

Disabled Children and Health Reform

Questions, Challenges and Opportunities

About EDCM

Every Disabled Child Matters (EDCM) is the campaign to get rights and justice for every disabled child. It has been set up by four leading organisations working with disabled children and their families – Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium. EDCM is hosted by the National Children's Bureau, charity number 258825

To download this briefing and sign up to support the campaign at www.edcm.org.uk

About The Children's Trust, Tadworth

The Children's Trust, Tadworth is a national charity providing highly specialised services to disabled children and young people across the UK. These services include expert nursing care for children with complex health needs, rehabilitation and support to children with acquired brain injury and residential education for pupils with profound and multiple learning difficulties at The School for Profound Education. Charity registration number :288018.

Find out more about the work of The Children's Trust, Tadworth at www.thechildrenstrust.org.uk

This briefing paper relates to England only

For information about health services for disabled children in the UK nations:

Wales Disabled Children Matter Wales www.dcmw.org.uk

Scotland For Scotland's Disabled Children www.fsd.org.uk/

Northern Ireland Children with Disabilities Strategic Alliance www.ci-ni.org/working_in_partnership.

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Thank You

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Contents

Executive Summary	2
Introduction: Change and opportunity	4
Questions	6
A system that works more efficiently in the interests of patients	7
Integrated services	11
Information	15
No decision without me: transparency and partnership with families	18
Assessment	20
Patient involvement and participation in the design of care pathways and system change	23
Conclusion: achieving equity and excellence for disabled children and their families	24
Summary of recommendations	25

Executive Summary

The current reform of the NHS is implementing fundamental, whole system change. Every Disabled Child Matters (EDCM) believes modernisation creates new opportunities to improve services for disabled children and their families. However, these services are not visible within current policy documents or discussions or within the new structures being developed as the modernisation of the health service gathers momentum. The Government has a choice to make between acting now to use the opportunity of reform to create a system that works better for disabled children, or perpetuating a system which leaves the families of too many disabled children and young people struggling to fill the gaps.

This briefing has been developed by EDCM, with the support of The Children's Trust, Tadworth to:

- focus attention on disabled children, young people and their families at a time of whole system change
- ensure that the voice of patients is heard
- make sure that the modernised NHS delivers better services for disabled children – particularly those with complex and/or palliative care needs

The difficulties disabled children, young people and their families experience using NHS services are well-documented¹. While there is obvious and established good practice in some places, it is significant that submissions to Parliamentary Hearings on Services for Disabled Children in 2006 indicated a high level of dissatisfaction. Almost half of disabled children's parents making submissions (48 %) and over a third of professionals (35%) described health services as 'poor'.

To ensure these experiences feed into the modernisation process, EDCM has conducted interviews with families across the country

and in this briefing, identifies and illustrates characteristic challenges reported by parents and carers.

The focus throughout is on improving the NHS at a time of whole system reform, not on individuals working for the system or the services provided in particular local areas. This is an important distinction that was highlighted by many of the people interviewed. They said, for example:

"I've had really good experience of Health and individual Paediatricians. The NHS saved my daughter's life and I've had so much good from them. The problems arise from the complexity of the system and the different services your child needs, and from the fact that services don't work together."

The particular issues identified by families relate to:

The inefficiency with which the current system operates

In particular, poor coordination of appointments and care, poor communication between different parts of the system, delays, problems accessing equipment and incontinency services and the confusion with which services for children relate to services for adults at the time young people make their transition to adult life.

The integration of services and service delivery

In particular, the difficulty achieving continuity of care or a holistic approach to treatment and support when many people, teams and agencies are involved. Families also talked about being caught between different agencies when funding is shared and of the need for key worker services to help them negotiate a complex system.

1. See Disabled Children and Health EDCM 2009

Information

In particular, the lack of robust, accurate information about disabled children and young people at local and national level and the difficulty some families still experience finding out which services are available in their local area and how to access them.

Transparency

In particular, the lack of transparency about how effectively health services operate for disabled children at national level and the need for a clear 'Local Offer' that includes health services.

The briefing also highlights particular issues relating to:

- the commissioning of services for disabled children and young people by Clinical Commissioning Groups
- the commissioning of specialised health services for high-cost, low-incidence groups
- ensuring that the voice of families with disabled children is heard at every level.

It poses 10 questions for Government as the modernisation of the NHS moves ahead and makes a series of specific recommendations for how the modernised NHS can be made to work more efficiently in the interests of families with disabled children.



Priority recommendations for immediate action:

National leadership

1. The Health and Social Care Bill should require the Secretary of State to set priorities for child health as part of his Mandate to the NHS Commissioning Board
2. As a matter of urgency, the Department for Health should set out a clear vision for the way in which the reformed system will meet the needs of disabled children and children with complex health needs

Commissioning

1. The NHS Commissioning Board should establish a Clinical Network for children, with a defined responsibility for developing care pathways for disabled children and young people
2. Health and Wellbeing Board early implementers should be asked to test and report on integrated working for the delivery of services for disabled children which includes all relevant partners – e.g. education services
3. Careful consideration should be given to the impact of current reforms on the commissioning of specialist health services for children and young people with high-cost, low-incidence conditions

Individual children and families

Information and support should be provided to disabled children, young people and their families to ensure that they understand the way in which the changing health system will affect them.

Introduction: Change and opportunity

The current reform of the NHS is implementing fundamental, whole system change. Every Disabled Child Matters (EDCM) believes that modernisation creates new opportunities to improve services for disabled children and their families. However, these services are seldom discussed within the current modernisation process, which suggests these opportunities are not widely recognised and may be missed. EDCM has therefore developed this briefing with the support of The Children's Trust, Tadworth to:

- focus attention on disabled children, young people and their families at a time of whole system change
- ensure that the voice of patients is heard
- make sure that the modernised NHS delivers better services for disabled children – particularly those with complex and/or palliative care needs

Children and young people with disabilities are a wide and diverse group who use a range of different services provided by the NHS. They are therefore disproportionately disadvantaged by a system that does not integrate care well at the point of delivery. Some children and young people with complex needs have life-limiting conditions and palliative care needs. Others experience periods of being well but have very high care needs at some times. Others have very rare or undiagnosed conditions and may need to access highly specialist treatment. It is an indicator of the complexity involved that families with disabled children often use services provided by all, or many of the following:

- Community based services, including Community Paediatricians, General Practitioners, Community Children's Nursing Services, and community dentists,

podiatrists and opticians

- Acute or Emergency services
- Outpatient services, including specialist feeding teams and a wide range of therapy services
- Specialist diagnostic services, such as genetics services
- Specialist treatment centres for children and young people with low-incidence, high cost conditions.

