)



2. People's experiences of the services they received

One of the ways we gather information from members of the public and people who use services is by working with 'SpeakOut', which is a network of community groups supported by CQC and the University of Central Lancashire. It enables groups who are often not heard to have a stronger voice about the health and social care matters which affect their communities. Groups are invited to tell us about their communities' experiences in a number of ways including:

- Involvement in a special review, which could be holding interviews with individuals.
- By facilitating a focus group in a community setting.

The network has over 80 groups who want to get involved with the work of CQC, and a smaller number who want to be kept informed, and get more involved when they feel ready.

In preparation for this review, we collected the views of disabled children and young people and families and carers (about 82 individuals) from the SpeakOut groups for two key reasons:

- To find out what they had experienced.
- To help develop key themes that could be used to guide any data collected from PCTs and acute trusts.

All the information collected was analysed by allocating comments to themes and topics. The key topics are described below, with examples of what individuals and families said about the services they receive, either as direct quotes or summaries of discussions. More detail is given in Appendix A.

Diagnosis

The comments we received about diagnosis generally related to the length of time it took to get a diagnosis and getting a diagnosis so that children could receive the right care. Parents' experiences of the time taken to get a diagnosis, and the ways they received the diagnosis varied, with the following comments illustrating their general experiences:

- **"First of all they wouldn't give us a diagnosis – It took 4 years constantly struggling to get one – then they discharged my son. Once they discharged him we couldn't get back in and couldn't access services – it's just ludicrous – we are not getting any support from anyone."**
- **All of the families had had a diagnosis for their child's disability. The time taken for families to get a diagnosis had ranged from 3 months to up to 15 years. On average, families had to wait up to 5 years to get a diagnosis. One family had to wait until the child was 15 – he was diagnosed as having severe learning difficulties. Many of the children had been diagnosed after they had started school and the school picked them up as slow. They were then treated through the special educational needs procedure. The more severe children were identified earlier but not given a diagnosis of autism until much**

later. Participants felt that the numbers involved and lack of expertise or specialists in autism was one of the reasons for a lengthy wait for diagnosis.

Involvement

We asked people whether they had been consulted on the provision of care or the planning of services. The majority said that they had not been involved:

- **“I would like to get involved to make things better.”**
- **None of the participants had been consulted or asked for their opinion by services. There was frustration in the group about not being listened to. They felt they were being ignored and left to their own devices.**
- **“We are the parents – we care for our children – they should be talking to us and finding out from our experiences.”**

Joined-up services

We asked whether families got access to the services they needed and if services communicated with each other. They reported variable experiences, with some reporting that they have had to ‘fight’ to get access to services:

- **“If your child is out of the social care network, then you can’t get any services – you just keep going round and round – you fight to get an assessment – once you’ve got that – you fight to get a diagnosis. Once you’ve got that you fight to get support and then you hit a brick wall.”**

Others thought that local services were not joined up:

- **The group agreed that different services were not working well together and were very dissatisfied with the level of support offered by local services.**
- **Do the different services work together to provide support? (e.g. hospital and community services): “We have found them to be very disjointed with often the left hand not even knowing what the left hand is doing! This only works to increase the burden on parents. My son was promised provision that never came; then staff were off sick; the litany goes on for ever.”**

Lack of information about how services interact, or how services differ from each other in what they provide was also highlighted as an issue by some participants:

- **Most of the participants could not distinguish between the different health services and classed them all as ‘NHS’.**

Communication

People also commented on their experiences of dealing with clinicians and managers – either in trying to get help or their experiences of the help that they received. Generally, they told us about negative experiences of dealing with clinicians and managers:

- **‘It’s like you don’t have a voice. They are the professionals, they want to provide what they think you will need; for example they offered a dressing helper which we didn’t need, because I’m his mum I can dress him. It was the**

transport that we needed help with not dressing. But if you have everything they offer then they cut the whole lot off.”

- There was a general consensus among the group related to ‘lack of support from and not being listened to by services’.
- “This is constant and ongoing. The lack of communication; no one listening to me. The professionals all seem to have preconceived ideas and that they know my child better than I do.”

Participants also felt that some professionals did not have the right skills and training:

- Do you feel that the professionals giving support (listed above) have the right skills, training and attitude? “No. They don't seem to make a decision or provide what is needed. ”
- Do you feel that the professionals giving support (listed above) have the right skills, training and attitude? “No. They work for the authorities and not in the interests of the child.”
- The group felt that staff attitude was generally poor and needed to change. The group felt staff lacked skills, had poor communication and cultural understanding and thought things were better in A than in B. They also wanted staff better trained.

