

Making all children matter:

Support for children with diabetes in schools



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

Sadly this is the experience of too many children with diabetes. We all believe that our children matter; they are our hope for the future and we care passionately about their safety, welfare and development. The Government's **Every child matters** policy agenda reflects this concern 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 and achieve economic well-being¹'.

Therefore, one would expect that children with diabetes and other long-term conditions receive support at school to manage their condition effectively and enjoy a full school life – but not all are so fortunate. Diabetes UK continually hears from parents telling us they have to fight for basic support from a school and do not always get it. Sometimes, they are unable to work as they have to go into school to administer medication, which can put heart-breaking strain on families both financially and emotionally. Some children have even been forced to move schools. In response, Diabetes UK has set up an Advocacy service offering vital help for families struggling with these issues.

The plight faced by some children with diabetes at school exemplifies fundamental failings in public policy in bringing health and education together at a national and local level. This is despite the range of welcome legislation and official guidance which promotes children's welfare and well-being, and explicit recognition by the Department of Health of the importance of effective diabetes management in children and young people.

Successfully supporting children with diabetes or any other medical condition requires a partnership between schools, local authorities and primary care trusts. We currently appear to have a postcode lottery in this regard. There are pockets of good

practice but we want to see this spread throughout the country.

This report has been produced as part of long-running efforts by Diabetes UK to improve life for all children with diabetes at school. We very much hope it brings us closer to achieving this so that, like their peers, every child with diabetes and other long-term conditions can be healthy, stay safe and enjoy and achieve.

As 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 in²".

A handwritten signature in black ink that reads "Douglas Smallwood". The signature is written in a cursive, slightly slanted style.

Douglas Smallwood
Chief Executive, Diabetes UK

2. Scope

This report looks at children with Type 1 diabetes at school in England. The difficulties that some children and parents experience in receiving appropriate support at school gives rise to some obvious questions:

- 1. Why does support in school matter?**
- 2. What do we know about the experience of children and parents?**
- 3. Is there an adequate legal framework to ensure school support?**
- 4. Is there Government policy and guidance to ensure school support?**
- 5. Is there an effective performance and inspection framework?**

This report seeks to answer these questions.

3. Executive summary

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 implementation 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 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".

Recommendations

To the Department for Children Schools and Families (DCSF)

Data collection

- The DCSF should take urgent 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 purpose⁴.

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. In the case of 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.

4. Why support in school matters

'Education is a very valuable part of children's and young people's lives. Appropriate diabetes care in the school and day-care setting is necessary for the child's immediate safety, long-term well-being, and optimal academic performance. Low and/or fluctuating blood glucose concentrations will impact adversely on academic performance as well as resulting in reduced school attendance. Children with diabetes may need to take more time off school to attend clinics; they can develop emotional problems or mental disorders such as depression; and they may have problems learning'.

Source: Making every young person with diabetes matter: report of the Children and Young People with Diabetes working group, Department of Health (2007).

Diabetes

Diabetes is a long-term medical condition where the amount of glucose (sugar) in the blood is too high because the body is unable to use it properly. This is because:

- the pancreas does not make any or enough insulin
- the insulin does not work properly
- or it is a combination of both.

Insulin is the hormone produced by the pancreas that helps glucose (from the digestion of carbohydrate), move into the body's cells where it is used for energy.

When insulin is not present or does not work properly, glucose builds up in the body. There are two main types of diabetes: Type 1 and Type 2.

Type 1 diabetes develops if the body is unable to produce any insulin. Children or young people with this form of diabetes need to replace their missing insulin, so, for the rest of their lives, will need to take insulin (by injection or pump therapy). The majority of children have Type 1 diabetes.

Type 2 diabetes develops when the body can still make some insulin but not enough, or when the insulin produced does not work properly. In most cases this is linked with being overweight.

Prevalence and effects

Overall the prevalence of Type 1 and Type 2 diabetes in children is increasing. Approximately 1,400 children have Type 2 diabetes directly as a result of being overweight or obese. A further 20,000 children under the age of 15 have Type 1 diabetes in the UK. Particularly worrying is that the number

of children under the age of 5 with Type 1 diabetes has increased five-fold over the last 20 years⁵. In fact approximately 2,000 children under the age of 14 are diagnosed with Type 1 every year in the UK⁶. Current estimates suggest that PCTs and local authorities will have between 100 and 150 children with diabetes living in an area.

Importance of diabetes management

Life expectancy is reduced on average by 23 years in people with Type 1 diabetes and 10 years in people with Type 2. Diabetes is the leading cause of blindness in people of working age, the leading cause of renal failure and second most common cause of lower limb amputation. Presently 100 amputations a week take place. Mortality rates from coronary heart disease are five times higher, and women with diabetes face additional risks during pregnancy, at birth and to the baby.

In view of these facts, it is essential that children are supported to manage their diabetes effectively, in order to prevent the development of early complications. Therefore, one of the main aims of controlling diabetes is the management and treatment of blood glucose (HbA1c) and blood pressure target levels. The longer a person has diabetes that is poorly controlled, the higher the risk of developing problems. For people with diabetes children are more at risk of experiencing hypoglycaemia (when blood glucose is too low), hyperglycaemia and diabetes ketoacidosis (when blood glucose is too high).

