

## Putting families with disabled children at the heart of the NHS reforms in England (2011)

Based on a survey of over 1,000 families with disabled children in England.

### Section 1: Key survey findings

- 76% don't visit the GP about their child's disability or condition.
- 13% don't visit the GP about their child's general health issues.
- For those that do visit the GP with their child, the quality of care is inconsistent:
  - Disability issues: 48% rated their GP service excellent or good, 24% rated it poor and 28% rated it fair.
  - A quarter said that their GP has no understanding at all of their child's condition or disability.
  - General health issues: 61% rated the service excellent or good, 10% rated it poor and 29% rated it fair.
- Almost three quarters (73%) say that their GP never offers them support in their role as a carer.
- 66% want GPs to have a better understanding of their child's condition.
- 61% want better support for parent carers and the wider family from GPs.
- 62% want to see improved joint working of GPs with other professionals.

### Section 2: Why these findings matter?

The Health and Social Care Act 2012 gives GP led clinical commissioning groups, a new role as commissioners of health services on behalf of their patients. Families with disabled children need a coordinated range of services across health, social care and education. Evidence demonstrates that services working together, in partnership, with the family achieve the best results for all.

Our survey findings raise concerns, because they show GPs are rarely involved in the care of disabled children, and so lack the understanding and contact with the services and support that help families with disabled children. A range of research has identified that many GPs do not have enough paediatric experience or training<sup>1</sup>. Clinical commissioning groups (CCGs) therefore may not have the knowledge to commission the range of universal and specialised services which families with disabled children need.

Although GPs cannot be experts in childhood disability or providers of specialised support for families with disabled children, as commissioners of health services, they will have an important new role via CCGs in commissioning effective healthcare services, including co-ordinating with other service planners and professionals across social care and education. Failure to do so will lead to family breakdown, and to disabled children not getting the care they need.

### Section 3: Recommendations

1. Clinical commissioning groups should work in partnership with parent carer forums in order that families experiences of services:
  - inform and scrutinize the commissioning of services for families with disabled children
  - help drive a culture change of collaboration and shared responsibility across health, social care and education.
2. Clinical commissioning groups should be required to publish evidence on how their commissioning processes are systematically engaging with families with disabled children and reducing health inequalities for them.
3. All clinical commissioning groups should have representations from across health, social care and education, and sufficient knowledge in a multidisciplinary approach to planning, commissioning and coordinating services for families with disabled children.
4. Although GPs cannot be experts in everything they should receive parent led training and demonstrate skills in:
  - understanding childhood disability and disability awareness
  - the impact of caring on family life
  - understanding the support and services relevant to families with disabled children
  - proactive signposting to help available according to individual family need; and e. .making reasonable adjustments for families with disabled children eg such as making appointments more accessible.<sup>2</sup>
5. National and local HealthWatch should meaningfully represent the views and issues of families with disabled children and ensure that parent carers are key members of the group.
6. Health and Wellbeing Boards, through their Health and Wellbeing Strategies must:
  - clearly define outcomes for disabled children and their families
  - have a transparent method of how these outcomes will be measured

<sup>1</sup> RCGP Child Health Strategy 2010-2015

<sup>2</sup> <http://www.cafamily.org.uk/what-we-do/parent-carer-participation/improving-health-services/>

- demonstrate how services across health, social care and education will work together and have joint responsibility for improving outcomes for families with disabled children. This includes considering how the local offer and short break statements link with this
  - publish how parent carers have been involved in developing these strategies and identifying the desired outcomes.
7. The Secretary of State for Health should ensure that improved outcomes for disabled children and their families will be a priority for the NHS Commissioning Board.

## Section 4: Purpose of survey

The Health and Social Care Act 2012 in England gives GPs a new role as commissioners of services on behalf of their patients through CCGs. The NHS Commissioning Board will be responsible for holding CCGs to account for the spending of NHS resources and for the outcomes they achieve as commissioners. They will also be responsible for commissioning specialised services for some families with disabled children.

In light of the NHS reforms and the ideas in the Special Educational Needs (SEN) and Disability Green Paper around GP led commissioning, concerns have been raised by families with disabled children about giving GPs more power and control over budgets.

"I have to say that none of the members of the general practice where we have been registered has had any contact with our daughter, ever. We (her parents) play the leading role in her care and in maintaining her wellbeing. Requests to the GP regarding our severely disabled daughters' health have been met consistently by what I feel could be indifference or, worse, hostility. I am extremely concerned about the government proposal to have healthcare for people like our daughter delivered through a GP. I regard this as a potentially life-threatening proposal."