Meeting the long-term support needs of this group is challenging. It requires a flexible, individualised and multi-agency approach that also delivers integrated healthcare as part of holistic support for families that includes support for carers and prioritises continuity of care.

As children with profound and multiple disabilities, complex health and/or palliative care needs rely on a broad range of services and are particularly vulnerable to the negative effects caused by delay, lack of integration and poor communication. As a result, addressing the way in which the modernised NHS will meet their needs should be treated as a matter of utmost urgency. For this group of children, any confusion or lack of clarity with regards to the commissioning and delivery of health services would represent a significant risk to their health and well being.'

At the time of writing, the modernisation of the NHS is gathering pace. The Government published *Equity and excellence: liberating the NHS and Achieving equity and excellence for children* in 2010 and has since responded to the report produced by the NHS Future Forum. The Health and Social Care Bill is passing through Parliament. The NHS Future Forum is continuing to work on the key issues of information, education, integrated care and public health². 132 local authorities have signed up as 'early implementers'

2. <http://healthandcare.dh.gov.uk/new-forum> to find out more

3. <http://healthandcare.dh.gov.uk/early-implementers-of-health-and-wellbeing-boards-announced>

4. <http://healthandcare.dh.gov.uk/clinical-senates-and-networks>

of health and wellbeing boards³. The role of clinical networks and new clinical senates is being developed⁴ and the Government's GP Commissioning Consortia Pathfinder Programme is developing fast. Meanwhile, 20 pathfinder projects have been announced associated with *Support and aspiration*, the SEN and disability Green Paper which requires local areas to focus on development of single health and care plans, promote strong partnership between local services and agencies and improve commissioning, particularly through links to health reforms⁵.

It is clear that the health service has entered a transitional phase. PCTs and local authorities are already making changes in anticipation of the reform that will be introduced by the Health and Social Care Bill. This has already had an impact on local health budgets, and the planning and commissioning of services. However, the Health & Social Care Bill does not reference the child health system. In addition, no detail was provided on the way in which the structure of the child health system will relate to the delivery of services for disabled children and those with complex health and/or palliative care needs within Government's response to the NHS Future Forum. Consequently, families with disabled children and child health professionals are operating within an environment of heightened uncertainty which may place vulnerable children at even greater risk.

The difficulties disabled children, young people and their families experience using NHS services are well-documented⁶. While there is obvious and established good practice in some places, it is significant that submissions to Parliamentary Hearings on Services for Disabled Children in 2006 indicated a high level of dissatisfaction. Almost half of disabled children's parents (48 %)

and over a third of professionals (35%) described health services as 'poor'.

To ensure these experiences feed into the modernisation process, EDCM arranged face-to-face interviews with families across England in July. Over 20 interviews were conducted and the material transcribed reflects the experience of parents with babies and children and the experience of those supporting young adults. Children and young people with a range of complex conditions including learning difficulties, physical disabilities, autism, acquired brain injury, Down Syndrome and life-threatening or life-limiting conditions are represented in the sample.

It is important to emphasise that the focus for discussion was on improving the NHS at a time of whole system reform, not on individuals working for the system or the services provided in particular local areas. While many families reflected on difficulties they had experienced, others had good experiences to share. Many people made a clear distinction between the frustrations they experienced with the system and the services they had received from particular people or teams. They said:

"Individual people have been fantastic but the system as a whole has let us down big time."

This publication both highlights the experience of families and makes practical recommendations. It focuses on children and young people with disabilities because services for this population need to improve, but also because these families test the quality, co-ordination and responsiveness of NHS services in a unique and helpful way.

5. www.education.gov.uk/a00198359/20-pathfinders-to-test-out-proposals-in-the-special-educational-needs-and-disabilities-green-paper

6. See *Disabled Children and Health* EDCM 2009

Priority recommendations for immediate action:

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Commissioning

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Individual children and families

Information and support should be provided to disabled children, young people and their families to ensure that they understand the way in which the changing health system will affect them.

10 questions for Government

Now is the time to ask questions about how the reformed NHS will work in the interests of disabled children:

1. What role should the NHS Commissioning Board play in terms of improving national delivery of health services for disabled children?
2. Where should responsibility lie for designing care pathways and shaping local services for disabled children within the modernised system?
3. How will Clinical Networks and Senates support Clinical Commissioning Groups to deliver high quality universal and specialist health care for disabled children?
4. What practical steps are being taken to ensure the experiences and interests of disabled people and families with disabled children are represented as an integral part of patient involvement at every level of the reformed NHS?
5. How should the success of the modernised NHS in meeting the needs of disabled children be monitored in local areas and how should this information be published?
6. How will Health and Wellbeing Boards work with Local HealthWatch and Clinical Commissioning Groups to achieve integrated care for families with disabled children who use health, social care and education services?
7. How should awareness of the particular needs of disabled children be built into the workforce development programme being developed by Health Education England?
8. How will the modernisation of the NHS work with 'Support and Aspiration' Green Paper pathfinders – particularly the development of a single education, health and care plan and a 'local offer'?
9. What plans are being made to improve the collection, use and protection of information about disabled children?
10. How will families seek redress if the package of care for their disabled child is not delivered, is not integrated with other care or if the quality of healthcare they receive is poor?

A system that works more efficiently in the interests of patients

Challenges

The Government promotes a vision of a more efficient NHS that achieves some of the best healthcare outcomes in the world. Current proposals for reform are rooted in the principles of:

- giving patients and carers more power – putting patients, carers and the public first
- focusing on healthcare outcomes and the quality standards that deliver them, rather than on narrow process targets
- giving frontline professionals more freedom, and cutting the bureaucracy that can get in the way of their work.⁷

Disabled children and young people are disproportionately high users of the health services and too many of them currently describe the operation of the NHS as inefficient. Government itself acknowledges that:

'Successive reports, such as the 2006 report of the Education Select Committee and Brian Lamb's report in 2009, have described a system where parents feel they have to battle for the support they need, where they are passed from pillar to post, and where bureaucracy and frustration face them at every step.' **Support and aspiration: A new approach to special educational needs and disability**

Characteristic issues for families have been extensively documented over the last ten years – for example by the joint review of services by the Treasury and DfES in 2006 and previous work undertaken by EDCM⁸. They include:

- poorly co-ordinated appointments
- poor communication across the system
- delays
- difficulty getting equipment
- difficulty accessing appropriate incontinence services
- a confusing transition to adult services.