Latest figures reveal that last year more than 3,000 children in England were admitted to accident and emergency departments with

diabetes ketoacidosis (DKA)⁷. DKA is serious and requires immediate medical attention.

Furthermore, the UK has the lowest number of children attaining good diabetes control in Europe; in fact 83 per cent of children do not have good control⁸. The National Diabetes Audit 2004/5 reported that less than one in five children with diabetes under 16 years of age achieved the HbA1c target of less than 7.5 per cent.

Medication and treatment

If a child has Type 1 diabetes, insulin is vital to keep them alive and they must have their insulin as recommended. Because insulin can not be taken by mouth, most pupils will use a pen-like device to inject their insulin in separate doses, but in some cases insulin pumps will be used. It is becoming more widely accepted that multiple injections/pumps is a more effective way of maintaining normal blood glucose levels. This means that more young children will need support with injections while at school. Children will also need to adjust their insulin dose and diet according to their day's activities and routine. In order to do this, they will need to test their blood glucose levels regularly using a finger-pricking device and an electronic blood glucose meter.

Hypoglycaemia (Hypo)

Children with diabetes can experience hypos. These occur when the level of glucose in the blood falls too low. They can be caused by too much insulin, a missed or delayed meal /snack, not enough food especially carbohydrate, strenuous or unplanned exercise. The warning signs vary, but include feeling shaky, sweaty, heart pounding, paleness, tingling lips, confusion and irritability. Treatment is very simple and requires some fast acting carbohydrate, such as a sugary drink or some glucose tablets. If left untreated the child may become unconscious and would need to be treated with an injection of glucagon (a hormone that raises blood glucose levels).

Healthy food and exercise

It is important that children with diabetes eat a healthy balanced diet. It is also important that they eat carbohydrates at regular intervals. Therefore some children may be advised by their

diabetes healthcare team to have a snack during class time in addition to their lunch in order to help avoid hypos. All children with diabetes can participate in physical activity just as other children. The only difference is that the child may need a snack prior to any activity to avoid hypos.

Impact of living with diabetes

The impact of living with diabetes on the child and their families is significant. The management of food, insulin, physical activity and mood is a daily part of self-management. An absence of school support can affect a child's attendance and full involvement as well as their physical and emotional development.

Emotional and psychological issues can and do arise. Once children start to understand their diabetes, they have to accept that it will never go away and if strict regimes are not adhered to it can cause serious impairments. Consequently children can experience problems such as mood disorders, needle phobia, poor self-esteem or eating disorders.



When a child with diabetes starts school, separation issues between parent and child can be more pronounced than for other children. Peer comparisons can highlight children's anxiety about being 'different' – a feeling which can persist throughout their school years especially where there is lack of education and understanding about diabetes.

Therefore, the attitudes and actions of schools are integral to a child's emotional and psychological health and well-being, as well as physical. It is vital for schools to appreciate that they are crucial partners in a child's diabetes care.

Conclusion and recommendations

Children with diabetes can and should enjoy a full school life providing they receive appropriate support. A Diabetes UK member's survey in 2006 of children and young people with diabetes revealed that one of the most important improvements they seek in their care is better communication between schools and diabetes services to help them manage their diabetes at school⁹. At the same time parents want the confidence that their child is safe at school, because the school has the relevant knowledge and skills.

Therefore good management of diabetes at school requires:

- monitoring of blood glucose levels
- taking medications (including invasive medicines)
- treating emergency situations
- access to healthy and appropriate food
- participation in physical activity programmes
- participation in extra curricular and social activities.

In practical terms, this means that all schools should have a medical conditions policy defining how it supports the health needs of children with a long-term medical condition. **In the case of diabetes the policy should ensure:**

- All children with diabetes are known to the school.
- Schools work in collaboration with paediatric diabetes teams to ensure that school staff are trained in supporting self-management and dealing with emergencies.
- An individual care plan is prepared for each child with diabetes in consultation with parents and paediatric diabetes staff. This should contain details of blood glucose monitoring, administration of medication, meals and snacks, prevention and treatment of hypoglycaemia;

treatment of hyperglycaemia, and management of emergencies, arrangements for extra-curricular and social activities.

- The school ensures that an adequate number of trained staff are available to supervise or deliver diabetes management tasks for and with the child, such as local authority support workers, school nurses, trained teachers and classroom assistants.
- All staff understand and are trained in what to do in an emergency for children with diabetes.
- A quiet room is allocated in schools for children to do their blood glucose testing and insulin injections, when required.
- There is a recognised link member of staff to liaise with the family and relevant professionals in the care of the child.

5. What is the experience of children and parents?

'Since Diabetes UK began its Advocacy service in March 2008, almost 800 enquiries have been received regarding schools, this amounts to a rate of 100 enquiries a month.'