**Parent quote from survey**

## Section 5: Context

Having a disabled child often has a significant impact on the health and well being of the whole family. Families with disabled children face a complex web of interdependent systems and pressures, leading to families often describing a 'constant battle for services' and feeling unable to cope. People providing high levels of care such as parents of disabled children, are twice as likely to suffer from poor health as those without caring responsibilities.<sup>3</sup>

Families with disabled children are more likely to be users of health services; however they often experience unequal access to both universal health services such as GPs, dentists and emergency care settings, as well more specialised services such as physiotherapists, speech and language therapists, occupational therapists and geneticists.

Reviews by both the Healthcare Commission (2008) and Sir Ian Kennedy (2010) found major problems in the provision of health services for disabled children.

'children with disabilities or those in situations that make them vulnerable, do not always get the attention and care from healthcare services that they need.'

**Healthcare Commission 2008**<sup>4</sup>

'Despite the high number of children coming into their surgeries, many GPs have little or no experience of paediatrics as part of their professional training. This means that, technical competence notwithstanding, many GPs lack the confidence to assess and treat children effectively, something that comes from specialist training and experience.'

***Sir Ian Kennedy 2010, Getting it right for children and young people, pp45-46***

<sup>3</sup> Carers UK, 2004

<sup>4</sup> Healthcare commission, State of Healthcare 2008, TSO 2008. P11

Health outcomes for families with disabled children remain problematic.

The House of Commons Health Select Committee on Commissioning (2009/10) highlighted the weak performance of primary care trusts in commissioning services. This criticism included specialised services for the many people with rare and complex conditions.

It is widely acknowledged that NHS reforms are needed and Contact a Family supports the aims of the NHS reforms to increase patient involvement in health service design and funding decisions, reducing health inequalities and improving joint working between health and social care. We are pleased that the DfE's Special Educational Needs (SEN) and Disability Green Paper proposes a joint planning and commissioning between health services and local authorities and pathfinders to explore the best ways of providing support for the commissioning of healthcare services for families with disabled children.

However, because the planned reforms in health are proposed alongside changes to education, the biggest shake up in welfare support for decades and cuts in local authority services, families with disabled children face uncertain times. Therefore the health reform need to give strong assurances that CCGs will be used to address the long standing problems families with disabled children face accessing sufficient healthcare and other services, and do not impact negatively on outcomes for them.

## Section 6: Summary of our survey results

We received over 1,000 responses from parent carers in England to our online survey over a six week period. Respondents were parent carers of children affected by a wide variety of disabilities and multiple conditions including those with life limiting conditions, rare syndromes, behavioural and mental health problems.

Contact a Family would like to thank all those that took the time to complete the survey. The high response rate shows that this is an important issue for families with disabled children and that they are keen to see GP practices improve.

## Section 7: GP involvement in child's general health

Overall families' experiences of GP practice in relation to their child's general health, is good.

87% do visit their GP for their child's general health issues. Of those, 61% said the service was good or excellent.

Half of families with disabled children visit the GP two to three times a year for general health issues (the same number of visits as non disabled school aged children). A significant number - 13% - never visit their GP for general health issues.

*"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."*

*"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."*

*"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."*

### Parent quotes from survey

However the quality of this service is inconsistent across GP practices and individual GPs. This is evident because 28% of families said the service was fair and 10% rated it as poor. The comments received indicate that referral to hospital was too often the default action for often very minor illnesses unrelated to the child's condition or disability. This puts unnecessary pressure on hospitals and gives already stressed parent carers yet another thing to do.

"Most of the time our GP just refers us straight to hospital, almost as if he is too difficult for the GP to deal with. Even if its for something as minor as an upset stomach, ear ache etc."

"Never listen...think we need to go to hospital for anything that is wrong...talk over my Ben as if he is not there. No support whatsoever."

### Parent quotes from survey

This shows that some GPs aren't always providing the quality of general healthcare to families with disabled children because they lack the confidence and experience around disability and the impact of caring on family life.

## Section 8: GP involvement in management of child's disability or condition

Overwhelmingly, families with disabled children say GPs have little involvement in the care of their child's disability or condition. Over three quarters (76%) say that their GP is not involved. This means GPs are not helping families to find information about their child's condition, the treatments available or sources of support. They also do not have contact with specialist health professionals or are part of the child's ongoing care planning and reviews.