The experience of families

The Kennedy Report highlighted the frustration that parents feel at the lack of co-ordination between services. Appointments are often scheduled on consecutive days and at multiple locations, when arranging them in the same place on the same day would save a long journey and time off work.⁹ Families interviewed by EDCM often commented on the negative impact of multiple and fragmented appointments on their lives. They said:

"Our personal best was 11 appointments in 4 days. The local hospital is half an hour away across town. The hospital for anything neurological is an hour away. The two older children are at school full time and we also have a three-year-old who goes to Nursery four mornings a week and one full day a week."
Parents of a ten-month-old baby with complex needs

"A four year old that I care for had three appointments in one week up in London in the same hospital. They couldn't co-ordinate their clinic appointments to accommodate the family. It's a two-hour journey up to London for a ten-minute appointment. By the end of the week everyone was so stressed out and tired."
Mother of a young adult with complex needs

7. Government response to the NHS Future Forum report June 2011

8. Disabled children and health EDCM and The Children's Trust Tadworth 2009

9. Getting it right for children: The Kennedy Report (2010)

"We see the Podiatrist, the Eye Consultant, the Orthoptist, the Paediatrician, the Physiotherapist and the Occupational Therapist. That's quite a few people and it's hard when you're talking to the Receptionist. If you try and co-ordinate things or want an appointment at the beginning or end of the day, they say the appointment will be in four months, rather than eight weeks. Sometimes you wait over an hour for an appointment and by the time you get in for an examination, she's so tired she can't do the things they want her to do."

Mother of a four-year-old with Cerebral Palsy

These difficulties are exacerbated by the experience that once a family has been referred to a tertiary or specialist centre, they tend to use local services less frequently. Parents said:

"We quickly found ourselves using very specialist, tertiary care services because of the obvious complexity of our daughter's needs. By the time she was five, we had two other small children. To attend appointments in London, my husband had to take three days off work. It was a long drive, with three small children in the back of the car and there was no financial help available. It was by chance that we discovered there was an Eye Technician working in our area who could provide the prosthetic service that we had been travelling such a distance to access."

Mother of a young woman with complex needs

Where families are using health services in different places, good and efficient communication between different parts of the NHS becomes even more important. However, families say:

"We had to re-tell our story so many times. 95% of appointment times were taking up with us telling our sorry story again."

Parents of a young man with complex needs including Autism

"We moved house and everything had to be totally re-done. They sent a person over to do a medical report and the first thing she said was, "I'm really sorry, but the only thing I know about your daughter is her name." So I had to sit down and go through everything again and then she wrote a long report and I was thinking, "There are people around who know everything about my daughter. It's common sense isn't it? Just get a report from the Paediatrician who knows us. But that's not the way the system works."

Mother of a child with complex needs following Meningitis in infancy

"The problem for us has always been that when you go to an out-of-county hospital, communication breaks down. If we lived locally to the hospital, they'd ring the local Health Visitor. That didn't happen for us the first time and we were left to do it ourselves – but we didn't know who to ring. A consistent pattern through every discharge we've experienced has been that people don't seem to know where to send the paperwork and who they need to speak to. It's haphazard."

Father of six-year-old with a rare condition

“Our whole life revolves around hospitals in 3 different places – sometimes 200 miles away. Communication is a big problem. For example, I struggle with medication. If we go to see a doctor in the specialist hospital and they change the medication, the time it takes for that information to get back to our local GP who prescribes the medicine is ridiculous. It can take months for the written information to work through the system – and his meds change a lot. From my point of view, that’s the biggest thing that could be improved quickly – speed of communication.”

Mother of a seven-year-old boy with complex needs

Families also spoke about the negative impact of delay on their quality of life:

“The Core Assessment for my family to get Direct Payments has been going on for two years. It was supposed to go to panel two weeks ago and it might have finally gone yesterday, but now they say they’re waiting to get Health involved. The boys haven’t been well and things have got worse, but it shouldn’t have taken this long. The Hospice and the schools have said they’re concerned about our family and that we need support. The Social Worker arranges meetings but nothing seems to move on. At weekends I have all three boys 24/7 and I’ve been doing this on my own now for over a year.”

Mother of two children with complex needs including Epilepsy

Many families highlighted particular difficulties with equipment and incontinence services (sometimes also called continence services), which they described as inefficient. They said:

“My daughter has a helmet and boots supplied by the Child Development Centre. She’s outgrown the helmet now and it took them two months just to make an appointment to measure her head. In the meantime, she’s confined to her wheelchair. They said they had the money to do it, but didn’t have the means to order it.”

Mother of a young child with complex needs

“Sometimes you’re told, “You’ve only waited six months – you’ve not been waiting that long.” They say, “Well these things take time, you know. Other people have been waiting two years.” Well, I know things take time, but if it didn’t need doing, I wouldn’t have asked. Meanwhile, I’m carrying a child up and down stairs every day and there are some parts of the house that aren’t accessible to her.”

Mother of a four-year-old with Cerebral Palsy

“Our son has a rare condition that means he can’t control his water balance. So we have to put 2 litres in per day and 2 litres come out. That’s a hell of a lot for a small child. We were buying 30 nappies a day. The service that provides incontinence pads just wouldn’t accept that he has this condition and can’t control the amount of fluid that leaves his body. To this day they’re trying to cut down the number of nappies they give him.”

Father of six-year-old

“My daughter’s allowed 6 nappies a day. But when she got older and I said she needed a higher absorbency nappy, they said, “Oh well, in that case, we’ll drop you down to 4.” It made no sense.”

Mother of a young woman with complex needs

The inefficiency of the current system comes to a head for many families as their children negotiate the transition to adult life and adult services. Difficulties transferring a patient’s care from one clinical team to another is a phenomenon created by the system and it is a problem exaggerated when services change abruptly when young people reach their 16th or 18th birthday. Families interviewed by EDCM returned to this point many times. They said:

“My daughter’s been seen by 2 consultants at least twice a year for the last 17 years so it shouldn’t be a surprise to anyone that she’s going to need continued monitoring and support from Health as she moves into adult services. But the divide between health services for children and adults is significant. Many of the professionals we have come to rely on shake their heads about it and shrug their shoulders, but there’s nothing they can actually do beyond offering to attend a meeting with us where they can hand over to someone who works for adult services.”

Mother of a young woman with complex needs

What does good look like?