There is a vast amount of disturbing evidence on how poorly some children with diabetes are supported in school, and the distress this causes for the child and the parent. For instance:

- A parent contacted Diabetes UK because the school that their 6-year-old child attended wasn't treating the hypos when they occurred and was also not telling the parents. The school also refused to test blood glucose levels as they felt too squeamish.
- A parent had to give up a job of 20 years, as the school refused to help with testing and supervising insulin injections of the 4-year-old child. Many months later a school nurse was finally awarded, but the school still refused to take responsibility to help support the child. This meant the child was required to wait outside the school gates until the nurse arrived, and was refused access to drinks and snacks in the classroom to treat hypos in case it made the other children jealous. The child was also excluded from the school each time the nurse was on leave or absent.
- A 5-year-old child was not allowed to attend the school sports day, and was frequently sent away from class to treat hypos alone. The school also would not hold supplies of insulin and blood glucose testing strips, and the school nurse refused to treat the child because the nurse alleged that the child did not say "please" and "thank you" on each occasion.

During 2007, Diabetes UK conducted a postal survey of all primary schools in England to try and understand if and how they are supporting children with diabetes. (Figures from the survey are rounded to the nearest percentage point).

Of the schools that responded to the survey, 52 per cent were found to have children with diabetes. Amongst these schools, where children were not able to inject insulin themselves, it was most commonly the parent that went into school to provide this help:

| | |
|--------------|------|
| Parent | 70 % |
| Teacher | 9 % |
| School nurse | 2 % |
| First aider | 13% |

| | |
|--------------------|------|
| Paediatric nurse | 2 % |
| Relative | 4 % |
| Other school staff | 13% |
| None of the above | 12 % |

Worryingly, schools reporting that they have children with diabetes do not all have appropriate diabetes policies in place. The report found:

Blood glucose monitoring (BGM)

42 per cent do not have a policy advising staff how to **supervise** BGM

48 per cent do not have policy to advise staff how to **carry out** BGM

Medications

41 per cent do not have policy to advise staff how to **supervise** the taking of medication

59 per cent do not have a policy to advise staff how to **give** medication

Schools reporting that they have children with diabetes also do not actively support them.

Blood glucose monitoring (BGM)

52 per cent of schools **supervise** BGM as well as having a policy

36 percent of schools **carry out** BGM, as well as having a policy

Medication

45 per cent of schools **supervise** children taking medication (including insulin) as well as having a policy

16 per cent of schools **give** medications as well as having a policy

Barriers to providing school support

The two barriers stated by the responding schools were:

- concern over liability
- lack of training.

Interestingly, the size of the response for these reasons is dwarfed by responses citing: 'none of these', 'other', and 'prefer not to.' What such responses actually mean is not known, or perhaps some schools chose to avoid the question. It is also interesting to note that insufficient time and lack of financial resources did not present significant barriers.

| | Carry out BGM | Supervise BGM | Give medication | Supervise medication |
|----------------------------|---------------|---------------|-----------------|----------------------|
| Lack of financial resource | 1% | 0% | 2% | 5% |
| Insufficient time | 2% | 0% | 3% | 7% |
| Lack of training | 10% | 4% | 12% | 12% |
| Concern over liability | 15% | 4% | 17% | 15% |
| None of these | 44% | 42% | 44% | 48% |
| Other | 35% | 39% | 28% | 33% |
| Prefer not to | 8% | 0% | 30% | 3% |

Given the responses, the question remains – ‘what are the real barriers?’ Interviews with parents help to shine some light on this.

What do parents say?

From the survey results, Kent, Staffordshire and the West Midlands were identified as areas with a high prevalence of parents going into school to administer insulin injections. A total of 10 parents were recruited from these areas for in-depth interviews. Recruitment took place through adverts using the Diabetes UK website, publications and through other patient organisations.

School and staff attitude

Parents described the attitude of school staff as being a key factor in determining whether they and their child had a positive experience. This can perhaps explain why there is significant geographic variation in school practice. For example, schools within one mile of each other can be found to react very differently to a child with diabetes. One school will not want any involvement in blood glucose testing or insulin injections, whereas another school will take on all activities.

Parents reported that some teachers refuse to allow children with diabetes into their class. While in other cases, head teachers can often be a major hurdle. Some parents find that individual teachers are willing to provide appropriate support but are then prevented by the head teacher. Attempting to communicate with the head teacher can often be fruitless:

‘I’m not able to talk to the head teacher anymore because she refuses to talk to me... she treats me like I’m a nuisance.’

Another hindrance to providing support, in particular giving insulin injections, but also blood glucose testing, is the perception of responsibility. According to parents, teachers and schools often seem to hold the firm view that providing support during school is parents’ responsibility. Interestingly, unions also advise teachers not to get involved stressing that their role is educational and not to provide care.

Parents also reported a general nervousness amongst staff such as concern about even having insulin in the fridge, a fear of needles, and some concern over liability for incorrect care. It was also felt that there was a general lack of appreciation of the seriousness of diabetes as well as poor support from the local authority. In one case a parent explained that:

‘It took a very bad hypo where the child collapsed, for the school to take some responsibility for supporting the day-to-day management of the child’s diabetes. Previously they depended on the parents to come in daily as well as be on call every day to provide this support.’

