



Making GP practices more welcoming for families with disabled children

Information for GP practice teams

It can be difficult for disabled children to visit their GP

In a recent national survey 75 per cent of parents of disabled children said they did not take their child to see their GP. Many parents say they find it easier to take their disabled child to A&E.

This booklet:

- explores the consequences if disabled children are seen in A&E rather than by their GP practice
- explains why families of disabled children find it difficult to visit their GP
- makes practical suggestions for GP practices, to make it easier for disabled children to visit their GP.

Disabled children can have complex health needs and be seen by many different health professionals in

primary, community, secondary and tertiary settings. When a large number of professionals are seeing a child, there is increased risk of fragmentation of care.

Of particular importance is information sharing with the GP, where a child's medical record is kept.



What parents told us about visiting their GP

"No GP involvement since diagnosis 13 years ago."

"My son has Duchenne Muscular Dystrophy and asthma and on several occasions I have been unable to get him a GP appointment and he has been admitted to hospital twice because of this."

"Our GP does not want to see our son because of his challenging behaviour, he diagnoses him without seeing him."

Consequences of inappropriate use of Accident & Emergency

Families of disabled children often prefer to take their child to A&E as they find it difficult to access their GP.

The consequences of this are:

- in A&E, the disabled child is seen by doctors not familiar with the child's medical condition or history.
- doctors in A&E are not able to view the child's medical record
- the child can wait for hours to be treated for simple illnesses which could be treated by the GP
- GPs do not see the child so miss opportunities to get to know them and their family and be kept informed about the child's additional needs and the support they access
- if the hospital does not have up-to-date details regarding a child's GP, discharge paperwork may get sent to the wrong surgery. This can result in important information not being transferred to the child's medical records
- GPs do not know if the child is getting the support needed early on to maximise health outcomes and ability to live independently as an adult
- when the child moves to adult services, the GP often becomes the lead professional responsible for coordinating care, yet has not seen the child for years so is not familiar with the medical condition and history
- GPs are the main contact by Department for Work and Pensions for Disability Living Allowance claims. GPs do not have the information they need to be able to respond to queries regarding the child's claim
- GPs can find it difficult to identify parents of disabled children to support their needs. This may include carrying out a carer's assessments and signposting families on to carers support organisations. Having a disabled child can affect the whole family's physical and mental wellbeing.

"I have not seen my GP since I was diagnosed with Osteogenesis Imperfecta at the age of two. They are frightened to treat me as they do not know anything about my condition. Last time I had a chest infection I had to wait for four hours in A&E to get a prescription for antibiotics."
Teenager with a form of brittle bone disease

Appointments – what families find difficult

When asked, families frequently talk about the amount of stress incurred by both parent and child even before they get into the consultation room.

Appointments and waiting

Children/young people with neurological conditions or learning disabilities can become very frightened if taken to a place they are not familiar with. Some have sensory overload making it difficult for them to be in a room full of lots of people. They can become very agitated if they have to wait a long time.

If the child cannot understand speech it can be difficult to explain to the child why they are there and why they need to wait. When a child is unwell, their behaviour may be negatively affected by other factors such as experiencing pain.

If the child becomes distressed or agitated, they might show it by becoming noisy, rocking forward

and backwards or trying to leave the building. This is the child's way of communicating their distress and desire to leave.

Parent carers often feel very uncomfortable when this happens. Parents frequently report that they think others in the waiting room blame them for their child's behaviour and do not understand it is because of their child's disability.

As the waiting time gets longer, it becomes more and more difficult to keep the child calm and quiet. It is much easier to manage a two year old having a tantrum than an older child/young person who has a severe learning disability.

If the child has become distraught in the waiting room, it is more difficult for the clinician to examine them and take a medical history.

What parents told us about appointments

"The reception staff were rude and unsympathetic when I asked how long we would have to wait."

"Our child had to wait too long, the GP could not examine him and we were sent to A&E for what was an ear infection."

Appointments – some simple solutions

Invite families to tell you how to best fit their additional needs regarding time, appointments, waiting, also:

- **offer carers appointment times at the start of clinics** when there is likely to be less of a wait
- **offer the option of waiting in a quiet room** if one is available
- **give parent carers a card to show to the receptionist** when arriving to tell them about their child's additional needs. For example: finds it difficult to wait, prefers quiet room, child upset by eye contact. The receptionist then becomes aware of the issues and the parent carer does not have to talk about it in front of others



- **offer parents the option of waiting in their car outside** and being telephoned on their mobile when the doctor is nearly ready to see them
- **ask receptionists to let parent carers know if there is going to be a long wait** so they can go for a walk and come back. This can be much easier than waiting for a long time
- try to ensure staff in the practice are trained in disability awareness.