Striking consensus has been established over the last ten years on practical steps that could be taken to improve the efficiency with which the

NHS operates for families with disabled children. For example, in relation to appointments, that:

- access to services is regularly reviewed and improved, in partnership with disabled children and their parents
- hospital departments and clinics synchronise their appointment systems as far as possible, so that families make a minimum number of visits to hospitals/clinics. For example, when multiple appointments are required, these are offered for the same day
- wherever possible, children and young people are offered appointments at school or outside school hours, to ensure a minimum absence from school
- children and young people with complex health care needs who are prone to health crises are seen urgently on request
- systems are in place to ensure that children and young people who find it hard to wait, e.g. those with autism spectrum disorder or with learning disabilities, do not have to wait too long at outpatient clinics, general practice surgeries or child development centres.
- where appropriate, disabled children are allocated longer appointments or the first or last appointment times of the day
- facilities for giving personal care in privacy are available in all locations in health, social care and education services that are used by families with a child with personal/health care needs.¹⁰

Some of the families interviewed by EDCM also provided evidence of good practice - responsive services that had provided them with continuity of care and an efficient service in difficult circumstances. They talked about the positive impact of services that looked beyond the chronological age of their child to acknowledge and respond to unusual difficulty waiting for appointments or understanding the concept of ‘nil

10. NSF for Children, Young people and Maternity Services Standard 8 DH 2004

by mouth', for example, and said:

"We can't fault the treatment and communication between the Acute Trust and our local PCT. Right from the outset, our local Community Health Team knew what was happening and when our daughter came home, the Community Physiotherapy and Occupational Therapy service were involved straight away. Our Primary School were just brilliant. There's medical funding available in our local area, precisely to enable children to return to school straight after an acute medical episode. It meant we didn't have to ask for anything or go through the Statement process. The school just applied for what was needed and got funding immediately – for example, for 1:1 support from a TA, which she needed to be safe in school. It was all really good and seamless."

Parents of an eleven-year-old who had a brain tumour removed and chemotherapy

"My daughter's not good at hospitals. It's been a nightmare in the past – she sometimes goes berserk because she finds unfamiliar situations frightening. However, things went really well the last time she was admitted to the local hospital. They have a Special Needs Team there. She was given Valium at home before we started out. When we got to the hospital, I left her in the car with someone looking after her while I did all the paperwork. Then the nurses come out and got her into her wheelchair. They know it's better not to talk to her and she went in straight onto a mattress on the floor (which is where she likes to be) with her own duvet. Then the Anaesthetist got down on the floor with her. Job done. Fantastic. It works because we have a relationship with the team in the hospital and they're flexible – they've got to know what works best."

Mother of a young woman with complex needs

Reform as an opportunity to improve services

EDCM recommends that the modernisation of the NHS:

- Prioritises improved routine two-way communication between tertiary specialist providers of health services and local and primary health providers with whom families have regular contact.
- Builds on the existing successful examples of patient passports and family held records – e.g. the Early Support Family File - to avoid requiring families to repeat the same information over and over again.
- Monitors the experience of health service provision by families with disabled children as an integral part of development activity in 'Support and Aspiration' Green Paper Pathfinder Areas.

Challenges

The history of fragmented responsibility and attitudinal and cultural differences between different parts of the NHS and between health, education and social care services challenges the development of integrated services, organised around children and their families. The Government often refers to opportunities to make integrate services better, building on the many examples of good practice that already exist. For example, it says:

'The health service now needs to drive integration in a way that has never happened before: in particular, to provide a better service for the growing number of people with long-term conditions. Too often, services have been fragmented and have failed to join up for the people who use them. We will therefore create a new duty for clinical commissioning groups to promote integrated services for patients, both within the NHS and between health, social care and other local services; and we will strengthen the Bill's existing duty on the NHS Commissioning Board to mirror this.'
[Government response to the NHS Future Forum report June 2011](#)

Under Government proposals, Clinical Senates will have responsibility for providing expert advice, which Clinical Commissioning Groups will be expected to follow, on how to make patient care fit together seamlessly in each area of the country. New Health and Wellbeing Boards will also promote integration across the NHS, social care and public health as part of their core activity.

However, families often report experiences of fragmented service delivery that are in sharp contrast to the rhetoric of central policy documents. For example, while national policy statements over the last five years have consistently reflected an expectation that

consideration should be given to providing families with support from a key worker, many families find that a service of this kind is not available in their local area.

Integration is particularly important for families with disabled children because, unlike other patients, they often use a range of services and meet many different people. Like other patients with long-term conditions, they are disproportionately and negatively impacted by a system that does not routinely organise services around them, and expect individual practitioners (only some of whom will be healthcare practitioners) to work as a team.

Local areas that have already developed team around the family approaches, key working and joint planning with families and young people provide relevant experience for the rest of the system to learn from. However, this learning will be lost to the modernisation process unless the NHS Commissioning Board focuses attention on the multi-agency needs of disabled children and young people and how best to provide coherent advice to Clinical Commissioning Groups on how to integrate service delivery for this group.

The experience of families

The families who were interviewed talked about the lack of co-ordination in the system they experienced and the difficulty they experienced securing continuity of care. They said:

"My daughter's at a stage now when she's not sitting quite right. We go to the hospital to monitor her spine and they say it hasn't moved in the last couple of years. She's also had surgery on both legs but I don't seem to be able to get anyone to look at the complete picture."

[Mother of a girl with a degenerative condition](#)

"The Physio and the Occupational Therapist have made referrals for us, but essentially we're still the people that have to make plans and go and make arrangements. We still seem to be the only people who have a complete list of everyone with all the contact details. The problem is that people are only interested in their bit. For example, the only thing the Neurosurgeon is interested in is the shunt."

Parents of a baby with complex needs

"Care's very segmented in hospital. My son's got to have his peg changed later this year. I've already been in touch getting them to sort it out and book him in because he'll need a HDU bed. They won't do it, because the doctor who's dealing with the surgery is only focused on that and isn't concerned about what else we know will happen to him as a result of the anaesthetic."

Father of six-year-old with complex needs

"I go to a lot of meetings with Health and no-one's looking out for us as a family. How's it affecting us as parents? How's it affecting my little girl? Meetings always seem to focus on one part of my son's care package. That may sound like a little thing, but it's not. You need someone who knows you on the end of the 'phone."

Mother of a six-year-old with a rare condition

They also talked about the experience of being caught between services that do not communicate well and 'pass the buck' when joint funding is needed. They said:

"Sometimes the local authority say, "Well, that's a Health issue and so the PCT should pay." Then the PCT turns round and says, "No, actually that's an Education issue." It feels like we're having to fight and it wastes valuable time because we have to wait for the local authority and the PCT to meet somewhere in the middle about something which could be helping and making a difference now."