Positive school attitude

There are some parents who tell of schools where the staff are engaging and open to embracing children regardless of their needs. In these cases parents didn’t incur barriers as the schools took on the care and support for children with diabetes and developed the necessary knowledge and systems very quickly. The initial lack of relevant knowledge, training and medical or diabetes policies were not regarded as insurmountable issues by the school or staff. As one parent explained with reference to their son:

‘The school he is now at has just said, we are an inclusive school, so far as we are concerned, you treat

the children individually, but equally. You don't single a child out because they have a medical need. They are going to do it all themselves, they say it's better for my son if it's a member of staff who is already there and knows the children. Then it's not making him stand out, they want him to feel as normal as they can'.

Absence of a child-centred approach

Schools can be very inflexible in their overall approach, such that they expect parents to go against clinical decisions and advice in order that the child can accommodate the school rather than the other way round. This serves to place the child's immediate and long-term health at risk.

For instance, some schools ask parents to change their child's insulin regime from four injections to two in order to fit in with the school. This is despite the fact that a diabetes healthcare team will have advised and agreed with parents the appropriate level of diabetes management for optimum control. In some cases children were not allowed to eat snacks in the classroom because the schools or teachers were concerned that the other children might be jealous. Other cases demonstrate a patent unwillingness to be understanding and flexible:

'They have their mid-morning snack at 10.30 am, but my son has his breakfast at 7am so the snack time is really too late because his blood sugars are too low. We asked if this could be moved and the teacher said *"I have already made a huge adjustment to allow him in my class."*

Parents also reported that children who were hypoglycaemic were made to walk unaided to the designated areas for medical treatment or testing, this is despite being warned by parents that during the journey children could fall unconscious.

A recurrent problem is also that training and education is rejected by schools. Parents report that paediatric diabetes specialist nurses willing to deliver programmes are refused by the school.

Impact on parents

Having to go into school on a regular basis has a huge impact, emotionally, financially and socially on parents and their children. Parents are not able to undertake necessary activities such as shopping, or do something

for another of their children, in case it might take them away too far from the school. This is so they can be on hand in case of an emergency, or because they have to go back and forth to school to give an injection and carry out testing. Parents stated that going to work was out of the question for them, as they have to be at the end of the phone in case the school needed to get in touch. Some parents have left their jobs to find work in the evening in order to be able to give the lunchtime injection. The constant strain is summed up by one parent:

"I have been put on anti-depressants because I felt my life was just revolving around school and worry."

How well do local authorities support schools? It would be unfair to hold schools entirely responsible for poor support. Local authorities (LAs) have an important role in enabling schools to build their capacity for supporting a child with a long-term condition. However the Diabetes UK survey amongst authorities in England demonstrates their neglect of this area.

- 56 per cent of responding LAs did not have a process to ensure that schools had policies in place to support children with diabetes.
- 51 per cent of responding LAs had not facilitated training for teachers or support staff on the management of diabetes in schools.
- 74 per cent of responding LAs did not have a link member of staff to work with primary schools to support children with diabetes.

Conclusion and recommendations

In view of the fact that a child spends a large part of the day at school, inevitably poor support during this time will contribute towards the fact that 83 per cent of children are not achieving recommended blood glucose levels. It is essential that schools have enough knowledge to keep children healthy and safe while at school. This means schools, local authorities and PCTs, must work together to develop appropriate policies and protocols as well ensure the necessary training for staff. In particular:

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

6. What does good practice look like?



Where schools, local authorities, PCTs and diabetes specialist services work together to establish the necessary knowledge and skills, child-centred care becomes possible. A child with diabetes is then able to have the optimum management of their diabetes at school.

The examples below demonstrate good collaborative approaches:

Medical Needs in Schools and Early Years Service – Birmingham

This service, provided by the Children's & Families Division of South Birmingham PCT's provider organisation, ensures that children and young people with medical needs receive essential support in schools and early years settings on a city-wide basis.

The 13-year-old service provides training and support for school and early year's staff on the needs of children with diabetes and other common chronic childhood conditions. It also supports schools in developing their own policies around medication and emergency aid.

When a child is diagnosed with diabetes or other medical condition, the service promptly goes into the school to provide relevant training to the class teacher and other key staff. The aim in every school is to train all staff, including teachers, classroom assistants and other support staff. Training is usually carried out after normal school hours but the service is flexible. The content is updated annually and full

account is taken of developments in health policies and prescribing practices. Training also covers aspects such as school activities and additional advice is available if, for instance, children are going on residential trips.

The written guidance and training materials provided to schools includes alert cards about individual children together with their photos for class registers – this is particularly important so that all staff are aware of children's medical needs including temporary supply teachers. Schools are very appreciative of this training and the uptake is very high.

Indemnity cover for school staff has not been a problem as Birmingham City Council provides insurance cover for all staff in education, dependent upon them receiving training from a health care professional and as long as they are acting within the scope of that training. Although the administration of medicines to pupils remains a voluntary matter as in other areas, this has not proved to be a problem, particularly because of the availability of training and ongoing support from the service.

The service regularly liaises with other professionals across health and education services, including diabetes home care teams and paediatric diabetes specialist nurses, and the local authority health and safety department. Guidance is also provided to school nurses about particular medical conditions, which is regularly updated.