Quality of care

People talked about their experiences of the care they had received. The majority reported that their experiences had been broadly negative on a range of issues. These included quality of care provided and access and timing of access to the right services:

- “The children are just not getting the service they need – there’s no opportunity for them to play independently or get support with their development – they don’t feel safe outside and are stuck at home – doing nothing – just getting bored and frustrated.”
- “I have always accepted what was offered to me and appreciated it. We have being left in the dark because we didn’t ask. I don’t know if I had made any request whether I would have been given that support.”
- “My experience has not been very positive – I have had to complain on two occasions about speech and therapy services; complain about her school Individual Education Plan so that it included health; complain about occupational therapy services which nearly resulted in a tribunal; I’ve had to fight for everything.”
- “I’m not making excuses – but if we had got the right support from the beginning my son wouldn’t have had such a terrible time. I didn’t get any support either.”

Stress

Some participants talked about many of their experiences being stressful and frustrating:

- **“At every stage we have had to fight for services – at one time even threatening legal action until we got our way. The whole process has been physically, emotionally and financially draining.”**
- **“It’s a battle just to get the right support.”**
- **“I wanted to be a mum, not have this daily battle.”**
- **“They only want to know you if you’re at a crisis point.”**

In addition to the above comments, participants also commented on a wide range of other topics. These included experiences of being at school, which services were commonly accessed by families (e.g. speech and language therapy (SALT), experiences of transition into adult services and provision of translation services and information in a variety of languages.

Practical steps to improve services

As part of a series of interviews with families, we asked them to indicate how an inspector would know that they were inspecting a good service and what made a good service. Families and individuals told us:

- Ensuring that the right support is given.
- Clients are happy and satisfied.
- Approachable and available service.
- Good timeframe for appointments.
- That there are more specialists in each field who have a designated amount of patients that they can effectively see regularly.
- Professionals keeping appointments – for example, we were told of a social worker who got someone to phone on the day of an appointment to say she had gone on holiday.
- It must take into account the specific needs of the family.
- Being treated as a client. Not as them doing you a favour and you being a drain on resources.
- People listening and telling you what is available.
- Meeting all the needs of the family.
- Treating people with respect, listening to parents.
- Understanding of child's special needs.
- A great referral system, so that the patient is assisted every step of the way and is followed up.
- Less hospital admissions.
- "Assessments should be done as early as possible and there should be continuity of staff".

- "Professionals just give you a label – they need to change their attitudes".
- "Services talking to each other".

Each of the key themes identified by the people with spoke with have been used to shape the questions we asked PCTs and acute trusts. In summary, the key themes that are explored by this review include:

- How well joined up are services for disabled children and young people?
- Do organisations include disabled children and young people and their families and carers in care planning?
- How good is the provision of access to specialist services such as speech and language therapy?
- How do PCTs plan and monitor the care given to disabled children, young people and their families and carers i.e. provision of equipment?
- How good are organisations in managing the transition of children into adult services?

Discussion of the results

The information we collected from PCTs and acute trusts reveals a complex and variable picture of how services are commissioned and provided to children and young people with a disability and their families and carers.

Information collected from SpeakOut groups and other stakeholders presents a variable picture. Generally, they reported that their experiences were negative – particularly around how well services were joined up, how involved they were in decisions and in the delivery of care, communication, and general quality of care provided. They also expressed frustration and felt that they had to be persistent in getting the services they needed.

Information we collected from PCTs and other sources in some ways supports these experiences, while in other ways does not. Use of health action plans, for example, varies, which means people using services have a range of different experiences depending on the service they get. A similar picture emerges with the coordination between services, such as community nursing and physiotherapy. Again, while a number of PCTs indicate that services are coordinated in the majority of cases (over 80%), there is variation between PCTs which means people's experiences will differ. This variability in experience may in some way explain why stakeholders generally reported poor experiences of their care and support.

Other information collected for our review partly contradicts the experiences of stakeholders, and partly reinforces their comments. For example, the majority of PCTs reported that movement between acute and primary care (i.e. discharge planning) is in place, while a significant number of PCTs told us that they do not involve children, young people and their families and carers in activities relating to training and selecting staff who deliver care packages.

When we asked PCTs about provision of specific services, such as speech and language therapy, we also found variability, though most services have coordinated appointments (in 80% or over of cases) and relatively few people have to wait more than usual for appointments.

As well as this variation in the way care is delivered, our findings also show some generic issues, like the low levels of complaints reported. We were disappointed, though in the proportion of PCTs that were unable to provide the data we requested from them. In particular, the five PCTs that couldn't say how many disabled children there were in their area, and the PCTs that could not provide data on referrals and waiting times for specialist services. Without a basic awareness of what the needs of the local population are, it is hard to understand how a PCT can assure itself it is commissioning services to meet them. We therefore urge commissioners to improve the quality of information they hold about these services.

Moving forward – an update on the information used in this review

This final section compares the findings of this review with what stakeholders told us about services for disabled children and young people in January 2012. We carried out this sense check with stakeholders to determine whether the the issues from the data we found in 2009/10 are still current and applicable. We carried out the sense check in two ways:

- Talking with organisations (stakeholders) that represent the interests of families who have a disabled child or young adult and who had contributed to the review at various stages of its delivery.
- Reviewing relevant external reports and documents.