Of those families whose GP is involved, a quarter say they have no understanding at all of the disability or condition.

Families are mostly in contact with a paediatrician to assess their child's needs and co-ordinate their health services. This is why families are concerned when the government says GPs know patients best, because this does not reflect their experience.

"GP doesn't have the time or expertise to treat my child's condition."

"No GP involvement since diagnosis 13 years ago."

"My GP has not been involved in my child's condition - Ataxia. We were referred

to a paediatrician at the local hospital by the health visitors when he was one year old and have been managed by them ever since."

### Parent quotes from survey

The quality of service for families visiting their GP about their child's disability or condition is hugely inconsistent: 27% rated the service fair, 26% said it was good, 24% rated it poor and 22% said it was excellent.

"GP is great for referring the child to the paediatrician in the first instance then the paediatrician then takes over with other specialist for the needs of his care. They all keep in contact with the GP and request things like prescriptions and inform in writing on every specialist appointment."

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

"6 weeks after my daughter was born with Down Syndrome my GP told me I had let myself in for a life time of problems, that was when my daughter had a chest infection."

"They have very little knowledge of his condition – Spina Bifida, and will pass it on to his paediatrician. They don't even pretend to understand what's going on, and will ask me for advice."

### Parent quotes from survey

## Section 9: Support for family carers

Almost three quarters of families with disabled children say that their GP never offers them support as a carer. Of those that are offered support by their GP, most (79%) said they are offered support with issues such as tiredness or stress. A few say they have been offered counselling, anti-depressants, a flu jab or a listening ear.

The lack of understanding and referral by GPs about services that help prevent families with disabled children reaching crisis point; such as short breaks, welfare information and parent support groups, often mean that families are only being given medical help such as a flu jab or anti-depressants by the GP, which are often not necessary or may not be the most appropriate sources of support.

"I don't think we are even considered, the doctor is aware my husband is on anti depressants and that I do not work due to anxiety/depression, but still if I go in and say I can't afford to be poorly I don't get much support."

"Our GP Surgery doesn't seem concerned about my child's disabilities only the general health issues. Even when seeing a GP myself due to depression due to coping with my child, I have just been offered anti-depressants which I refuse to take as I told them our family needed support not tablets, but none has ever been offered or advised upon."

"I don't think GPs understand what it is like to live with a disabled person. Being put on carers list seems important enough. GP gets involved with carer only in crisis situations."

### Parent quotes from survey

GPs can be seen as the first port of call when families experience illness or disability. Carers say getting early advice and information from their GPs can transform their experiences of caring by allowing them to access support from the outset. However, our findings show a real lottery in the support that different GPs provide to carers

## Section 10: How GPs can help

When asked how GP care for families with disabled children could be improved, the biggest priority (66%) was better understanding of their children's conditions. Families also overwhelmingly want improved joint working of GPs with other professionals (62%) and better support for parent carers and the wider family from GPs (61%).

"Taking carers health and well being seriously. I recently went to the GP regarding obesity. I spend a lot of time at home alone and comfort eat when I'm very anxious, my weight is now a major problem. I felt my GP has done nothing since to help. Not only do I have a child with a life limiting condition I also have another child of 7 who has a language disorder and an autistic spectrum disorder. I rarely get time to think about myself, so when I visit the GP. I would hope they would listen and help me access other support."

### Parent quote from survey

In their responses, parents identified several other improvements to GP services including training on disability awareness and caring, referring families to organisations such as Contact a Family, taking time to listen to the needs of the whole family and seeing the parents as the expert.

"There should be more training for all GPs as they all work differently which unfortunately gives out mixed messages, especially those parents who have a lot to deal with on a daily basis and get no help at all, which could also lead to depression and all kinds of medical illnesses. GPs need to take the time to listen, understand and empathise with each patient - I do understand there is a limit to appointment slots."

“I would like to be offered a regular opportunity to sit down and discuss the effect that coping with my child’s disability is having on the health and well being of the rest of the family.”

“It should be compulsory for GPs to receive annual training about childhood health and disability and in recognition that carers input and knowledge is invaluable.”

Parent quotes from survey

## Section 11: Conclusion

Many of the comments received from parent carers show high anxiety that the needs of disabled children will be compromised by the lack of relevant expertise and joint working with other professionals by GPs and therefore CCGs.