Mother of a teenager who experienced a brain haemorrhage as a child

"It doesn't feel like Health, Social Care and Education are partners. It's obvious to us that our daughter's situation requires tri-partite funding and a pooled budget to deliver best value but Health seem to be saying that because her needs are 'more in the social care area', they don't have any responsibility. I don't understand it – surely it's not one or the other."

Mother of a young adult with complex needs

"Both of my boys have complex epilepsy. They're mobile and have no sense of danger. One of them has seizures where he stops breathing – he needs suction and oxygen to help him recover. It's a big responsibility for me as a carer to leave him in someone else's care. I get some help when I'm in the house using Direct Payments but I believe Health should be providing more so that I can get some sleep. I need someone who's properly trained by Health to be awake and watching both boys."

Mother raising children on her own

Several families also talked about key workers. They said:

"I think that every family should have a key worker allocated on diagnosis that their child has a disability. They can pull all the services together, co-ordinate everything and be there on the end of 'phone... It's needed through every different stage of a child's life. I also think that parents who have a disabled child would make very good key workers – that would be a way of using the skills and experience that are out there already."

Mother of a daughter with quadriplegia cerebral palsy

What does good look like?

An integrated approach to working with families means contacts with different aspects of healthcare are co-ordinated, communication between different agencies and teams is good and healthcare is linked into the support that other agencies can provide. It involves partnership working with parents over time, the opportunity to develop key relationships and joint planning that is multi-agency in scope.

Some of the families interviewed were able to talk about their experience of these approaches in action. They said:

"Our WellChild Nurse has made a real difference. She came up with the idea of a Hospital Passport, which was such a good idea. The first page was my daughter's name, who her family is – much like the Family File you get with Early Support. A4, 4 or 5 sheets. The idea is that you keep that in your bag so you can hand it over so you don't have to go through everything again, and again, and again, and again."

Parents of a baby with complex needs

"The Community Team from the Children's Trust, Tadworth have helped us since we've returned home – for example the sort of things we should look for in the two secondary schools we've been considering. At the time of discharge from the specialist centre, they got our local team involved in the discharge meeting. One of the Physios travelled South and sat in on the meetings. They'll provide Brain Injury Education for the school we've chosen, as well."

"I've requested that all the people my son has appointments with meet together and at my son's place to have a team meeting. It's easier for him than meeting all of them separately in different places. They've always been great about it and they all learn from each other. They get a lot more information and also get to meet one another and pass on ideas."

Mother of a young man with complex needs including Autism

"When things were particularly difficult and we thought our son only had months to live, we had a care planning meeting. The Consultant Endocrinologist, who oversaw a lot of his care asked me who we would like to have there and we organised the meeting for a day when all the key people could come – including the Consultant Neurologist. They also asked me where I wanted to meet and whether I wanted to Chair. That was brilliant."

Mother of a young man with complex needs

Reform as an opportunity to improve services

EDCM recommends that the modernisation of the NHS:

- Establishes a Clinical Network for children as part of the development of NHS Commissioning Board activity, with a defined responsibility for developing care pathways for disabled children and young people. Some good examples of pathways already exist that should be incorporated into this activity – for example, care pathways for particular conditions such as Down Syndrome and the ACT Pathway for children with palliative care needs. Therapy services should be involved in this activity appropriately alongside medical staff and any new care pathways or national standards should build coherently on the National Service Framework for Children (NSF) and work already completed by NICE.
- Promotes the development of key worker services for families with disabled children and engages with the national training for key workers being planned as part of development activity associated with the *Support and Aspiration* Green Paper. The expectation that health professionals will sometimes take on the role of key worker for a multi-agency team of practitioners should be explicit within NHS Commissioning Board advice and guidance.
- Encourages tertiary and acute services used by families who live at a distance to employ a nurse with designated responsibility for co-ordinating appointments and service provision and communicating with local services in the area a family lives
- Ensures it is in the financial interests of providers to work in an integrated way – for example, meeting jointly with families, rather than making appointments

to see them separately.

- Clarifies how Clinical Commissioning Groups, Local Health and Wellbeing Boards, Health Education England and the NHS Commissioning Board will work together to improve the integration of services for families – all have defined responsibilities in this area.
- Collects and publishes successful experience of joint planning and joint funding by NHS services and local authorities to meet the service needs of disabled children and young people, to support the early development of Health and Wellbeing Boards.
- Participates in the development of the new single assessment and annual review process using an Education Health and Care Plan being developed in *Support and Aspiration* Pathfinder Areas. This initiative provides a critical, new opportunity for health and other agencies to share information about individual children and young people.

Challenges

Information is an important element within the modernisation of the NHS generally and in the continuing work of the NHS Future Forum. The Government says:

'We know that navigating the NHS can be challenging, particularly for the families of children with multiple needs. In a context of far more openness and transparency about local health services, families will have access to a much greater range of information, which will help them to make the most of the services available. This will include better information on patient experiences.'

Achieving equity and excellence for children (2010)

The families interviewed often returned to the The The difficulty of developing accurate, robust data in a standard format about disabled children and young people is an enduring issue for local areas and for national agencies. The Government review of services in 2006 noted that the information available does not present a full picture of the quality of provision for families in different areas, but that there was evidence disabled children and families were offered different levels and standards of care and that those most in need were not always the most likely to get support.¹¹

Reliable performance information about the use and value of services is critical to commissioning decisions. Good information and a culture that enables patients and carers to make use of information are both critical to shared decision-making. At operational level 'good information' means, amongst other things, clear information for families about the services and options available, and an effective dissemination strategy to ensure families receive information they need at the right time. Clinicians also need high quality, user-friendly information about conditions and the services that are available to use with families at the time of diagnosis.

As a matter of principle, information for families should be created in partnership with parents. User generated content is higher quality and usually better-targeted. Community-based disability organisations and disabled people should also be included in local initiatives to develop better information for families about health services to check accuracy and to ensure a more positive image of life as a disabled person is projected.

The experience of families

The families interviewed often returned to the theme of information and highlighted particular difficulties with accessing accurate information about the services available in their area and bad

experiences at the time that information about their child's disability was shared with them. They said:

"I would have liked someone to have talked us through a checklist of information about the services that are available locally early on – a sort of menu of things that we might not need right now, but might need later."

Father of a young son with complex needs including Autism

"She had various tests. One was a brain scan and I was told that the discs at the back of the eyes weren't right. That meant nothing to me. Then we went to have some blood tests and I told the Phlebotomist who said, "Oh, I like that sort of thing, can I look in her eyes?" Then he said, "Oh, she's blind, isn't she?" That's how we found out."

