

MAKING GP PRACTICES MORE WELCOMING



FOR DISABLED CHILDREN, YOUNG PEOPLE & THEIR FAMILIES



contact

**Every child has the
right to the best
possible health.**

*UN Convention on the Rights
of the Child, Article 24*

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INTRODUCTION

Disabled children can have complex health needs and often need to access many different health practitioners in primary, community, secondary and tertiary settings. However, children with disabilities are just like any other children and can get all the usual childhood illnesses and infections.

The family's GP is a vital point of contact when a large number of practitioners are seeing a child, because there is increased risk of fragmentation of care. Of particular importance is sharing information with the GP, where a child's medical record is kept.

Contact's *Caring More than Most*¹ research showed how disabled children and their families are at a significant disadvantage in many key aspects of life including their health, economic situation, employment and housing. This booklet:

- ***explains why families of disabled children find it difficult to visit their GP***
- ***explains why it is important to build relationships with families of disabled children as early as possible, and the importance of continuity of care***
- ***explores health inequalities and their impact on families with disabled children***
- ***suggests examples of reasonable adjustments that may help and introduces Parent Carer Forums as a source of advice***
- ***highlights the importance of Annual Health Checks for children and young people over 14 years***
- ***makes practical suggestions and offers a checklist for GP practices to make it easier for disabled children to visit.***

1 Caring More Than Most, Contact (2017)

WHAT FAMILIES FIND DIFFICULT

It can be difficult for disabled children to visit their GP. Research by Contact showed that 75 percent of parent carers of disabled children said they did not take their child to see their GP.¹ Many parents say they find it easier to take their disabled child to A&E.

Many disabled children will also have a learning disability, and recent work in this area shows that children with a learning disability are more likely to have unmet or unidentified health needs.² We also know that people with a learning disability are more likely to have poorer health than the general population.³

WHY IT CAN BE DIFFICULT FOR FAMILIES WITH DISABLED CHILDREN TO VISIT THEIR GP

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

- **Children/young people with neurological conditions, autism and/or learning disabilities can become very frightened** if taken to a place they are not familiar with.
- **Some children have sensory overload**, making it difficult for them to be in a room full 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 them 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 as other people may not understand the reasons why.

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.

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.

1 GP involvement in disabled children's care (2011)

2 Public Health England (2015) People with learning disabilities in England

3 Disability Rights Commission (2006)

GETTING TO KNOW FAMILIES EARLY

Disabled children are just like any other children and can get all the usual childhood illnesses and infections. However, normal childhood illnesses can have a different and sometimes greater impact on a child with an existing medical condition or disability. They can also be difficult to identify if it is the first time you have seen the child.

If a child is known to a paediatrician it can be tempting for the parent carers to go straight to the specialist support and not make contact with their GP. However, it is still important to build those relationships as it provides a holistic view, not just of the disabled child, but the whole family. It is particularly important to get to know more about families with disabled children when their child is approaching transition to adulthood, as this can be a very stressful time for them.



WHY SEEING THE SAME GP IS IMPORTANT

Seeing the same GP can help with continuity of care and building relationships. The NHS Constitution highlights that families can ask to see the same GP yet families tell us that in some GP practices this is not possible. Being able to see the same GP on subsequent visits means that:

- **The parent does not have to repeat their child's considerable medical history on each visit**, which can be both time consuming and distressing.
- **The child becomes familiar with one doctor**, which makes subsequent visits less stressful.
- **The doctor becomes familiar with the child**, their medical history, and how the child might respond to being examined.
- **Doctors are less likely to fall into the trap of diagnostic shadowing**, or sending the child to hospital for minor illnesses.
- **The family are more likely to visit their GP practice again.**

Equal access to healthcare is absolutely vital to the health and wellbeing of all disabled people. When services are designed and delivered by compassionate, caring staff with a flexible approach to access, communication and outcomes are improved.

Disability Matters in Britain (2016)

HEALTH INEQUALITIES & DISABLED CHILDREN

Children with disabilities are more likely to be impacted by health inequalities and have poorer health than the general population. Specific work around children with learning disabilities shows that they are more likely to live in poor households, less likely to have access to timely appropriate healthcare, including health promotion, and less likely to have the resources to build resilience.