Stakeholder consultation

We asked stakeholders a range of questions about issues that had emerged as part of our review, including raising concerns about services and involvement in the development and planning of services. Additional comments from our stakeholders reflected what we collected during our review and included the following:

- **“You have to raise formal written complaints, as verbal complaints do not get actioned. Local managers usually are the first in the chain to try and resolve the issues, but they [the complaints] are usually about them so that wastes time.”**
- **“As parents we are not involved in planning or delivery of services but they pretend to do so. They just won't listen to anything that does not comply with their way of thinking or that may threaten their very tight control and budgets.”**
- **“Getting to the people who are accountable for resolving issues is, in my experience, problematic and challenging.”**
- **“The story does not change – length of time for diagnosis, being listened to, unease about medication.....”**
- **“...we find that support and resources can vary according to which part of the East Midlands a family lives in.”**
- **How long are people currently waiting for equipment and wheelchairs?
“Again this is something that varies according to the area the family lives in.”**

- “The issue is not the waiting time but getting an assessment then a refusal to supply.”

Document review

In addition, we looked at key documents that were released during the time of our review, and these also echoed our findings. *Disabled Children and Health Reform*, which was released in December 2011 by the Every Disabled Child Matters campaign, discusses some of the key challenges and opportunities that current proposed reforms of the NHS pose. The key findings, based on interviews with a range of families, include:

- Inefficiencies of the current system, including poor coordination of appointments and care, poor communication between different parts of the system and problems accessing equipment.
- Poor integration of services and, in particular, difficulties of achieving continuity of care or a holistic approach to treatment and support.
- The need for robust and accurate information about disabled children and young people at local and national levels.
- The need for increased transparency about how effective local health services are for disabled children and young people and the need for a ‘local offer’ that includes health.

A report published at the same time, *Parent carer forum involvement in shaping health services* (December 2011), based on a survey of 151 parent carer forums, also highlighted the need for clear involvement in the development and delivery of services for disabled children and their families. This is particularly the case as new structures and roles develop in the health and social care landscape. The report drew attention to the roles of the local Health and Well Being Boards and HealthWatch England.

While slightly earlier (September 2011), the release of the Green Paper *Support and aspiration: A new approach to special educational needs and disability* aims to redress some of the many issues that affect families with a disabled child or young person. The Paper draws on issues raised by families. Again, these reflect the findings from this review:

- “Disabled children and children with special educational needs tell us that they can feel frustrated by a lack of the right help at school or from other services. For children with the most complex support needs, this can significantly affect their quality of life.”
- “...parents tell us that it can feel like a struggle to get the right support for their family from education, health and social services.”
- “...many families share a concern that the system can feel impenetrable, bureaucratic and inefficient, and does not sufficiently reflect their family life.”

A report from the National Network Parent Carer Forum (February 2011) highlights the ongoing issues of providing good-quality care to families with a disabled child or young person. In promoting changes in policy and the delivery of good care services, the report makes a number of recommendations based on their experiences as parents. These included:

- “Smarter use of scarce resources – Parent carers are often asked the same questions by different providers and there is no systematic cross reference.”

- “Strategic involvement of expert parent carer representatives at policy design stage, and in monitoring patterns of service delivery.”

Conclusion

The additional stakeholder comments and findings from key documents clearly reflect the findings of this review and have helped to validate the data we collected. Our review therefore adds to the information and debate about what needs to be tackled to provide better services to families with a disabled child or young person.

Appendix A – Analysis of what SpeakOut groups said about services

This review focused on families with disabled children aged 0–19 who require ongoing specialist support. The range of needs included learning disability, autism, communication needs, sensory needs, mental and behavioural support and mobility needs.

This Appendix focuses on data collected from ‘SpeakOut’ groups as part of the national review of disabled children’s services.

Methods

SpeakOut groups across the country ran a number of events using interviews, group sessions and questionnaires to ask families about their experiences of local services and the issues that mattered most to them. The broad aims of these groups were:

- To find out what they had experienced.
- To help develop key themes that could be used to guide any data collected from PCTs and acute trusts.

We collected comments from about 82 people through a series of interviews, group discussions and questionnaires.

A topic guide was used to guide the groups’ conversations, or to be used as an interview schedule / questionnaire. Questions focused on family experiences, involvement in care of children or young people and their families, service improvement and use of information from the review.

All the information collected was analysed by allocating comments to themes and topics. The key topics are described in the following analysis section and are illustrated with some examples of what individuals and families said about the services they receive. The information collected from the groups was a mixture of direct quotes and summaries of discussions provided to us by the SpeakOut groups.

How CQC used the information

The information collected from the SpeakOut groups helped us understand the experiences of, and difficulties faced, by children or young people with disabilities and their families. We used it, alongside the views of other stakeholder and topics from the *Aiming High Review*, to collect information from PCTs and acute trusts that commission and / or provide the services that they use.

