GPs’ role in coordinating care for disabled children and young people

WHY DOES GEORGE FIND VISITING THE DOCTOR SO DIFFICULT?

George has severe learning disabilities, behavioural problems, poor balance and is non-verbal. He sometimes lies on the floor or takes his clothes off at inappropriate times. He does not sit still for more than a few minutes and is easily scared by noises others may not even notice. Imagine sitting next to George in the waiting room…

After five minutes he is ready to leave the surgery and they haven’t even seen the GP.

Minimising these stresses can improve the chances of assessing George before he becomes distressed

Increase in numbers of ASD & BESD

The most recent reliable data on types of severe disablement shows an increase in numbers: as a result, the largest segments of children with particular impairments were Autism and Behavioural disorders (25.0%); mental handicap (15.2%); and Cerebral Palsy (13.9%).

Emotional and Social Difficulty (E & S D) which collectively form part of the definition of Autism Spectrum Disorder (ASD) and BESD (Behavioural, Emotional and Social Difficulties) which collectively form part of the definition of Autism Spectrum Disorder (ASD) and BESD (Behavioural, Emotional and Social Difficulties) which collectively form part of the definition of Autism Spectrum Disorder (ASD) and BESD (Behavioural, Emotional and Social Difficulties) which collectively form part of the definition of Autism Spectrum Disorder (ASD) and BESD (Behavioural, Emotional and Social Difficulties) which collectively form part of the definition.

There is a weight of anecdotal evidence to suggest that these conditions have continued to grow, and our interviews consistently indicated unmet demand and a shortage of the services that parents want for children with ASD and BESD.

SURVEY OF OVER 1,000 FAMILIES WITH DISABLED CHILDREN


Contents

• Makes practical suggestions for GP practices to make it easier for disabled children to visit their GP

To request printed copies email Sheila.Davies@cafamily.org.uk

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 november 2013

www.cafamily.org.uk/104survey

Pathway Complex

Identified at birth or soon after

• Many different professionals and services involved

Funding

Discharge – as ‘no medical treatment for condition’

Children and young people are not getting the support they need

Wide variation in child development teams

• Decline in numbers of professionals working within the team

• Transition services underdeveloped

% of CDTs with professionals ‘available’ to the team

NHS with increases/decreases in numbers between 2004 and 2009

How GPs can help

It is not reasonable to expect GPs to have knowledge of the thousands of long term conditions that cause disability. However they could support families around commonly presenting issues

Many families receive no information to help them meet the additional parenting challenges they face as carers.

In England, GPs led clinical commissioning groups (CCGs) became responsible for commissioning services and told to invite patients/careers in improving services.

Could this provide an opportunity for GPs to become more involved in coordinating care for disabled children and young people?

CHILDMORPHE AND YOUNG PEOPLE ARE NOT GETTING THE SUPPORT THEY NEED

CHILDREN AND YOUNG PEOPLE FALL THROUGH GAP

CONSEQUENCE

Child and family not supported on common problems

Note: ‘Gaps’ represent number of disabled children who have a support need but not a service ready to meet it

Concentration of children with learning disability

• Speech/Language

• Toilet training & conditions

• Learning

• Sleep

• Behaviour

• Movement/Daily living

• Feeding/Eating

How GPs can help

• Health services that disabled children might need

• Issues that disabled children frequently present with and who can support them

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