Leeds Teaching Hospital

The children's diabetes nurse specialist team at Leeds Teaching Hospitals NHS Trust has been encouraging and supporting schools for several years to help children with diabetes intensively manage their condition. About 50 schools in the area are carrying out blood glucose monitoring and supervising/ administering insulin. Only one school has refused to participate and there has been positive feedback from children, families and schools. The aim now is to roll out the work across the Yorkshire region.

The programme, developed by the clinical director for paediatric medicine and the children's diabetes

nurse specialists (CDSNs), uses a collaborative approach involving parents and health and education staff and authorities. The team recognised the need to offer specialist information for schools and, crucially, to provide training and ongoing support for school staff whilst ensuring that the consultant paediatrician remains in control of what is best for the child as a patient.

A model tri-partite agreement provides a practical basis for school staff to administer a bolus of insulin using an insulin pump or injection. The agreement is between the head teacher, named staff, the child's parent or carer, the CDNS and the consultant paediatrician.

The agreement clarifies the parent or carer's support for an intensive insulin regime for the child, such as multiple injections or insulin pump therapy, in consultation with the consultant paediatrician and the children's diabetes team. It makes it clear that named members of staff will give the bolus of insulin, who have demonstrated their competence to a CDNS. The agreement also sets out the role of the CDNS, including the provision of ongoing support and training to the school.

To address a key concern often expressed by schools, the agreement states that neither the school nor its staff will be held liable for any injury or death arising directly, or indirectly, from the administration of the

prescribed medication by appointed staff, except through the negligence of the local authority's employees. It makes it clear that the decision to provide emergency medical treatment rests with the medical authority.

In addition, separate written guidance is available from the team about the knowledge and skills required by someone at school for supporting a child with diabetes. The guidance also covers aspects such as treatment of a hypoglycaemic episode, blood glucose testing, age and cognitive ability to manage decimal points and assistance with the use of insulin pumps including decision support tools.



7. The legal framework

A question that looms large is 'whether there is adequate legislation in place to ensure support at school for children with long-term conditions and how well it's applied?'

An examination of the legal framework shows that there is legislation in place to support the health, safety and well-being of children and school pupils. There are also anti-discrimination and equalities duties placed on public bodies including schools.

The main pieces of legislation that appear to have a bearing on the provision of support for children with diabetes in schools are discussed below. (This is not intended to be a comprehensive guide to the law, but merely highlights aspects that are especially relevant.)

Common law duty of care

There is no legal or contractual duty on staff to administer medicine, or supervise a child taking it. However, anyone caring for children, including teachers and other school staff, has a common law duty of care to act like any reasonably prudent parent¹⁰ This relates to the 'common law': the body of law derived from court decisions made over the years, as opposed to law which is set down in statute. The duty means that staff need to make sure that children are healthy and safe, and in exceptional circumstances the duty of care could extend to administering medicine and/or taking action in an emergency. The duty also extends to staff leading activities taking place off site, such as visits, outings or field trips.

Health and Safety at Work Act 1974 (HSWA)

This Act places duties on employers regarding the health and safety of their employees and anyone else on the premises. As far as schools are concerned, this includes staff and children.

The duties placed on employers, (local authorities and school governing bodies); include having a written health and safety policy, and ensuring that staff are aware of the policy and their responsibilities to implement it. Employers are also required to make sure that staff are properly trained and receive guidance about their responsibilities. Related regulations (the Management of Health and Safety at Work Regulations 1999) place requirements on employers about risk assessment and control, and the

provision of information to employees in this regard. The HSWA and related regulations also apply to employees, and include requirements to co-operate with their employers, to carry out activities in accordance with training, and to inform their employer of any serious risk.

The Education and Inspections Act 2006

This legislation has placed a new duty to promote the well-being of pupils at the school on the governing bodies of maintained schools, primary, secondary, special and pupil referral units (an equivalent requirement was placed on new academies through their funding agreements). The duty took effect in September 2007. At the time of writing the DCSF was consulting on draft guidance on the role of schools in promoting pupil well-being (see page 25).

Education and Inspections Act 2006

38 General duties of governing body of maintained school

(5) The governing body of a maintained school shall, in discharging their functions relating to the conduct of the school—

- (a) promote the well-being of pupils at the school ..."*
- (b) in the case of a school in England, promote community cohesion.*

It says that in doing so, 'the governing body will:

- have regard to any relevant children and young people's plan.
- have regard to any views expressed by parents of registered pupils.'

Disability Legislation

(Details given below on disability legislation are from the Code of practice for schools, published in 2002 by the former Disability Rights Commission).

The Disability Discrimination Act 1995

The Disability Discrimination Act (DDA) says a disabled person is someone with 'a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'.

This means that conditions such as cancer, diabetes, multiple sclerosis and heart conditions are included within the definition. People in these circumstances

will have rights under the DDA to protect them from discrimination¹¹.

In September 2002 new duties came into effect, extending the DDA to cover education. The Special Educational Needs and Disability Act 2001 amended the DDA Part 4 to prevent discrimination against disabled people in their access to education.