We also asked the SpeakOut groups how they thought that the information gained from the review should be used and this is discussed in the following analysis section.

Thematic analysis

While a topic guide was used to guide the discussions and interviews, a very wide variety of issues arose. Most comments were on themes around diagnosis, involvement in care and communication, and quality of care and service provision. In addition to these larger themes, participants also commented on a number of other issues that affect their day to day lives, such as being at school.

Experiences of services

Though the children or young people and their families that took part in the groups had a wide variety of different disabilities and backgrounds, they often had complex and ongoing health care needs, requiring support from a number of different services and health care professionals.

Diagnosis

Comments generally related to the difficulties and the length of time it took to get a diagnosis:

- **“First of all they wouldn’t give us a diagnosis – It took four years constantly struggling to get one – then they discharged my son. Once they discharged him we couldn’t get back in and couldn’t access services – it’s just ludicrous – we are not getting any support from anyone.”**

Some comments suggested that participants did not feel professionals took them seriously:

- **“I know there is something wrong with my child – but when you go the doctor [GP] he just ignores what I am saying – he is so dismissive.**
- **“I was a single parent when I had my daughter and was instantly dismissed when I pointed out that something wasn’t right with her – they wouldn’t listen to me. My daughter couldn’t hear or talk and at 15 months the health visitor finally referred her for further tests.”**

Some people thought that there is reluctance among professionals to give a diagnosis:

- **“They [hospital consultants] are reluctant to give you a definite diagnosis – in case they get it wrong or they don’t want to spend money on you – so they just drag it out.”**

Getting a diagnosis was important to ensure that children received the right care:

- **“Once we got a diagnosis and were in ‘the system’, things got better.”**

Access

Some participants reported feeling that they have had to ‘fight’ to get access to services:

- **“If your child is out of the social care network then you can’t get any services – you just keep going round and round – you fight to get an assessment – once you’ve got that – you fight to get a diagnosis – once you’ve got that you fight to get support and then you hit a brick wall.”**

- **“My wife’s a fighter – she doesn’t give in – if she wasn’t a fighter she wouldn’t have got any help – but then they label you as a trouble maker.”**

Some participants described difficulties accessing particular specialist services they use:

Child and Adolescent Mental Health Services (CAMHS):

- **“CAMHS have been involved for four years, but we [parents] have to drive everything – we feel they meet you and then push everything on the back burner and nothing happens – you meet them again after a few months and nothing happens – there is no follow up – no practical support – just pen pushing. If you push for something you’re called ‘aggressive parents’ – it’s atrocious the way they treat you.”**
- **“There’s no specialist counselling service – that’s because mental health issues among children are not given any importance or priority – we don’t have any specialist services.”**

Speech and language therapy:

- **“She was assessed and started receiving speech and language support, which continued at nursery and infant school but stopped at secondary school. I had to fight and took the local authority to tribunal to get the support that my daughter needed. I paid for private assessment and although I won the case – the local authority have to pay for NHS delivery – the support is still not in place.”**
- **The speech and language therapist is very good, but we only see her once a month which is simply not enough so we’ve had to go private twice a week. The therapist admitted to us that there aren’t enough of them working in this area.”**

Some participants commented that there is a long wait between appointments and that appointment times were not always convenient:

- **The bad part was the very long initial waiting of 6 months until we received an appointment. Linked to this was the extreme infrequency between appointments.**
- **Timing of appointments needs to be with agreement from the family.**

Some comments suggested frustration with a lack of progress following an initial contact or appointment with services:

- **“After a recent meeting with the doctor, it has been suggested that they will try to arrange some respite care for me, but so far nothing has happened.”**
- **[Re. Independent Living Team.] “Requested alterations to the home to make life easier and meet our daughter’s needs. Have been waiting over 16 months and only just received some attention after threatening an official complaint. Now been told they won’t help.”**

There were some comments about difficulties in navigating their way through a bureaucratic system to access the services needed:

- "...but you have to work so hard to set them all [services needed] that it is like running a business. All the respite care services have 24-page long forms that need filling and most of the information required is the same. Different providers use different forms instead of one form that is the same for all."
- "It's too much – the paperwork that comes through – this appointment and that appointment – piles of letters – you have to juggle and prioritise all the appointments – which ones are important – which can be changed around – then you have to fit them around the school so that he's not taking time off during school hours and missing too much school – sometimes I get so overwhelmed by it."

There were some positive comments about services once they have been accessed:

- There was consensus among the group that waiting times "were too lengthy". However, once their child had been diagnosed the group agreed that the support available from health services was "fairly good".
- When we were finally seen we had a good overall experience and the standards of service and care given to us were good.
- "CAMHS were brilliant but had to wait four months for an appointment."
- "The good experience was that, with my younger son, despite the fact that psychiatry was unwilling to intervene (as he was under six) the specialist was very forthcoming and available and I could phone her. As medical intervention was premature, clinical psychology gave me a six-week course on parental management delivered in my home. However, to get this you must know your system and how to ask; they won't tell you, you must ask the right questions."