Mother of a young woman with complex needs

"We've struggled with lack of communication, or mis-communication and it's been an issue right across the system - at the hospital, with our GP - everywhere. For example, we were shown around the local Hospice, which is lovely. We understood that we could stay there with our daughter and that they could then unlock the adjoining door and the other children could stay with us. We could all be together. We arranged a stay there but then it turned out one of us could stay with our daughter while everyone else would be upstairs. If we're split up, it's not respite to us. We ended up not going, because we weren't comfortable with it."

Parents of a baby with complex needs

“Information’s very hit and miss. I’ve worked for the NHS and so can say that no-one tells you anything. For example, I only heard through other people that I could get nappies from the Incontinence Service when my child was 3 although I was attending groups regularly where there was a Health Visitor.”
Mother of a young woman with complex needs

“Someone said, “You know you won’t be able to work and you’ll have to claim DLA, don’t you?” I said, “Are you telling me my child’s disabled?” It was quite shocking to me that I wasn’t prepared for that. That someone didn’t sit me down and explain there might be developmental implications. We were asked a lot of questions by medical people, but no-one ever explained why they were asking.”
Mother of a young son with complex needs

What does good look like?

Families also talked about their good experiences. They said:

“I know people are there to give advice and I know I can ring them to get advice.”
Mother of a young man with complex needs

“We find it’s always helpful to talk to people at least twice. The first time covers the obvious things, but you need to come back when you’ve had time to process it. We keep a notebook by her bed and write down all the questions we need to ask. People are good when you do that and will answer exactly what you ask.”
Parents of a baby with complex needs

Reform as an opportunity to improve services

EDCM recommends that the modernisation of the NHS:

- Requires local authority and NHS systems to standardise the data they collect on service use by families with disabled children and requires Local Healthwatch groups to monitor the quality of information coming into the system about families with disabled children.
- Requires Health and Wellbeing Boards to develop a joint dissemination strategy for information about the health, education and social care services available in their local area and to link this activity with the development of the ‘Local Offer’ proposed by Support and aspiration, the SEN Green Paper.



Challenges

Transparency is a guiding principle for many different aspects of NHS provision. At one level, the NHS Outcomes Framework puts information about the quality of services delivered into the public domain to deliver accountability. At another, governing bodies of Clinical Commissioning Groups will be required to meet in public and publish their minutes. Clinical Commissioning Groups will also have to publish details of the contracts they have entered into with health services. At an individual level, patients cannot participate in decision-making about their care or treatment in partnership with clinical, nursing or therapy staff if they do not have a transparent picture of the options and services available. The Government says:

'Our White Paper declaration, 'no decision about me without me' aspires to an NHS where patients are involved fully in their own care, with decisions made in partnership with clinicians, rather than by clinicians alone.'

Government response to the NHS Future Forum report June 2011

Disabled children and young people are unusually heavy users of health services and are disproportionately disadvantaged by the poor operation of services, but families with disabled children often do not receive transparent information about the services they use or what is likely to happen next. The services they use are not specified within the NHS Outcomes Framework, which seriously compromises accountability. At the same time, and at an individual level, the ideal of partnership and joint decision-making between families and health services links directly to the use of Family Service Plans with young children and person centred-planning with young people – both of which are multi-agency in approach. However, very little has yet been said to link the notion of 'no decision

about me, without me' as understood by the modernisation of the NHS to the development of Education, Health and Care Plans in SEN Green Paper Pathfinder Areas.

It is difficult to be confident that the service needs of this particular group will attract greater attention as the Outcomes Framework develops, given the pace and scope of change being developed through the operation of Clinical Commissioning Groups – which means transparency remains an issue.

The experience of families

Families are well aware of issues relating to transparency at national level. They said:

"What's so sad is the years that have been lost because there doesn't seem to be any clinical leadership for services for disabled children or even children in this area. And there haven't been any targets that they need to reach and so they're not interested. They're only interested in targets and services for adults."
Mother of a child with complex needs (group discussion)

They are also aware of the unjustified variation in service quality and service provision in different parts of the country. They said:

"I struggle to understand why Health feels my daughter is not their responsibility as we plan for her transition to adult services. We're looking for an integrated package of care to address her sensory needs, incontinency needs, mobility and equipment needs, hormone management and mental health/behaviour support needs. Health is one important component of that package and we know this sort of thing is available in other parts of the country. We've been told that a Continuing Healthcare Assessment will be carried out, but that this only covers nursing care and is normally only available in life threatening and life limiting conditions. I know from conversations with families in other parts of the country that this is not the situation elsewhere. How have such incredibly tight eligibility criteria been allowed to develop in our area? Why is there such a postcode lottery?"

Mother of a young woman with complex needs

Families need information about services and about how the system operates in order to be able to participate in joint decision-making. Some parents talked in particular about the lack of transparency they had experienced as critical decisions were taken about educational placements for their children or referrals to a specialist centre outside their local area. They said:

"It's a mystery to me how the whole thing works to be quite honest. For some things, one agency makes a decision. For other things, three agencies seem to have to be involved."

"I was told, following a very traumatic start, that it was crucial for my daughter's recovery that she came to the specialist facility here. Some of the neurological pathways had been severely damaged and some had been completely obliterated and so she needed to learn to do everything again. But the PCT refused to fund even an initial assessment, which was a week-long process where children are seen by a range of professionals. It seemed like I was on the 'phone or writing letters and emailing every minute of every day. Everyone treating my daughter was behind us, the services here were waiting to admit her, but the PCT was not responding to emails or 'phone calls. It took six months and it has remained a mystery why there was such a problem."

Mother of a teenager who experienced a brain haemorrhage as a child

Reform as an opportunity to improve services

EDCM recommends that the modernisation of the NHS:

- Makes services for children and young people with disabilities an identified priority for improvement within Domain 4 of the NHS Outcomes Framework (Ensuring people have a positive experience of care).
- Develops thinking and practice around the health related quality of life for carers (2.4) identified within Domain 2 (Enhancing quality of life of life for people with long term conditions), which is critical.
- Ensures that Monitor plays an active role in assuring health services are delivered in the interests of disabled children, young people and their families'
- Ensures a set of standards for service delivery to children and young people with SEN and disabilities is developed to support the emerging activity of Health and Wellbeing Boards. This work should be supported by the Department of Health and Department for Education, building on Standard 8 of the National Service Framework for Children, should cover local authority, NHS and joint activity and be linked to competence requirements.