The duties make it unlawful to discriminate without justification, against disabled pupils and prospective pupils in all aspects of school life. The principle underpinning this legislation is that wherever possible disabled people should have the same opportunities as non-disabled people in their access to education. The two core duties to ensure schools do not discriminate against disabled pupils are:

1. Not to treat disabled pupils less favourably.
2. To take reasonable steps to avoid putting disabled pupils at a substantial disadvantage. This is known as the reasonable adjustments duty.

Therefore discrimination against a disabled child can occur in two possible ways. Discrimination is either:

1. Treating a disabled pupil or prospective pupil less favourably, for a reason relating to his or her disability, than someone to whom that reason does not apply, without justification
2. Failing to take reasonable steps to ensure that disabled pupils or prospective pupils are not placed at substantial disadvantage in comparison with their non-disabled peers without justification. This is known as the reasonable adjustment duty.

It is against the law for education providers to discriminate in the following areas:

- admissions (including placing requests)
- the curriculum, teaching and learning and other services which are provided wholly or mainly for students – including school trips and outings, school sports, leisure facilities and school meals, libraries and learning centres, work experience and student accommodation
- by excluding a child from an education institution or course.

Special Educational Needs (SEN)

The duties in the DDA are designed to dovetail with existing duties under the SEN framework. The main

purpose of the SEN duties is to make provision meet the special educational needs of individual children.

The definition of SEN is understood as being primarily about children with learning difficulties. However, it is important to recognise that the definition of children with learning difficulties includes children with a disability where any special educational provision needs to be made. It means that children with a disability have special educational needs if they have any difficulty in accessing educational provision and if they need any special educational provision to be made for them, that is, anything that is additional to or different from what is normally available in schools. Pupils may have either a disability or special educational needs or both. The SEN framework is designed to make the provision to meet special educational needs. The disability discrimination duties, as they relate to schools, are designed to prevent discrimination against disabled children in their access to education.

The Disability Discrimination Act 2005 made important changes to the original legislation, introducing a new legal duty on public authorities to have due regard to the need to promote disability equality. This is known as the Disability Equality Duty which came into force in December 2006. All bodies covered by the specific duties (including schools) must have a Disability Equality Scheme which they are required to implement.

Disability Equality Duty

The duty to promote disability equality requires all public authorities, when carrying out their functions, to have due regard to the need to:

- promote equality of opportunity
- eliminate unlawful discrimination
- eliminate disability-related harassment
- promote positive attitudes towards disabled people
- encourage participation by disabled people in public life
- take steps to meet disabled people's needs, even if this requires more favourable treatment.

These elements together are referred to as the 'general duty'. All schools in England were required to produce a Disability Equality Scheme by the 3 December 2007. Although, how many actually have is an important question.

There is a statutory requirement to involve disabled people in the production of Disability Equality Scheme (DES). Moreover, schools are required to include in their Schemes details of how the impact (or likely impact) of policies and practices on disabled children and adults will be assessed. They are integral part in helping schools to define the right action.

Care Standards Act 2000

Although this legislation relates to social care regulation, it is relevant because it reforms the regulation of child-minding and child day-care provision. The Act paved the way for the introduction of a large number of care standards for adults and children in care settings, which include for example 'National standards for under 8s day-care and child-minding'. The responsibility for meeting specified standards is clearly placed on registered persons, who can be de-registered if they fail to meet necessary requirements.

The registered person in an early years setting, such as day-care or child-minding, is required to have a clear policy on the administration of medicines.

The child minder does not administer any medicine or other treatment to children unless the parent has discussed its use and given prior written permission. This forms part of the contract with parents. If medicine is to be given, the child minder ensures that:

- Medicines are stored in their original containers, clearly labelled and inaccessible to children.
- Medicines are not usually administered unless they have been prescribed for that child by a doctor.
- A child minder caring for a child with a specific condition on a long-term basis makes sure that they have a thorough understanding of the medical condition and the medication (if any) that they are required to administer. Written records are kept of medicines administered to children and the parent signs the record book to acknowledge the entry.
- If the administration of any prescribed medication requires technical/medical knowledge then individual training is provided for the child minder from a qualified health professional. Training is specific to the individual child concerned¹².

Under this Act, from 1 April 2007 Ofsted has been responsible for the regulation and inspection of children's social care, including providers of day-care

or child-minding services. As a result it is Ofsted's duty to ensure that the requirements set out in the national standards for under 8s day-care and child-minding are met.

The Medicines Act 1968

This sets out the way that medicines are prescribed, supplied and administered within the UK and places restrictions on dealing with medicinal products, including their administration. According to the legislation, anyone may administer a prescribed medicine, with consent, to a third party, so long as it is in accordance with the prescriber's instructions. The administration of prescription-only medicine by injection may be done by any person but must be in accordance with directions made available by the prescriber in respect of a named patient.

The Children Act 2004

This Act amongst its provisions establishes a duty on local authorities to make arrangements to promote co-operation between agencies and other appropriate bodies (such as voluntary and community organisations) in order to improve children's well-being, as well as a duty on key partners to participate in the co-operation arrangements.

Well-being is defined in section 10 of the Act as:

- physical and mental health and emotional well-being
- protection from harm and neglect
- education, training and recreation
- the contribution made by them to society
- social and economic well-being.