Services working together

Most families receive support from more than one service and participants were asked how well the different services they receive work together. Participants had different experiences:

Some were positive:

- "After much work they have begun to communicate together to coordinate appointments etc. Initially we were sent conflicting appointments but they've now begun to accommodate us."
- "Yes – our GP, hospital staff, consultant, community nurses all worked well in providing the appropriate care and support for my daughter."

But others were less positive:

- "We have found them to be very disjointed with often the left hand not even knowing what the left hand is doing! This only works to increase the burden on parents. My son was promised provision that never came; then staff were off sick; the litany goes on forever."

- “You must always follow things through. It’s up to you to chase up the results of assessments and reports or appointments because otherwise things won’t get done.”
- “The other difficulty is that services don’t work together – for example, the County Council is paying for private speech therapy but the PCT are not involved. They don’t talk to each other.”

Lack of communication and involvement in the system was another issue, and a sense that the child could get ‘lost’ in a bureaucratic process:

- “They pass you on from one to another and then close the file. They also talk to each other not me. I have been made aware that there is a transition meeting to be held next week and I have not been invited.”
- “[Child’s name] sees many different specialists. He is seen as body parts rather than one whole child.”
- “No, there is far too much emphasis on processes and systems and too little on the needs of the family and children.”

A lack of information and therefore knowledge about how services interact, or how services differ from each other in what they provide was also highlighted as an issue by some participants:

- Most of the participants could not distinguish between the different health services and classed them all as ‘NHS’.
- When asked if the different services were working well together none of the participants were aware of what community services were available and what support they could access.

Health care professionals

Central to delivering services are the health care professionals who work for them. Participants were asked if the health care professionals they receive support from have the right skills, training and attitude. Views were mixed:

Some were generally positive:

- “Yes, overall they seem well trained and they seem to know what they’re doing and they’re knowledgeable.”
- “Yes, I feel that staff are well trained although ethnic needs are not always properly understood.”
- “I have found that most people are tolerant, supportive and pleasant. When you have a challenging child that disturbs the family this knowledge makes a big difference to families.”
- “My daughter’s community nurse has been very supportive and has provided information on her condition to her high school. She has provided them with a care plan as well, in case she has a crisis. Also a care plan for any trips or residential.”

Though others were more negative:

- “Not for people with learning difficulties. Some of the professionals do not understand what is required. Parents should not be dismissed from the planning of treatment and their answers should carry the same weight as the professionals.”
- “The support I have received has been good, they do have the right attitude and ideas in place. However, the support I have received from the community services such as occupational therapy has been really good because they have put in new ideas to better the use of our home.”

There were some concerns about a lack of continuity in staff seen by the children, and issues around staff shortages:

- “It’s really frustrating when they keep changing the physiotherapist or speech therapist – you just get used to one lot and then they change them and you have to start all over again.”
- “The problem is staff shortages – when experienced and specialist staff are away they don’t get replaced quickly enough and families lose out.”

Some comments suggested that although health care staff are supportive, they are constrained by, or perhaps not independent from, the ‘system’:

- “Some of them are OK – they sympathise with you – but they are only the ‘foot soldiers’ – it’s their superiors who make the decisions and they don’t want to know.
- “My social worker seems more a messenger for the Local Authority than supporting either my son or my family.”

Comments suggested that more help, advice and information could be provided by professionals:

- “They (professionals) don’t tell you about any help or support that’s out there – no one told me about respite care [or other support] – it’s my friend who told me that I could get help.”
- “No one told me about respite care, or getting financial support for holidays – I just found out after 13 years that I could get some help and that’s through this group.”

Involvement in services

This section considers issues around involvement. Two different kinds of involvement are considered: involving children or young people and their families in the care they receive; and involving them in planning and improving services.

Involvement in care:

Comments generally related to wanting to be actively involved by health care professionals in the care their child received, such as by shared decision making:

- “[Child’s name] has a social worker from the disability team who is helpful – and they put together a care plan but they never consulted me about it – they don’t involve you in anything – they go against you so you have to fight them to get help and support.”
- “My daughter has a Common Assessment Framework but the services are not joined up. All the assessments were separate and not joined up care. They don’t work with each other or the parents who I feel they view as ‘inferior’ to them. But they collude together and keep parents in the dark. There is no parental involvement, no consultation, no joint decision making with the parents – you’re not invited to any meetings – you’re kept in the dark.”

Comments suggested that some respondents do not feel listened to by health care professionals, and therefore not involved in their child’s care:

- “It’s like you don’t have a voice. They are the professionals, they want to provide what they think you will need, for example they offered a dressing helper which we didn’t need because I’m his mum I can dress him. It was the transport that we needed help with not dressing. But if you have everything they offer then they cut the whole lot off.”
- “This is constant and ongoing. The lack of communication; no one listening to me. The professionals all seem to have preconceived ideas and that they know my child better than I do.”
- “The professionals talk to each other and exclude us – yet we are the ‘real experts’ – they don’t want to work with us but against us.”