There are many possible reasons why disabled children, including those with learning disabilities, can have poorer health than their non-disabled peers, including:

- **Healthcare staff lack of confidence or knowledge** about disability.
- **Difficulties of health care providers to make ‘reasonable adjustments’.**
- **A symptom of physical ill health being overlooked** and attributed to a mental health/behavioural problem or the person’s learning disabilities.
- **People with a learning disability not being able to express their ill health/pain.**

The consequences of families not visiting their GP can also add to the difficulties in accessing appropriate healthcare:

- **The child can wait for hours in A&E 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
- **Discharge paperwork may get sent to the wrong surgery** if the hospital does not have up-to-date details regarding a child’s GP. 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.
- **The GP often becomes the lead professional responsible for coordinating care when the child moves to adulthood**, yet has not seen the child for years so is not familiar with the medical condition and history.
- **GPs are the main contact for Disability Living Allowance and Personal Independence Payment claims** by the Department for Work and Pensions. They may 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 assessment and signposting families on to carers' support organisations. Having a disabled child can affect the whole family's physical and mental wellbeing.

WHAT PARENTS TOLD US

"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."

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

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

REASONABLE ADJUSTMENTS – SOME SIMPLE SOLUTIONS

Learning disability, autism and other disabilities have protections under the Equality Act 2010. These include reasonable adjustments to communication and services. Ideally these should be person and child-centred. Families and children and young people could be invited to tell you how to best meet their additional needs regarding time, appointments and waiting. Try to:

- **Arrange an appointment when the child is not ill to get to know their needs under less stressful circumstances** – the Annual Health Check could be used to develop this knowledge. It may also help the child become more familiar with the GP practice environment.
- **Offer parent 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 is then made 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 texted or called 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.

STAFF TRAINING

There are various free training courses that practice staff can access to improve the experience of parent carers and their children at your surgery.

Disability awareness training

Disability Matters has free online training, co-produced with parent carers.
www.disabilitymatters.org.uk

Accessible information training

NHS England has information to ensure staff are meeting the Accessible Information Standards.
www.england.nhs.uk/ourwork/accessibleinfo

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.”

REASONABLE ADJUSTMENTS FOR CONSULTATIONS

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

- **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.
- **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.
- **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.
- **Use a traffic light tool**, developed by a community paediatrician, to help parent carers identify issues they are concerned about. Find it under the SEND resources at www.bacdis.org.uk
- **Ask the parent carer 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** to help parent carers 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.
- **Make sure information about reasonable adjustments is highlighted in the Summary Care Record and pass onto others if referring the child** for consultations/tests/treatments. Make sure the referral letters include information about any reasonable adjustments they might need to make.

HOSPITAL OR COMMUNICATION PASSPORTS

Families sometimes use a hospital or communication passport to share information about their child with health professionals. See page 23 for more information. You can ask the family to bring it with them when visiting the GP surgery so the practice finds out about the different professionals involved and treatments being carried out. The hospital or communication passport is also useful in explaining other things about the child, like what might upset them, how they express themselves, routines they follow, and how to tell if they are in pain.



You can find examples of hospital passports by searching for them at **Bristol University Hospital's** website www.uhbristol.nhs.uk or **Cambridge University Hospital** at www.cuh.nhs.uk

LEARNING DISABILITY REGISTERS & ANNUAL HEALTH CHECKS

Reducing health inequalities for people with a learning disability is one of the key priorities in the NHS Long-Term Plan. Since 2014/15, all children and young people with a learning disability should be included on GP learning disability registers, and young people aged 14 and over should be offered an Annual Health Check.

Many disabled children and young people may not have a specific diagnosis of a learning disability but would benefit from the early intervention and support the Annual Health Checks provide.

Some children or young people may need significant preparation before having clinical interventions or even just to attend the surgery. Discussing the Learning Disability Register and Annual Health Checks with parent carers will enable practice staff to understand the child or young person's support needs, and any reasonable adjustments that may need to be considered.



The Royal College of General Practitioners has developed a toolkit on the registers and practicalities of Annual Health Checks. Search 'health checks' at www.rcgp.org.uk

NHS England also has information and resources at www.england.nhs.uk

BENEFITS OF BEING ON THE REGISTER & OFFERING ANNUAL HEALTH CHECKS

- **Better and more person-centred health care** for those individuals.
- **Building the child or young person's confidence** and familiarity with practice staff.
- **Better information about the health needs of people with disabilities** and any reasonable adjustments required.
- **An ability to anticipate an individual's needs** before they attend health or care settings.
- **Identification of parent carer's and sibling's needs** as carers.
- **Better planning of health and care services** for people with learning disabilities.
- **Better understanding and integration of needs** across health, care, education and employment.
- **Better transition planning for young people with learning disabilities** who are leaving school or college and approaching adulthood.