What parents told us

"I wait in the car until the doctor is ready to see me – the receptionist rings me and we walk straight in."

"My son regularly attends the doctors due to asthma and allergies. Service is exceptional, our GP is patient and understands the difficulties bringing him to the surgery brings."

"I have a card which I show to the receptionist and doctors. It says my son has fetal alcohol syndrome and I am his foster mother. This means I don't have to say it out loud and they don't blame me for his condition."

Seeing the same GP – why this is important

Families tell us that in some GP practices, it is not possible to ask to see the same named GP on subsequent visits.

The consequences of this are:

- the parent has to repeat their child's considerable medical history on each visit, which can be both time consuming and distressing
- the child does not become familiar with one doctor, which makes subsequent visits just as stressful as the first
- the doctor does not become familiar with the child, their medical history and how the child might respond to being examined
- doctors are more likely to fall into the trap of diagnostic shadowing, or alternatively send the child to hospital for minor illnesses
- the parent finds their GP practice is not helpful so does not come back.

Changes in behaviour can be a symptom of a medical problem

If a child has severe communication problems then it is often a change of behaviour that alerts the parents that there is something wrong.

If it is the first time the GP has seen the child it is difficult for them to know



what typical behaviour is for that child. The doctor will need to do a more thorough physical examination to try and determine the nature of the problem.

Children with disabilities can find it very stressful to be examined by a clinician, especially if they are unable to understand what is going to happen and why.

What parents told us about being able to see the same GP

"Not helpful, I see a different one all the time."

"Health issues are too complex – they cannot read all the notes."

"If they do not know them, how can they help."

"Our daughter has not seen her GP in almost 4 years because of an incident that scared her at the surgery she will not go in – we have to bring her to A&E."

Consultations – what can help

Have an appointment system that allows patients to book an appointment with the same GP, accepting this might not always be possible for urgent appointments and:

- **offer double appointment times** – so there is more time in the consultation to communicate with the child and parent and to find what has been happening since the child was last seen
- **make use of a hospital passport³** – families sometimes use hospital passports or communication passports to share information about their child with the health professionals involved. Ask the family to bring it with them

Spot the Sick Child² see www.spottingthesickchild.com

This is a new interactive tool commissioned by the Department of Health to support health professionals in the assessment of the acutely sick child.

A module on working with children who have learning disabilities or find it difficult to communicate is to be added in Winter 2012/13.



when visiting the GP surgery so the practice finds out about the different professionals involved and treatments being carried out. The hospital passport is also useful in explaining things about the child, such as what might upset them, how they express themselves, routines they follow and how to tell if they are in pain

- **listen to parent carers** - they are often very knowledgeable about their child's medical condition and know what is typical behaviour and how their child communicates pain or distress
- **ask the parents what the child might find stressful** – before carrying out physical examinations explain to the parent/carer what the procedure entails and ask them whether they have any suggestions about how best to handle this

- **make use of easy read information**⁴ – to help parents familiarise the child with any medical procedures to be carried out – either in the GP practice or at hospital
- **ask the specialist in charge of the child's care for guidance** – regarding prescribing for minor illnesses or changing doses in their regular medication
- **have a disability/children's lead in the GP practice** – who works with families to find out what might be difficult for them when visiting the surgery and keeps the rest of the practice informed
- **pass information about reasonable adjustments to others** – if referring the child for consultations/tests/treatments make sure the letters of referrals includes information about any reasonable adjustments they might need to make.

NB Many of these suggestions are also likely to be helpful to other patients in your care, including adults with learning disabilities or dementia.



What parents told us

"We always get a fast appointment. The doctors take time to listen to my daughter and talk directly to her. They only ask me to help if she is unable to answer their questions about symptoms. They respond to my requests for referrals as needed and have undertaken research to find the best treatment."

"Our daughter has had lots of infections and whenever we ring the doctor they always get her in on the same day. They are also very considerate when it come to repeat prescriptions for her medications and the staff are always aware that she won't wait in the waiting area long and are very good at keeping me informed of locum doctors and nursing staff to help prepare her for the visit."

"Our GPs is good as she does admit she has limited knowledge of Noonan syndrome but will try her best to help."