Professionals are not always able to communicate directly with the children or parents in ways they can understand, which means they are not able to be effectively involved:

- “No, they talk and I don’t understand them. I have never met a nurse who can sign. I have never met a doctor that can sign. There are no doctors that sign.”
- “At [place name] one of the doctors spoke to me in my own language and within a couple of hours he had told me about all the support services that I could access and I was able to tap into these straight away.”

Involvement in planning and improving services:

Participants were asked whether they had ever been asked their opinions about the services they receive, or the planning of services, such as by sitting on an advisory group or taking part in meeting. The majority indicated that they had not, as shown in the summaries from group discussion:

- None of the participants had been consulted or asked for their views about services, etc. The group were hugely frustrated at being ignored and excluded from decision making processes.
- The majority of children and young people reported that they were not involved in planning their care. Moreover the information gathered suggests that this group of children are not consulted about what they think about the people that provide this care, or able to choose who provides this care. It was clear that children were not familiar with the concept of complaining.

Of those who had been involved, methods included surveys, feedback forms and attending meetings. Very few said that they knew if their feedback had been listened to, or used to make changes or improvements:

- **“I was invited to Respite. Also the Learning Disabilities Partnership Board where I have a Carer/Parent role. This organisation is officially there to ensure delivery of Government plans for services.”**
- **“I once attended a focus group from the PCT on how it wanted to remodel community services but after attending the event heard no more from them about it.”**

Comments suggested that participants would like to be more involved:

- **“I would like to get involved to make things better.”**
- **“We are the parents – we care for our children – they should be talking to us and finding out from our experiences.”**

Service improvement

In order to understand what services need to do to improve, participants were asked a number of questions to consider what qualities makes a good service for families with disabled children, and how a CQC inspector would know if they were inspecting a good service.

While there were a very large number of suggestions, the comments below highlight some of the main themes of involvement, communication, supporting both the child *and* the family, and joined-up care:

Information provision:

- **Information of what is available and how to access support.**
- **Giving more support, advice and information.**
- **“Honesty, truth and help getting what my child needs. I want to know what is going on. I have had to get my information from other mothers at the school gate.”**

Holistic / person-centred services:

- **It must take into account the specific needs of the family.**
- **“A good service looks at all the needs of the individual, as Sickle Cell affects not only the person medically, but also socially, economically and the whole family. The hospital only deals with the medical aspects of a person. We did not receive any counselling. We were not given any time to ask questions, we were left to deal with our child’s care by ourselves, and right now we are struggling to attain the support. Sometimes we are not sure if we are doing the right thing.”**

Communication:

- **Ability to empathise with patients (listening to us not just treating us – we know how we feel) openness to other ideas.**

- I would check and ask patients if they were being heard by the professional.
- Being in regular contact with families to establish their changing needs.
- We need outside information as often people just don't know what services they need or are out there.

Involvement:

- See evidence of how families with disabled children are involved in local action plans.
- Include the child. Getting the views of the parents and careers; only they can tell you what their child's needs are, what they can do and what their requirements are. By listening and talking, also taking in their views, you will be able to create a good service.

Provision and delivery of services:

- A great referral system, so that the patient is assisted every step of the way and followed up.
- More speech therapy, earlier and longer-term therapy, more occupational therapy.
- Talking with all the other services making sure they work well together e.g. transport to hospital, also to school. Doctors support parents with school absences.
- Good timeframe for appointments.
- Appropriately qualified staff.
- That there are more specialists in each field who have a designated amount of patients that they can effectively see regularly.
- I would determine if this treatment is available to everyone or just one person.
- Children identified several things that would improve their direct health care experience. These included a more homely environment, continuity of care, privacy, being listened to and being at the centre of communication.

Participants were also asked what the signs are that families are receiving the support that they need:

- If [services] cater for the needs of the child and his family.
- Making sure families are happy.
- If the family are coping with the child.
- Happier, less stress, less inclined to go into crisis, more inclined to use the services available and more confidence in the health services. Open communication with service users.

In terms of how inspectors, or others, should understand what makes a good service, it was felt essential to talk to and involve those who receive services:

- **“We would be approached by local services and asked to contribute to surveys/targets.”**
- **“Inspectors talking directly to parents from [group name] not just those put forward by the Authorities.”**
- **“Talking to people from all sections of the community.”**

Suggestions were made about what makes for a good relationship with professionals, or what could be improved. While a very wide variety of comments were made, generally the comments related to themes of listening and communication, involvement in care and a more holistic perspective:

- **What type of support would you want, need or expect from professionals?:**
“They are friendly, empathetic and can be trusted to treat me holistically. Also that they know their jobs and know what they are doing.”
- **“To be informed of my condition and all the options available to me ... to be asked what help I need ... Talking about things, being confident – I am already ... Being given all the information and being able to ask questions.”**
- **“It’s nice to involve parents in the treatment as well because this maximises the impact.”**
- **“They should see us as people – not as a problem.”**