What is clearly demonstrated is that many GPs do not appear to have the knowledge and in some instances the skills to appropriately support families caring for disabled children. The experiences of families with disabled children show GPs are already struggling to support them and lack the knowledge about disabilities.

In light of the NHS reforms, it is clear that our recommendations need close consideration, and plans must be developed in partnership with parent carers to help address the issues raised. Whilst acknowledging the role of the GP is a complex and demanding one, it is essential that they understand and meet the needs of disabled children and their families, particularly if their role in the coordination of care and support for disabled children is likely to be significantly increased. There is a risk that healthcare services for families with disabled children become more fragmented.

The NHS reforms must therefore safeguard the interests of families with disabled children. This can be achieved through putting families with disabled children at the heart of NHS reforms.

## Section 12: Methodology

Contact a Family conducted an online survey called ‘GP Involvement in Disabled Children’s Healthcare’ between 24th March and 4th May 2011. The aim was to gather information on the experience of families with disabled children about their GP service.

We promoted the survey through our our helpline, regional and local offices, family support workers and volunteer parent representative. We also used our networks that include:

- National condition support groups
- Local parent support groups
- Parent Carers Forums
- Facebook and Twitter users

Contact a Family thanks all those parents that took the time to reply.

## Section 13: About Contact a Family

Contact a Family is the only UK-wide charity providing practical and emotional support and information to families with disabled children – regardless of disability or health condition.

We deliver this through local, regional and nation offices plus family workers and volunteer parent representatives. We enable parents to get in contact with other families through a family linking service, our network of parent support groups and online resources.

Contact a Family is committed to helping parents work with professionals to improve the local services they need.

Our freephone helpline offers a one stop shop advice service to families on any aspect of caring for a disabled child including welfare rights, community care issues, education needs and housing issues with access to interpreters.

Last year we supported more than 340,000 families through our range of services. We give families with disabled children the skills and confidence to live the lives they want to lead.

### How we can help GPs:

- Our medical directory – See <http://www.cafamily.org.uk/medical-information/> - provides reliable information on many medical conditions, including rare syndromes, and also provides details of UK condition support groups
- We have a range of resources and support for clinicians and health commissioners in planning, delivering and working in partnership with parent carer forums to improve health services for disabled children
- Our promoting Self Care Leaflet informs professionals about the different types of information families might need with details of organisations who can provide support.

## Glossary of terms

**Commissioning** – a way of deciding how and on whom public money should be spent. The process includes assessment of need, specifying resources, securing and monitoring of services to meet people's needs at a strategic level.

**Health and Social Care Act 2012** – set out the restructure of the NHS in England and create a separate NHS Commissioning Board. Giving GP led clinical commissioning groups the power to commission services on behalf of their patients, it also intends to promote patient choice, and reduce NHS administration costs.

**Clinical commissioning groups** – groups of GPs and clinicians responsible for commissioning healthcare services such as those for children, including those with complex healthcare needs, wheelchair and continence services.

**NHS Commissioning Board** – will be responsible for the day to day running of the NHS in England. It will allocate resources and provide support for GP consortia. It will commission some specialised services.

**HealthWatch** – organisation aimed at strengthening the voice of the patients in the NHS via influence on Health and Wellbeing Boards.

**Health and Wellbeing Board** – part of a local authority responsible for health improvement and bringing together GP consortia, children's services, adult social care and others. Will conduct a 'Joint Strategic Needs Assessment' and a 'Joint Health and Wellbeing Strategy' that both local authority and NHS commissioners will be required to have regard to.

**Parent carers** – parents of disabled children includes those with any health condition.

**Parent carer forums** – Local groups that enable parents to get involved in service planning and decision making so that services meet the needs of families with disabled children and resources are not wasted on services which parents and families do not take up.

If you would like to discuss this briefing paper in more detail, please contact Una Summerson at Contact a Family on 020 7608 8742 or email [una.summerson@cafamily.org.uk](mailto:una.summerson@cafamily.org.uk)

Contact a Family  
209-211 City Road, London, EC1V 1JN  
Tel 020 7608 8700  
Fax 020 7608 8701  
Email [info@cafamily.org.uk](mailto:info@cafamily.org.uk)  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

Incorporating The Lady Hoare Trust  
Registered Office: 209-211 City Road, London, EC1V 1JN  
Registered Charity Number: 284912 Company Limited by guarantee  
Registered in England and Wales Number: 1633333  
Charity registered in Scotland Number: SC039169  
VAT Registration Number: GB 749 3846 82