WORKING WELL WITH FAMILIES

STOMP AND STAMP

STOMP stands for Stopping Over-Medication of People with a learning disability, autism, or both, with psychotropic medicines.

STAMP stands for Supporting Treatment and Appropriate Medication in Paediatrics.

STOMP–STAMP is about all health care providers improving the use of psychotropic medicine, offering non-drug therapies and making sure that people, families and staff are fully informed and involved. It aims to:

- 1. Make the lives of children and young people with a learning disability, autism or both, and who are prescribed psychotropic medications, better.***
- 2. Make sure that children and young people who need medication get it for the right reason, in the right amount, for as short a time as possible.***
- 3. Help people to understand more about these medications and have the confidence to ask why they are needed.***
- 4. Make more non-medication treatments and support available.***
- 5. Make sure the person with their family and paid carers are involved in any decisions to start, stop, reduce or continue taking medication.***
- 6. Get more children and young people with a learning disability to have an Annual Health Check, starting from the age of 14.***



Find more information about STOMP–STAMP on the **NHS England** website www.england.nhs.uk

Although STOMP–STAMP is about psychotropic medication, the principles of the right medication, at the right time, for the right reason applies equally well to all disabled children. Regular and timely reviews that balance the effectiveness of medication against potential side-effects would be beneficial to all disabled children and young people. An Annual Health Check is a useful way to ensure all medication is reviewed regularly.

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 comes 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 GP is good as she does admit she has limited knowledge of Noonan syndrome but will try her best to help.”

ASK LISTEN DO – NHS ENGLAND

Giving feedback, raising concerns and making complaints can be difficult and time consuming. When caring for someone with a disability, this can be even harder.

Ask Listen Do has worked with families to develop a range of resources and top tips for giving feedback, raising concerns and making complaints. In developing these, families and carers wanted organisations to:

- ***understand the complex lives of families***
- ***think holistically about all the commitments families have***
- ***think about how it feels to be a parent carer***
- ***be aware of the whole picture when they speak to families and carers, and***
- ***treat them as equal partners, in the spirit of co-production.***

Co-production is a legal requirement under the Children and Families Act 2014 and Care Act 2014. It means organisations need to support people and families to have their say about the support and services they receive, and make sure people can influence the way that services are designed, commissioned and delivered.

It is important to ensure that children and adults with a learning disability and/or autism and their families, and those with other disabilities, know how to give feedback, raise concerns, or if they need to, make complaints. It is also important their voice is heard through existing engagement processes and reasonable adjustments are made for this to happen.



For more information look on the **NHS England** website
www.england.nhs.uk



COMMUNICATION PASSPORTS

A disabled child with communication needs may have a plan or passport that details how they communicate or any support they need to communicate. A Communication Passport provides a practical and person-centred approach to passing on key information about people with complex communication difficulties who cannot easily speak for themselves. A conversation with the parent carer will identify whether they have communication support needs.

FURTHER INFORMATION

Communication Matters

Information on supporting different communication needs and communication passports.

www.communicationmatters.org.uk

Mencap

Information on communicating with people with a learning disability.

www.mencap.org.uk

Disability Matters

Free e-learning modules learning packages, including an *Introduction for Health and social care staff*.

www.disabilitymatters.org.uk

ACCESSIBLE INFORMATION STANDARD

The Accessible Information Standard has been developed to help people who have a disability or sensory loss get information in a way they can understand, or to have support to communicate with health and care services. This means health and care services must:

- **Ask people about their communication needs** and how to meet them.
- **Clearly record those needs.**
- **Flag or highlight the person's notes** so that anyone can see and understand the persons communication needs and how to meet them.
- **With consent, share the person's communication needs** and how to meet them with other health and care staff.
- **Make sure people receive information in a way they can understand, or have the support to enable them to understand.** In practice this can mean some simple solutions such as easy-read documents, understanding and using a person's communication passport or providing communication support such as an interpreter.



Find more information on the **NHS England** website at www.england.nhs.uk

SUMMARY CARE RECORD & ADDITIONAL INFORMATION

Parent carers often tell us about the difficulties they face when meeting a new health care professional or when they have to repeatedly tell their child or young person's story.

A Summary Care Record, and the additional information that can be recorded in it, can help to minimise the difficulties families face when accessing health care services.