Some comments suggested that health care professionals and health care services may need to better understand and account for families’ cultural needs:

- **“Some of the staff do need to change their attitude – they see your name – your dress and stereotype you. You know, you’re a Muslim so you must be a terrorist.”**
- **“Staff are generally well qualified in their specific fields with it often being very silo orientated. They also rarely have appreciation of ethnic or cultural needs.”**
- **“With my younger one there wasn’t the right service out there. He was offered a place at a weekly coordination club or a day place in a care club; however these were not culturally appropriate so we had to refuse them.”**
- **“Try harder to please specialist communities and be more culturally diverse and aware.”**

Using information

Participants were asked how they thought that the information gained from the review should be used.

Unsurprisingly participants hoped that the information could be used to improve services, and highlight variability in the availability of services:

- “We could use the information from this study to help us promote more excellence within community specialist health care services.”
- “By working with the poorest service providers to ensure that they improve their standard of service to the community.”
- “I would want to know why I can’t get a particular service here, but that it is available in other areas. I would use the information to challenge the LA [local authority] – i.e. respite care for children who are challenging.”

The review may also promote awareness:

- “To find out what is available to people in my situation in the good areas and use it to get the same level of service here.”
- “Make our voice stand out louder, as I’m not the only one saying the same thing.”

Various methods were suggested for sharing and communicating the results, including receiving copies of the report, leaflets, websites and newsletters which could be distributed by post or email. Translated formats were suggested to help accessibility. Some participants acknowledged that communication needs and personal preferences would vary, which is reflected in the varied responses.

Some participants wanted the results publicised through local media and other services to increase awareness and ensure accountability of providers:

- **Share information from this study via public meetings, local press accountability.**
- **To put pressure on the authorities to provide the support and service they should.**
- **“The best way would be to look at the community. Work with community centres like [organisation name] so we can get the information from them. You can use leaflets, posters, flyers. Display them at hospital and in the community.”**
- **“I would prefer it to be in writing as well as in the local paper. There should be leaflets and/or posters in different languages. CQC should also have a copy on their website as well as ask all those who carried out the research to have a link on their website.”**

Other themes and issues

In addition to these more common themes discussed above, some participants also commented on a number of other issues that affect their day-to-day lives, such as being at school.

Family experiences

Some participants talked about many of their experiences being stressful and frustrating, and how this is affecting them:

- “At every stage we have had to fight for services – at one time even threatening legal action until we got our way. The whole process has been physically, emotionally and financially draining.”
- “It’s a battle just to get the right support.”
- “The stress has got to me – I’m on medication myself for depression.”

There were comments about lack of day-to-day support, or not feeling able to access further support:

- The group expressed concerns about the shortage of provision and support for carers looking after disabled children. They didn’t know of any specialist provision locally and were frustrated that they had to fight to get support from outside specialist providers.
- “I didn’t want them involved in case they took my children away – you know saying that I couldn’t cope – and because I had 3 children under 3 years of age of whom 2 had a disability. It drove me mad – I’ve gone mad and had to deal with my own mental health issues all on my own – no family support – nothing.
- There is a lack of formal support. Looking after your child is a 24/7 job for parents, but there is no support for parents.

Funding

Some comments recognised that difficulties with access to services were due to funding:

- Funding is a big issue – if you need anything they just give you the excuse that there is no funding.
- It all boils down to money – if it’s going to cost anything then they don’t want to spend it – yet they are prepared to go to tribunals and spend all that money on ‘fighting’ the parents.
- “[Child’s name] needs a special buggy, costing around £800.00. The occupational therapists at [name of service] have told us he needs it but we have no prospect of being given one and told to fund it ourselves.”

Complaints

There were some comments about difficulties in knowing how to complain:

- “The complaints procedure leaflet is so small – they put on a corner of the notice board – you can hardly notice it – the complaints procedure should be independent of the hospital.”

Transition between adult and children’s services

There were mixed experiences of the transition between children’s and adult services, with some comments suggesting a lack of support to prepare for this and anxieties about the changes this entails:

- “The transition was poor as there was too much lip service. At age 16-18 Connexions came in and took over. The Social Service advised us of the

helpers and of any work experience. The Adult services stopped at age 16 and the family were not properly advised, thus they did not understand what was happening and the possibility of any services.”

- “My son is going to be 16 and I am very worried when he changes to adult services – we are going to have to start all over again – working with new staff – and I am really stressed out about it – I am not getting any support to help prepare me for this change.”