References

¹ *Report into the extent of GP's involvement in disabled children's care 2011:*

www.cafamily.org.uk/professionals/research/

² Spot the Sick Child – interactive tool commissioned by the Department of Health to support health professionals in the assessment of the acutely sick child:

www.spottingthesickchild.com/

³ Examples of hospital passports for children:

www.cafamily.org.uk/parentparticipation

⁴ The Easy Health website has leaflets designed for people with learning disabilities which explain different medical procedures with pictures that can be downloaded and printed:

www.easyhealth.org.uk

Further reading

About profound and multiple learning disabilities – general fact sheet about people with profound and multiple learning disabilities, including information about their physical, sensory, mental health and communication needs and information about understanding their behaviour:

www.pmlldnetwork.org

Communication and people with the most complex needs: What works and why this is essential (July 2010) Different ways to communicate with people with complex needs and useful tools:

www.mencap.org.uk

DH - Equal access? – A practical guide for the NHS: Creating a Single Equality Scheme that includes improving access for people with learning disabilities:

www.dh.gov.uk



General Medical Council: Learning Disabilities – aims to help doctors provide better care for people with learning disabilities by identifying the issues and highlighting patient perspectives. It also provides practical ways to reduce the likelihood of discriminating against people with learning disabilities and the reasonable adjustments that should be made:
www.gmc-uk.org/learningdisabilities/default.aspx

Improving health and lives – reasonable adjustments – database of reasonable adjustments made for people with disabilities using examples sent in by NHS Trusts:
www.improvinghealthandlives.org.uk/projects/reasonableadjustments

UK health and learning disability network – includes a network for GPs with special interest in promoting primary health care for people with learning disabilities:
www.jan-net.co.uk/



About Contact a Family

Contact a Family is a UK charity that provides vital support and information to families with disabled children whatever the condition or disability. Through a national helpline and family support service, we provide advice on any aspect of raising a disabled child, including help with finances, education and getting the right support for children and their families.

How Contact a Family can help GPs

Our **medical directory** – see www.cafamily.org.uk – provides reliable information on many medical conditions, including rare syndromes, and also provides details of UK condition specific support groups

Our GP practice guide *services for disabled children* contains information to assist GPs in coordinating the care of disabled children.

We provide parent guides on a range of topics, including *Concerned about your child* which explains the role of the different health professionals and how they support disabled children

GP practice's can signpost families of disabled children to our freephone helpline on 0808 808 3555 for support on a wide range of topics.

We manage the Annette Chumley library which holds a range of information, reports and resources relevant to disabled children, their carers and the professionals who support them.

You can send the library and information team an enquiry: library.team@cafamily.org.uk

This guide was written by Sheila Davies of Contact a Family.

Thank you to the following for advice on content

Ella Baines – GP and parent of a disabled child

Janice Allister, Clinical Champion for Child Health, RCGP

The British Academy of Childhood Disabilities

<http://www.bacdis.org.uk/>

Carrie Britton –National Network of Parent Carer Forums

www.nnpccf.org.uk



Making our GP practice more welcoming

These questions are to support your GP practice to discuss how they might become more welcoming to patients with long term conditions or disabilities.

NB It might not be practical to implement all of these.

Activity	Yes/No	Lead person/people
Identifying patients with additional support needs and their carers		
1. Can we identify patients additional support needs on our computer system?		
2. Can we identify carers on our computer system?		
3. Could we introduce a card scheme so carer/patients can alert staff about their additional support needs?		
4. Any other ideas?		
Reducing stress of waiting		
1. Is it possible for receptionists to warn patients/carers with additional needs of long delays?		
2. Is it practicable for receptionists to telephone people who prefer to wait outside, so they know when doctor / nurse is nearly ready to see them?		
3. Is there a quiet room available some of the time which could be offered to patients with sensory overload?		
4. Any other ideas?		

Making our GP practice more welcoming continued...

Activity	Yes/No	Lead person/people
Appointments		
1. Is it possible to offer early morning/afternoon appointments to patients who find it difficult to wait because of their additional support needs?		
2. Is there a process for offering double appointments for patients with more complex needs?		
3. Can patients with long term conditions/disabilities book non urgent appointments to see the same doctor?		
4. Any other ideas?		
Consultations		
1. Do we have easy read information to use when explaining medical tests/treatments to patients who find it difficult to understand spoken language?		
2. Does our local hospital have a communications passport, and if so do we encourage patients/carers to use it?		
3. Who might check about feeding/eating, dental care, toilet training, behaviour and sleep in disabled children registered with us – and refer if necessary?		

Making our GP practice more welcoming continued...

Activity	Yes/No	Lead person/people
Consultations continued...		
4. Can we signpost carers to sources of support and do we offer health assessments for carers?		
5. Any other ideas?		

Notes

Notes

Getting in contact with us

Free helpline for parents and families
0808 808 3555

Open Mon–Fri, 9.30am–5pm

Access to over 170 languages

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:
209–211 City Road, London EC1V 1JN
Tel **020 7608 8700**
Fax **020 7608 8701**
Email **info@cafamily.org.uk**
Web **www.cafamily.org.uk**



Other information booklets available

Contact a Family provides guides for parents of disabled children on a range of topics.

The following ones might be of particular interest to health professionals. Most have been translated into six community languages:

- *Helping your child sleep*
- *Toilet Training*
- *Feeding and eating*
- *Understanding your child's behaviour (English only)*

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