

Briefing

Making all children matter:

Support for children with diabetes in schools



Background

*"I like school, but school doesn't like me",
Daniel age 5, Type 1 diabetes*

Sadly this is the experience of many children at school in England with Type 1 diabetes. Diabetes is a life-long condition that needs daily effective diabetes management – including during school hours. Successfully supporting these children requires a partnership between schools, local authorities and primary care trusts. However, in this regard, we currently have a postcode lottery.

Ed Balls the Secretary of State for Children, Schools and Families says *"we want this to be the best place for children to grow up in¹"*.

The Government's *Every child matters* policy agenda is a reflection of this intent and aims to ensure that all children and young people aged 19 and under have the necessary support they need to:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic well-being².

For children with diabetes or other long-term conditions to reach these goals and enjoy a full school life, like their peers, they must have the necessary support at school to manage their condition.

Key findings

- 20,000 children under the age of 15 with Type 1 diabetes in the UK.
- Estimated that 2,000 children are diagnosed with Type 1 diabetes every year in the UK.
- Diabetes UK Advocacy service receives approximately 100 enquiries every month from parents.

Diabetes UK survey of primary schools in England found that:

- 52 per cent of schools have children with diabetes
- 70 per cent of these schools say where children are unable to inject themselves; parents have to go in to administer insulin.

Of schools that have children with diabetes:

- 42 per cent do not have a policy advising staff how to **supervise** Blood Glucose Monitoring (BGM)
- 48 per cent do not have a policy advising staff how to **carry out** BGM

- 41 per cent do not have a policy advising staff how to **supervise** medication
- 59 per cent do not have a policy advising staff how to **give** medication.

and:

- 52 per cent supervise BGM as well as having a policy, but do not carry it out
- 36 per cent carry out BGM as well as having a policy
- 45 per cent supervise the taking of medication (including insulin) as well as having a policy
- 16 per cent give medications as well as having a policy.

Parents tell us:

- they can't go to work because they have to go to school to administer injections
- their children are excluded from school trips
- their children are denied access to snacks
- their children (as young as age 5) are left to inject insulin themselves.

Barriers to providing support at school:

- up to 17 per cent said "concern over liability and lack of training"
- up to 12 per cent said "lack of training"
- up to 48 per cent said "none of these".

Key issues

The difficulties that some children and parents experience in receiving appropriate support at school gives rise to some obvious questions

Why does support in school matter?

Managing diabetes is not a choice, but a necessity for children to remain healthy and be able to have a full school life. Everyday there are children with diabetes who enjoy a full school life because their school gives them the necessary support – every child with diabetes should be entitled to this opportunity. Diabetes is a life-long condition that can lead to serious complications such as strokes, blindness, kidney disease, heart disease and amputations. Effective diabetes management from diagnosis is essential to reduce the risk of these complications. For children with Type 1 diabetes insulin is vital for life and they must receive this hormone via injection or pump, several times a day. Therefore many children will need an insulin injection during school as well as needing to test their blood glucose levels and have access to snacks during class time to keep levels stable.

What is the experience of children and parents?

The experience varies greatly from no school support, very patchy support to good child-centred provision. Absence of a child-centred perspective causes serious problems, including some schools expecting parents to ignore clinical advice and change a child's insulin regimen so that the child can accommodate the school rather than the other way round. This can be detrimental to the child's diabetes control and puts their short- and long-term health at risk. At the same time parents suffer fear and strain because they cannot be confident that their child will be safe at school.

While some schools can have a fear of liability and also lack knowledge and training in diabetes care, evidence from parents suggests that the leadership and attitude of the school is the most critical factor. Schools with a holistic approach seem to support and integrate a child with diabetes successfully.

Is there an adequate legal framework to ensure school support?

Many of the statutory requirements under relevant legislation are very broad and do not explicitly require schools to support children with diabetes and long-term conditions. For instance, all schools have a common law duty of care; they also have a duty to promote pupils' well-being. Because these obligations are so broad, support for long-term conditions can be easily overlooked. However, it is interesting to note that requirements for daycare and child-minding are far more robust than anything for schools, and are clearly set out in national minimum standards that Ofsted is required to monitor and inspect. Moreover, the definition of disability has changed in recent years, such that conditions like diabetes, cancer and others fall within the legal definition in the Disability Discrimination Act because, in summary, they can affect the ability to carry out normal day-to-day activity³. Two core duties under this Act require schools not to treat disabled pupils less favourably; and to take reasonable steps to avoid putting disabled pupils at a substantial disadvantage. This is known as the reasonable adjustments duty. Furthermore, all schools are required to have a disability equality scheme. This should have been in place by 3 December 2007.