School

Some participants spoke of their children’s experiences at school, the particular issues they face and the difficulties in accessing the services and schooling they need:

- “My child was placed in a mainstream primary school where he was bullied to the extent that he began self harming and on one occasion put a skipping rope round his neck. I had to pull him out of school he was having nightmares and refusing to go.”
- “The school didn’t want to know – I had to fight them to take me seriously – eventually my son was assessed and was statemented after which he started to get one to one support.”
- “What has been poor, however, is the services linking up with the school. The communication between them has been poor, meaning my son didn’t receive proper support in school for ages.”

Appendix B – Case studies for acute trusts

For this review, we asked acute trusts to return information about delayed discharge or transfer of care for services they provide for disabled children and young people. On 30 September 2010, 76 disabled children or young people across 36 trusts had a delayed discharge or transfer of care into another service. The majority of trusts said that they had no delays.

For those trusts that had delays, the average delay was 11 weeks and the range for all trusts was 0 to 182 weeks. In cases where there was a delay, 49 trusts said that they had a named PCT commissioner to contact about the delayed discharge or transfer. Three common causes of delayed transfer or discharge were presented to the acute trust, and we asked them to indicate the numbers of children and young people in each category:

Cause	Number of cases
Other acute care not prepared to accept referral	13
Family have refused discharge at this time	9
PCT does not have community arrangements in place	37
Total (note – does not add up to 76 as not all delays were categorised under the three options)	59

The case studies

We asked acute trusts to tell us how they would provide care for three young people. The first was Naseem:

Case study one – Naseem

Naseem is nearly 16 years of age. Naseem has a learning disability. It is midnight on a Saturday and Naseem is at your A&E department, accompanied by his mother who speaks little English, and his 13 year old sister. Naseem may hit and bite himself and others when upset.

Twenty-six acute trusts indicated that the Accident and Emergency/urgent care/walk in/minor injuries unit services would be able to fully meet Naseem’s immediate communication needs. Other acute trusts indicated that they could partly or mostly meet his needs (156 responses):

Response	Number of acute trusts
Mostly	93
Partly	34
No	3

Acute trusts were then asked to indicate whether they would use Naseem’s mother to translate. This is how they responded (156 responses):

Response	Number of acute trusts
Never	7
In exceptional circumstances	123
Possibly at certain times	17
Probably	9

We also asked trusts about whether staff would be available with specific training needs of people with learning disabilities to support person-centred assessment of Naseem’s needs and whether they would be able to meet his clinical needs. The majority of trusts said they have fully flexible arrangements in place which would assess and meet his individual needs, 54 said it would be dependent on the facilities available at the time and 6 could not reach a consensus after discussion with colleagues.

Case study two – Sarah

Sarah requires urgent in-patient admission. Sarah lives with her family and is supported by her continuing care team. She is on long-term ventilation (LTV). Sarah uses a hoist at home to help lift and move.

Acute trusts were asked a range of questions about the care given to Sarah, in cases where the trust would have admitted her. The most common response is given for each question:

Question	Response
We would have a plan already in place for urgent admission of Sarah	76 - In full (Would have a current and personalised plan, pre-agreed with family and community based team)
We would involve Sarah’s community based team in planning her care	87 - Completely: (We would do all of this)
Would Sarah’s family be expected to provide the liaison between the continuing care team and your acute service?	69 - No (would not happen)
Would Sarah’s family be expected to deliver any personal care during her in-patient stay?	52 - Would never happen
Would your service meet Sarah’s needs around moving and lifting?	86 - Completely: we could meet her need with appropriate equipment and trained staff immediately
Would your service meet staffing/skill-mix requirements for Sarah’s LTV?	45 - Completely: in full & immediately, with appropriately trained & supervised staff

Case study three – Chris

Chris is 13. He has had a long in-patient stay. He has had complex health needs since he was born and during his time with you, commenced Parenteral Nutrition (PN). His health needs are now stable and you are planning discharge. Chris lives with his mother (who is a single parent) and his siblings. Chris's mother is crying a lot and says she doesn't know if she can cope when he comes home.

As with case study two, the most common responses to the questions asked are given below:

Question	Response
How would you ensure that Chris's mother has her own needs for support met?	53 - Offer a formal carer's assessment & info about other support e.g. benefits, groups, making referrals
Would you meet Chris's psycho-social needs?	51 - Completely: we could meet these needs in full, immediately
Would Chris's educational needs be met during his time as an in-patient?	73 - Completely: we have arrangements in place with education services to meet needs in full, immediately
Would your staffing/skill-mix meet Chris's need for PN?	84 - Completely: in full & immediately, with appropriately trained & supervised staff

The majority of trusts answered 'yes' to the following scenarios:

- Chris's mother will have received competency-based training to be able to fully meet his health needs at home.
- Chris's mother will have received basic training to meet his needs in an emergency.
- Chris would have an opportunity for a phased discharge home.
- Chris's mother knows that a key worker or main link contact is available for practical advice and support.
- Chris's mother is clear about how ongoing supplies will be arranged at home.
- Chris's mother knows about a follow-up meeting with herself and the care team.
- We would have considered the need for a package of care under continuing care guidance.

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