Guidance on this 'duty to cooperate', issued under section 10 of the Act and to which all local authorities and 'relevant partners' must have regard, was issued in 2005. This explained that acting in accordance with the duty, and with the spirit and intention of **Every child matters**, implied putting in place 'children's trust arrangements' which put improved outcomes for children and young people at the centre of all activity.

The Children Act 1989

The Act gives local authorities a general duty to safeguard and promote the welfare of children within their area who are in need. Much of the Act concerns the processes which must be followed if a child is in need or at risk, focusing particularly on the role and

actions required of local authorities (including children 'looked after' by the local authority). The Act defines a child in need as follows:

- he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority
- his health or development is likely to be significantly impaired; or further impaired, without the provision for him of such services
- he is disabled.

The legislation also states that every local authority shall provide services designed:

- to minimise the effect on disabled children within their area of their disabilities
- to give such children the opportunity to lead lives which are as normal as possible.

The Education Act 2002

As well as the governance of maintained schools, financial assistance, and admission arrangements, the Act placed duties on local education authorities and governing bodies of maintained schools to carry out their functions with a view to safeguarding and promoting the welfare of children. All the bodies concerned must also have regard to any guidance issued by the Secretary of State in deciding what arrangements they must make to comply with their duty (see page 22 on the Children, young people and maternity services national services framework.)

The Education (School Premises) Regulations 1999

All schools are required to have a room appropriate and readily available for use for medical or dental examination and treatment and for the caring of sick or injured pupils. It must not be teaching accommodation, under these regulations. If this room is used for other purposes, the body responsible must consider whether dual use is satisfactory or has unreasonable implications for its main purpose.

Conclusion and recommendations

To some extent, the current legal framework does offer a basis for provision of support for children while at school. It is difficult to see how schools can meet their statutory obligations to promote pupils' well-being, carry out their common law duty of care, observe health and safety, as well as meet their

equalities and anti-discrimination duties, if they fail to put in place effective policies and satisfactory practical support for children with diabetes or other long-term conditions.

However, statutory requirements under relevant legislation are too broad; as a result much of the onus falls on parents if education authorities or governors fail to meet their legal obligations. There is also a notable comparison to be drawn between the formal requirements for day-care and child-minding providers and the guidance issued for schools in relation to management of medicines. The former are not only much clearer and more specific than the latter, there is also clear monitoring and inspection by Ofsted.

- If schools are to fulfill their common law duty of care, their equalities and anti-discrimination duties, and their duty to promote pupil well-being, the Government needs to be pro-active and place specific duties on schools/employers and local authorities.
- 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 medical needs. 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 those providing services in child-minding.
- The EHRC should take action to raise awareness among school employers and staff of their statutory obligations under the DDA.
- The EHRC should undertake an audit of schools to see how many have a Disability Equality Scheme in place.
- The Education (School Premises) Regulations should be amended to require schools to make accommodation available for the administration of medicines to pupils, including self-administration, and for monitoring of pupils' health.

8. Current guidance and policies

Although the existence of various pieces of guidance and policy is welcome, it underlines the question 'what difference is it all making to improving support in schools?'

As with the legislation in the previous section, there is an enormous web of official policy and guidance available for schools, local authorities and primary care trusts explaining the need for explicit policies on school support for children with medical needs. In addition, together with other long-term condition charities, Diabetes UK has produced a resource pack for schools.

Other more general pieces of official guidance are also highly relevant, especially proposed new guidance about schools' duty to promote pupils' well-being.

The underlying problem is the lack of implementation and statutory teeth to ensure that guidance is followed in a consistent way across the UK. This section provides an overview on the abundance and range of relevant guidance and policy. Such as:

- **Medical conditions at school partnership**
- **Guidance on managing medicines in schools and early years settings**
- **National service frameworks**
- **Making every young person with diabetes matter**
- **Every child matters**
- **Children's plan**
- **Children's trusts**
- **Disabled children's review**

Guidance

Medical conditions at school partnership

Diabetes UK, The Anaphylaxis Campaign, Asthma UK, Epilepsy Action, and the Long-term Conditions Alliance have produced a policy resource pack on medical conditions at school, which is aimed at assisting primary and secondary schools to implement a tailored and effective medical conditions policy¹³. The partnership recommends that schools have a medical conditions policy to ensure children and young people with medical conditions can achieve the five **Every child matters** outcomes. The pack includes an example policy and

guidance to help schools develop their own medical conditions policy; awareness information for school staff on four key medical conditions including diabetes; information on legislation and guidance and on further advice and resources.

Managing medicines in schools and early years settings, 2005

DCSF and DH have produced joint guidance on supporting children in school with medical needs which was updated in 2005. The guidance does not have a statutory basis but is intended to provide a framework for schools, local authorities, PCTs and families to work together to develop policies to ensure that children requiring medicines receive the support they need while in school. The guidance takes account of relevant Government policy, Medicines standard of the national service framework for children, young people and maternity services and the **Every child matters** programme.

The guidance also covers the responsibilities of schools under the Disability Discrimination Act, as well as raft of measures that are important for the management of medicines, including the need for a clear policy on support for children with medical needs in schools that is regularly reviewed and updated; appropriate training and support for staff from health professionals; robust systems to ensure that medicines are managed safely; and for an assessment of the risks to the health and safety of staff and others and for measures to manage any identified risks.