What does Government policy and guidance say?

There is an enormous web of official policy and guidance available for schools, local authorities and primary care trusts explaining the need for policies on school support for children with medical needs. There are two fundamental problems: the lack of implement-

ation and statutory teeth to ensure that guidance is followed, and a lack of recognition that children with long-term conditions are a vulnerable group. Disturbingly, the Government does not know the number of children at school with a long-term condition, it also does not know the numbers and characteristics of children with a disability, and nor is there a common definition of disability in operation across education, health and social care. Therefore, services cannot be planned and provided appropriately. The Government's forthcoming Child health strategy needs to make clear how it will ensure implementation of policy and guidance to ensure appropriate support in schools for children with long-term conditions.

Is there an effective performance and inspection framework?

Alongside policy and guidance, there is a panoply of accompanying mechanisms and indicators to measure and assess the performance of local authorities and health services. Regarding schools, Ofsted inspectors are meant to cover the five outcomes of *Every child matters*. This ought to include policies and support for children with diabetes and other medical needs as a matter of routine. In reality, however, the varied circumstances of schools and the relatively short period for individual inspections mean that this cannot be taken for granted. Consequently, it is vital that the requirements for inspections are tightened up.

Key recommendations

To the Department for Children, Schools and Families (DCSF)

Data collection

- The DCSF should take action to gather and publish information on the actual numbers of children in primary and secondary schools that have a long-term medical condition. This should be updated annually.

Legislation and guidance

- If schools are to fulfill their common law duty of care towards children with diabetes, their equalities and anti-discrimination duties, and their duty to promote pupil well-being, Government needs to be proactive and place specific duties on schools and local authorities to ensure support at school.
- The DCSF should issue a regulation through a Statutory Instrument under the Education and Inspection Act 2006, which would require schools (governors and local authorities as employers) to have

medicines policies and to provide trained support for children with long-term conditions. This Act is especially appropriate due to its focus on pupils' well-being. Such a duty would also ensure that schools have similar requirements to organisations providing child-minding.

- The DCSF should also issue guidance on the minimum requirements that should be included in a protocol or similar for schools to meet this statutory requirement. **The Medical conditions at school policy** resource pack, should be formally disseminated by DCSF for this purpose.⁴

Child health strategy

- This joint strategy, between DCSF and the Department of Health, should address support for children with long-term conditions. In particular it should spell out how the Government will ensure implementation of relevant legislation and guidance amongst schools, local authorities and primary care trusts.

Performance assessment

- To ensure that schools have similar requirements to organisations providing services in early years settings, Ofsted should routinely inspect whether schools have clear medicines policies and procedures to support children with diabetes and other long-term conditions. This requirement should be reflected in the new school indicators for Ofsted due to take effect in 2009.

Professional education and training

- To ensure teachers are prepared with at least a basic foundation for receiving children with long-term conditions in their class, the **Medical conditions at school policy** resource pack should be a mandatory part of teacher training.

To the Department of Health (DH)

Primary care trusts (PCTs)

- There should be a statutory duty placed on PCTs to ensure the availability of training on long-term conditions to school staff. For diabetes this should be provided by paediatric diabetes specialist nurses.

National healthy schools programme

- The programme should be revised so that no school is deemed a 'healthy school', unless it has in place a medicines policy and appropriate support system for children with diabetes and other long-term conditions.

Child health strategy

- This joint strategy, between DCSF and DH, should address support for children with long-term conditions. In particular, it should spell out how the Government will ensure implementation of relevant legislation and guidance amongst schools, local authorities and PCTs.

To the Equality and Human Rights Commission (EHRC)

Disability Discrimination Act (DDA)

- The EHRC should take action to raise awareness among school employers and staff of their statutory obligations under the DDA.

Schools audit

- The EHRC should undertake an audit of schools to see how many have a Disability Equality Scheme in place.

Disability definition

- The EHRC should work with education, health and social care to develop a common definition of disability, so that reliable data can be gathered on characteristics and numbers to aid planning.

References

¹Department for Children Schools and Families (2006) *The Children's Plan: Building Brighter Futures*

²<http://everychildmatters.gov.uk/aims/>

³Definition of disability and all related information can be found on the Equality and Human Rights Commission website, www.equalityhumanrights.com

⁴www.medicalconditionsatschool.org.uk



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