

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

contact a family
for families with disabled children

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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 his mum is ready to leave the surgery and they haven't even seen the GP.

SURVEY OF OVER 1,000 FAMILIES WITH DISABLED CHILDREN

Full report: Putting families with disabled children at the heart of the NHS reforms in England (2011) www.cafamily.org.uk/GPSurvey

76%

don't visit the GP about their child's disability or condition

66%

want GPs to have a better understanding of their child's condition

62%

want to see improved joint working of GPs with other professionals

73%

say their GP never offers them support in their role as a carer

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

"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 it's for something as minor as an upset stomach, or ear ache."

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



Contents

- Explains why families with 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.

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"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."

CHILDREN AND YOUNG PEOPLE ARE NOT GETTING THE SUPPORT THEY NEED

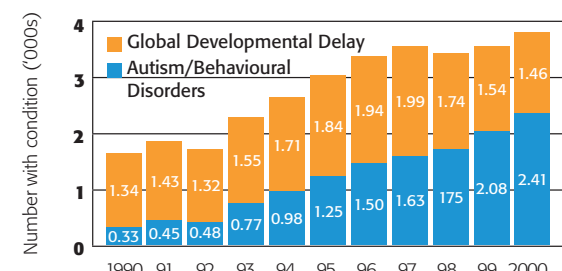
Increase in numbers of ASD & BESD

"The most recent reliable data on types of severe disabling conditions (2000) indicated that the largest segments of children with particular impairments were autism and behavioural disorders (25.0%), mental handicap (15.2%); and Cerebral Palsy (7.9%). No other severe disabling impairment exceeded 4% of the total.

"The most pronounced demand-side trend of recent years is that of the growth of ASD (Autistic Spectrum Disorder) and BESD (Behavioural, Emotional and Social Difficulty) which collectively grew from 5% in 1990 to 25% in 2000, a growth rate of approximately 22% per annum.

"There is a weight of anecdotal evidence to suggest that these conditions have continued since 2000, and our interviews consistently indicated unmet demand and a shortage of the services that parents want for children with ASD and BESD."

DCSF, Market for Disabled Children's Services - A Review, PricewaterhouseCoopers LLP



Note: Totals represent total number of children on Family Fund Database and not the total number of disabled children within the UK - Source: Family Fund Database, ONS, PwC analysis

Autism/learning disability/rare condition

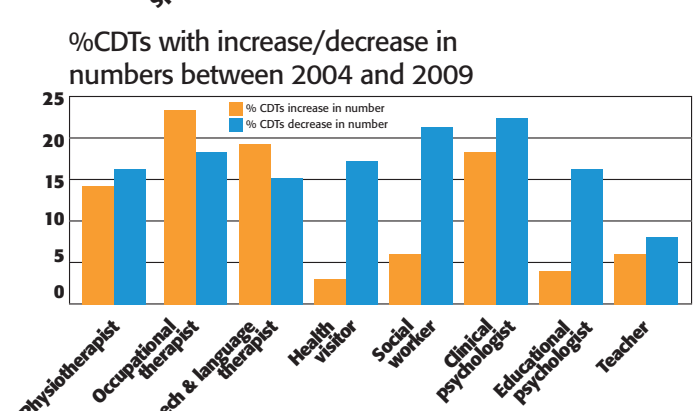
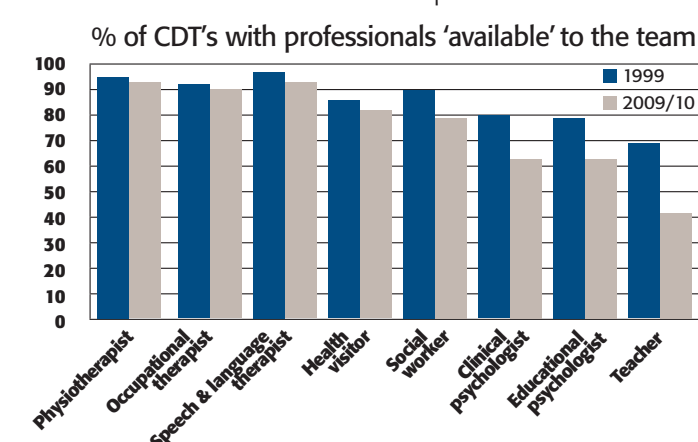
- Identified around age 2 to 3 with developmental delay
- Referral to child development team (CDT), assessments, tests and sometimes diagnosis
- Discharge - as 'no medical treatment for condition'

Pathway Complex

- Identified at birth or soon after
- Many different professionals and services involved. Frequent appointments and parents repeating their story
- Transition at 18 years to GP who is unknown to young person.

Wide variation in child development teams

- Decline in numbers of professionals working within the team
- One-third of all teams reported a reduction in their funding over the last 5 years but more children being seen
- Transition services underdeveloped.



Parr, J. R., Jolleff, N., Gray, L., Gibbs, J., Williams, J. and McConachie, H. (2013), Twenty years of research shows UK child development team provision still varies widely for children with disability. Child: Care, Health and Development. doi: 10.1111/cch.12025

CHILDREN AND FAMILIES FALL THROUGH GAP

CONSEQUENCE

Child and family not supported on common problems



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, GP led clinical commissioning groups (CCGs) became responsible for commissioning services and told to involve patients/carers in improving services.

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



Contents

- Health services that disabled children might need
- Issues that disabled children frequently present with and who can support them

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

Can you help us make this happen?
www.cafamily.org.uk/healthprofessionals

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