General Practitioners are at the heart of

current reforms. The Government says that their proposals for future NHS commissioning arrangements are designed to be rooted in, and build upon, the central role that general practice plays in coordinating patient care and acting as the patient's advocate. The Future Forum's report agreed that general practice has a unique role to play. When people need healthcare, general practice is often the first place they turn, giving GPs and other practice staff a strong relationship with their patients and a broad overview of their community's health needs. They also say:

'GPs are central to the integration of patient care. They can link patients to other patients and carers and to a range of different clinicians, and can link those clinicians to each other and to other health and social care professionals.'

Government response to the NHS Future Forum report June 2011

For families with disabled children it is significant that GPs also have a key role to play in monitoring and maintaining the health and wellbeing of carers.

The experience of families

However, a recent survey conducted by Contact a Family indicates that standard assumptions about the relationship between GPs and patients often do not apply in the case of disabled children referred to secondary and tertiary services or placed in residential special schools. The survey of more than 1,000 families with disabled children in England reported that 75% never visit their GP about their child's disability or condition. Almost the same number reported their GP never offers them support in their role as a carer. 66% wanted their GP to have a better understanding of their child's condition. 61% wanted better support for parent carers and families from GP. 62%

wanted to see better joint working between GPs and other professionals.¹²

Families interviewed by EDCM confirmed that GPs are not normally central to the care of children and young people with complex needs. They said:

“If you have a child with complex needs, you rarely see your GP. Everything comes through your Paediatrician. They’re your main contact.”

“Every appointment your child goes to, a letter goes to your GP – he should be the main guy. But I don’t feel I have a relationship with my GP when it comes to my daughter – I just feel he’s got no time. You’ve got a five-minute slot and what needs to be done can’t be done in five minutes.”

Mother of a child with complex needs including Autism

This creates particular challenges at the time of transition to adult services and when children are in a residential setting away from home but still need their GP to prescribe medication:

When my daughter moved to residential school at 11, she was registered with the GP near the school. Soon she’ll be discharged from Paediatric Services into the care of our GP. We’ve tried to keep her alive in the minds of the people at our local surgery, but our GP hasn’t actually seen our daughter since she went away to school. You feel anxious losing the paediatric service that you know and the knowledge of our daughter they’ve built up over the years.”

Mother of a young woman with complex needs

“My GP eventually asked whether my daughter could move to a GP here because they were being asked to prescribe all kinds of medication for a child they never see. The children are seen by doctors based at the school. I don’t know how this work if GP Consortia go ahead and it worries me. Are the GPs who happen to be located close to a specialist facility like this one going to fund all these children? Has anyone thought about it?”

Mother of a child with complex needs

The families interviewed also highlighted issues for carers. They said:

“I’ve lived for 23 years now with sleep deprivation and chronic stress, but my GP’s never once said, “I’d like to do an M.O.T. on you. Can you make an appointment and come in?”

Mother of a young man with complex needs

“I kept being sent to the GP. I asked, “Is there anything practical you can do to help?” They said, “Well, I can offer you some anti-depressants.” I was offered pills four times.”

Mother of a young boy with complex needs

12. Putting families with disabled children at the heart of the NHS reforms Contact a Family May 2011

What does good look like?

In sharp contrast, some of the families interviewed talked about the positive experiences they had with GPs and the impact this had on their daily quality of life:

"I've got a good relationship with my GPs and the receptionist now, although it's taken 4 years to build that up. One of the doctors told me he wasn't worried about my son, but he was worried about me. He actually listened to me for the first time and he's the one who asked me what difference I think all the changes for GPs might make to our lives. He was really interested and that was good - I haven't heard about many GPs asking their patients who have disabled children that."

Mother of a child with complex needs

"My son has very special needs but also has run of the mill illnesses. I'm lucky because with his consultants I know that all I need to do is pick the 'phone up if I have any worry or concerns and we can talk about medication. Same with my local GP. If we've had an appointment at hospital and he's received a letter, he quite often gets on the 'phone to discuss it."

Mother of a young man with complex needs

Reform as an opportunity to improve services: effective commissioning of specialised services for children with complex health needs

- The experiences reported by families indicate an unacceptably wide range of contact and quality in the services families with disabled children receive from their GP and that many community-based GPs and Clinical Commissioning Groups do not have

the knowledge and experience required to commission universal or specialist services for disabled children and young people. Clinical Commissioning Groups, being smaller in size than Primary Care Trusts (PCTs) and commanding smaller budgets, may also struggle to meet the costs of specialist health services for children and young people with complex, low-incidence conditions. At the very least, Clinical Commissioning Groups will require specific advice and guidance from the NHS Commissioning Board to discharge their responsibilities for families with disabled children. In the particular case of children and young people with high-cost, low-incidence conditions, it is not clear how the commissioning of specialist services fits into the reformed health system. It may be necessary for some of these services to be commissioned at regional or national level, perhaps under the auspices of Clinical Senates.

EDCM recommends that the modernisation of the NHS:

- Makes it an explicit responsibility of the NHS Commissioning Board to maintain national oversight of service provision to families with disabled children and to develop guidance and advice to Clinical Commissioning Groups about this population.
- Includes careful consideration of how reforms will impact on the commissioning of specialist health services for children with high-cost, low-incidence conditions
- Builds better understanding of the service needs of disabled children and young people through the activity of Health Education England and ensures the letter and spirit of 'reasonable adjustment' under the Equalities Act is followed as universal services are delivered.

Patient involvement and participation in the design of pathways and system change

Families with disabled children often have unusually rich and varied experience of using NHS services to share, and therefore should be key partners for the modernisation process as it reviews and improves services. The Government says:

'If we are to meet the needs of families, young people, families and carers, it is vital that we listen to them in designing services, gather information on their experiences and priorities, provide them with the accessible information they need to make choices about their care, and involve them in decision-making.'

Achieving equity and excellence for children (2010)

In the case of parents of children and young people with disabilities there is already useful learning available about the positive impact of participation and partnership working with service users to develop appropriate pathways and services. The ACT *Integrated Multi-agency Care Pathways with Life-threatening and Life-limiting Conditions* and the development of the National service Framework for Children provide good, practical examples at national level¹³ and the experience of many local areas through the period of *Aiming High for Disabled Children* is also highly relevant.

Parents and carers should, therefore, be involved in the modernisation of the NHS at every level. In practice, this means Health and Wellbeing Boards and Clinical Commissioning Groups engaging with Parent and Carer Forums, particularly in early implementer, pathfinder or pilot areas. National agencies like the NHS Commissioning Board should approach and engage the National Network of Parent Carer Forums in their planning

and development activity, as the most efficient mechanism to tap the collective voice of families.¹⁴

Strengthening the individual and collective voice of patients is key to ensuring better outcomes as modernisation of the NHS gathers momentum. Parents of disabled children said:

"I think with all these services that if the people who make the big decisions actually spoke to parents, I'm sure they could do things better. But they need to really listen, rather than just turn up and then tick a box to say that they've attended and have consulted with parents."