Having a conversation about adding additional information to the Summary Care Record will help improve understanding of the disabled child or young person's support needs. Once consent is gained, adding information to the Summary Care Record can help to improve the integrated care of disabled children and young people. Some examples of what could be added:

- **Reasonable adjustments** including: difficulties with waiting, needing a quiet room, longer appointments, wheelchair access.
- **Medical conditions** and who else is involved in the child or young person's care.
- **Any behaviour triggers** or issues with clinical interventions.
- **How the child or young person communicates** and how to support them.




More information is on the **NHS England** website at www.england.nhs.uk

MENTAL CAPACITY ACT 2005

This is applicable to young people 16+ and it is important to understand it and the rules around Gillick competence.

Family members cannot give informed consent on behalf of a disabled adult unless they have Deputyship, or Lasting Power of Attorney is in place through the Court of Protection. Families must be consulted as part of supported decision making (principle 2).

 You can find more information by searching on the NHS England website www.nhs.uk or by looking on **Disability Matters** e-learning at www.disabilitymatters.org.uk



HOW YOUR LOCAL PARENT CARER FORUM CAN HELP

What is a Parent Carer Forum?

A Parent Carer Forum is a group of parent carers of disabled children who work with local authorities, education settings, health providers and other providers to make sure the services they plan and deliver meet the needs of disabled children and families. In England there are Parent Carer Forums in almost all local authority areas.

Why work with a Parent Carer Forum?

Parent Carer Forums are often the one consistent element within the SEND agenda locally.

- **They have an understanding of what is happening** on the ground for families, they know what works and what doesn't work.
- **Forums should be working at a strategic level** with ALL area partners so can offer insight into the effectiveness of these strategic mechanisms for participation.
- **Parent Carer Forums are knowledgeable** about co-production and how this can improve services.
- **Parent Carer Forums have links** to local, regional and national networks and all the intelligence and information-sharing this can achieve.



For more information and contact details for your local Parent Carer Forum visit www.contact.org.uk

IMPROVEMENT CHECKLIST

This checklist will help 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		
Can we identify patients' additional support needs on our computer system?		
Can we identify carers on our computer system?		
Could we introduce a card scheme so carers/patients can alert staff about their additional support needs?		
Any other ideas?		
Reducing stress of waiting		
Is it possible for receptionists to warn patients/carers with additional needs of long delays?		
Is it possible for receptionists to call or text people who need to wait outside, so they know when the GP/nurse is nearly ready to see them?		
Is there a quiet room available some of the time which could be offered to patients with sensory overload?		
Any other ideas?		

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

RESOURCES & FURTHER READING

Disability Matters

Is a free e-learning resource for the UK workforce, co-produced with parent carers and young people. There is a wide range of e-learning modules and resources on all aspects of disability and caring for disabled children and young people.

www.disabilitymatters.org.uk

Easy Health

Leaflets designed for people with learning disabilities that explain different medical procedures with pictures to download and print.

www.easyhealth.org.uk

Mencap's *Don't Miss Out* guides

Guides and resources to help people understand Learning Disability Registers and annual health checks.

www.mencap.org.uk

General Medical Council's guidance on learning disabilities

Guidance 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

Improving health and lives – reasonable adjustments

A database of reasonable adjustments made for people with disabilities using examples sent in by NHS Trusts.

www.improvinghealthandlives.org.uk

HOW CONTACT CAN HELP GPS

Contact is a UK charity that provides support and information to families with disabled children, whatever the condition or disability.

GUIDE FOR GPS AND HEALTH PROFESSIONALS

Our guide *Health services for disabled children and young people* contains information to assist GPs in coordinating the care of disabled children. You can also order free leaflets about how Contact can help parents, credit-card sized helpline cards and posters for your surgery:
020 7608 8700 info@contact.org.uk

RESEARCH

Our research can help you understand the difficulties families experience in accessing services and support:
www.contact.org.uk/research

OUR SUPPORT FOR PARENTS

Contact's website provides advice and information about any concern parents might have about raising a child with additional needs or a disability. They can also call our free helpline:
0808 808 3555 helpline@contact.org.uk

OUR MEDICAL DIRECTORY


Our online medical directory has reliable, medically verified information on more than 400 medical conditions, including rare syndromes, plus details of UK condition-specific support groups parents can go to:
www.contact.org.uk/medical-information

GUIDES FOR PARENTS


We have free guides for parents on a range of topics. For a full list of our publications please visit:
www.contact.org.uk/publicationslist

GET IN CONTACT


Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

 0808 808 3555

 info@contact.org.uk

 www.contact.org.uk

 twitter.com/contactfamilies

 facebook.com/contactfamilies

 youtube.com/contactfamilies

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We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

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