Mother of a son with a rare condition

Reform as an opportunity to improve services

EDCM recommends that the modernisation of the NHS:

- Identifies families with disabled children as a particular focus within the Government assessment of how well Pathfinder Clinical Commissioning Groups are involving patients and the public in their activity and publishes information about this group
- Puts the guiding principle of strengthening the collective voice of patients into practice by encouraging Health and Wellbeing Boards, Clinical Networks and Clinical Senates to engage with Parent and Carer Forums in local areas and the NHS Commissioning Board to engage with the National Network of Parent Carer Forums.

13. To find out more, visit www.act.org.uk

14. To find out more, visit www.cafamily.org.uk/families/parentparticipation

Conclusion: achieving equity and excellence for disabled children and their families

Achieving equity and excellence for children

describes how the modernised NHS will put children, young people and their families first and:

- shared decision making will become the norm: *no decision without me*
- patients will have access to the information they want, to make choices about their care
- the system will focus on personalised care that reflects individuals' health and care needs, supports carers and encourages strong joint arrangements and local partnerships.

It also describes how Government will strengthen the collective voice of patients and the public through arrangements led by local authorities and, at national level, through a powerful new consumer champion, HealthWatch England, located in the Care Quality Commission (CQC).

This briefing highlights families with disabled children as a group with highly-developed experience of NHS services in operation and practical experience of inefficiency and fragmentation to contribute as services are reformed. They are a key group with whom the modernisation process should consult.

It also identifies key questions for the reformed system – particularly about how the NHS Commissioning Board will develop to support Clinical Commissioning Groups to deliver high-quality, well-integrated services for families and about how the system will be accountable.

EDCM has been careful to acknowledge that many examples of good practice have developed in local areas that can also be used to support service improvement. The issues are about the system, not particular practices or individuals. As one parent said:

"I worry about the parents who are so tired and ground down that they just give up. They don't have the skills to fight and don't know where to go. When I got involved in the Parent Carer Network it brought home to me that the question is why the system works so well for some parents and not others. The good things that are happening are not happening for every family."

Parent of two children with complex needs including Autism

It is not acceptable for the current modernisation of the NHS to perpetuate a system that fails families with disabled children. EDCM believes that there is a clear choice for Government: act now and use the opportunity of reform to create a system that works for disabled children, or proceed with reform concentrating mainly on adults and leave families with disabled children struggling to fill the gaps.



Summary of recommendations

Priority recommendations for immediate action:

National leadership

The Health and Social Care Bill should require the Secretary of State to set priorities for child health as part of his Mandate to the NHS Commissioning Board

As a matter of urgency, the Department for Health should set out a clear vision for the way in which the reformed system will meet the needs of disabled children

Commissioning

The NHS Commissioning Board should establish a Clinical Network for children, with a defined responsibility for developing care pathways for disabled children and young people

Health and Wellbeing Board early implementers should be asked to test and report on integrated working for the delivery of services for disabled children which includes all relevant partners – e.g. education services

Careful consideration should be given to the impact of current reforms on the commissioning of specialist health services for children and young people with high-cost, low-incidence conditions

Individual children and families

Information and support should be provided to disabled children, young people and their families to ensure that they understand the way in which the changing health system will affect them.

Further recommendations for the modernisation of the NHS

We recommend that the modernisation of the NHS:

- Prioritises improved routine two-way communication between tertiary specialist providers of health services and local and primary health providers with whom families have regular contact.
- Builds on the existing successful examples of patient passports and family held records – e.g. the Early Support Family File - to avoid requiring families to repeat the same information over and over again.
- Monitors the experience of health service provision by families with disabled children as an integral part of development activity in ‘Support and Aspiration’ Green Paper Pathfinder Areas.
- Promotes the development of key worker services for families with disabled children and engages with the national training for key workers being planned as part of development activity associated with the ‘Support and Aspiration’ Green Paper.
- Encourages tertiary and acute services used by families who live at a distance to employ a nurse with designated responsibility for co-ordinating appointments and service provision and communicating with local services in the area a family lives.
- Ensures it is in the financial interests of providers to work in an integrated way – for example, meeting jointly with families, rather than making appointments to see them separately.

- Clarifies how Clinical Commissioning Groups, Local Health and Wellbeing Boards, Health Education England and the NHS Commissioning Board will work together to improve the integration of services for families – all have defined responsibilities in this area.
- Collects and publishes successful experience of joint planning and joint funding by NHS services and local authorities in meeting the needs of disabled children and young people, to support the early development of Health and Wellbeing Boards.
- Ensures that Monitor plays an active role in assuring health services are delivered in the interests of disabled children, young people and their families’
- Participates in the development of the new single assessment and annual review process using the Education Health and Care Plan being developed in ‘Support and Aspiration’ Green Paper Pathfinder Areas.
- Requires local authority and NHS systems to standardise the data they collect on service use by families with disabled children and requires Local HealthWatch groups to monitor the quality of information coming into the system about families with disabled children.
- Requires Health and Wellbeing Boards to develop a joint dissemination strategy for information about the health, education and social care services available in their local area and to link this activity with the development of the ‘Local Offer’ proposed by Support and aspiration, the SEN Green Paper.
- Makes services for children and young people with disabilities an identified priority for improvement within Domain 4 of the NHS Outcomes Framework (Ensuring people have a positive experience of care).
- Develops thinking and practice around the health related quality of life for carers (2.4) identified within Domain 2 of the NHS Outcomes Framework.
- Ensures a set of standards for service delivery to children and young people with SEN and disabilities is developed to support the emerging activity of Health and Wellbeing Boards. This work should be supported by the Department of Health and Department for Education, building on Standard 8 of the National Service Framework for Children,
- Makes it an explicit responsibility of the NHS Commissioning Board to maintain national oversight of service provision to families with disabled children and to develop guidance and advice to Clinical Commissioning Groups about this population.
- Builds better understanding of the service needs of disabled children and young people through the activity of Health Education England and ensures the letter and spirit of ‘reasonable adjustment’ under the Equalities Act is followed as universal services are delivered.
- Identifies families with disabled children as a particular focus within the Government assessment of how well Pathfinder Clinical Commissioning Groups are involving patients and the public in their activity and publishes information about this group.
- Encourages Health and Wellbeing Boards to engage with Parent and Carer Forums in local areas and the NHS Commissioning Board to engage with the National Network of Parent Carer Forums.