Examples of the types of issues that should be covered in such policies are set out. These include:

- Procedures for managing prescription medicines which need to be taken during the school day.
- Procedures for managing prescription medicines on trips and outings.
- A clear statement on the roles and responsibility of staff managing administration of medicines, and for administering or supervising the administration of medicines.

The guidance goes on to outline how an individual health care plan can help staff identify the necessary safety measures to support children with medical needs and ensure that they and others are not put

at risk. In addition, the guidance provides basic information specifically about the medical conditions in children that most commonly cause concern in schools: diabetes, asthma, epilepsy and severe allergic reaction (anaphylaxis).

Making every young person with diabetes matter, 2007

This is the report of the Children and Young People with Diabetes working group at the Department of Health (DH), of which Diabetes UK was a member. It contains detailed proposals for improving care for children and young people with diabetes ensuring that national standards are met. It has the status of best practice guidance, intended to help commissioners of services arrive at locally appropriate service specifications.

The report covers a wide range of issues, including specific and quite trenchant recommendations about support in schools. Particularly relevant is the recognition of the importance of appropriate diabetes care in the school setting for a child's immediate safety, long-term well-being and optimal academic performance, and of the benefits for schools in supporting the full range of options for managing diabetes.

The report acknowledges there are schools offering good levels of support for pupils and parents, but refers to substantial variation in practice and concluded that care in early years and school settings can be a significant concern for children and their families. It states that all settings should be encouraged to offer good levels of support so that parents can work rather than attend school to administer medicines; provide appropriate environments (such as an empty classroom at break times) for monitoring or insulin injections; facilities for sharps disposal; and ensure inclusion in school activities and visits.

The report recommends joint working arrangements across health; social care and education are sensitive to the needs of children and young people with diabetes, their parents, and the constraints on individual schools. It highlights the importance of co-operation between local authorities and other



partners in children's trust arrangements to provide comprehensive care, stressing that care in school should not fall automatically to parents.

The report advises that local protocols for staff training, support and supervision, access to appropriate facilities and equipment be drawn up by each PCT and local authority. And that children and young people's specialist multidisciplinary diabetes (CYPsD) care teams provide education about diabetes to teachers and other school personnel on a regular basis. Specific recommendations are made with reference to implementation of the DDA. These include the need for an individualised diabetes medical management plan to be agreed by the parent/guardian, the school, and the CYPsD team, which describes all parties' responsibilities, addresses the child's needs and provides clear instructions for ongoing and emergency care, including the administration of insulin and carrying out blood glucose testing as necessary.

National service frameworks (NSFs)

Although the NSFs do not tend to impose statutory obligations, they are an expression of official Government policy and offer a way of assessing the effectiveness of service performance. NSFs are therefore integral to the Department of Health standards-based system for promoting continuous improvements in quality and safety. There are two that are applicable – the *Diabetes national service framework* and the *Children, young people and maternity services national service framework*.

Diabetes national service framework (NSF)

In the context of support in schools for children with diabetes, there are some key aspects of the overarching *Diabetes NSF* that should be highlighted:

- **Standard 3:** states that all children, young people and adults with diabetes will receive a service that encourages partnership in decision-making, supports them in managing their diabetes and adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. And where appropriate parents and carers should be fully engaged in this process.
- **Standard 5:** says that all children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day-care, will be supported to optimize the control of their blood glucose and their physical, psychological, intellectual, educational and social development.

The report produced in 2007 by the Department of Health on progress to date in fulfilling the Standards under this NSF did not specifically refer to support in schools¹⁵. However, in general it stated that despite some excellent examples of local progress, services for children with diabetes and their families are still below standard in many areas, and went on to refer to the joint working group set up by the DH with Diabetes UK to examine the issues for children and young people and what needs to be done to improve care.

Children, young people and maternity services national service framework (NSF)

The Children, Young People and Maternity Services NSF was published in 2004 and comprises of 11 Standards. Each Standard is intended to provide markers of good practice to help the NHS, local authorities and their partner agencies achieve and demonstrate high quality service provision. Key aspects are outlined below. (This is not a comprehensive list of all salient points across these Standards, but identification of those that are particularly relevant to achieving improved support in schools).

• **Standard 10: Medicines for children and young people**

The rationale for this Standard states that: *'Some children and young people, particularly those who are disabled or have long-term conditions, have to take medicines during the school day, and with some assistance from health, early years or school staff they are able to take part in most activities. There is, however, anecdotal evidence that the storage of medicines and access to medicines in these settings can vary. Therefore, it is important that local health and education services work together to ensure that children and young people are able to receive their medicines during the school day.'*

The need for schools to consider carefully their arrangements for managing an individual pupil's medicine is specifically mentioned. The Standard highlights the fact that, ultimately, the employer of school staff at a maintained school (either the local authority or the school's governing body), is responsible for the health and safety of staff, pupils and visitors and must be satisfied that arrangements for managing medicines safely in school protect – as far as is reasonably possible – their health and safety. The need for schools to have sufficient members of support staff who are appropriately trained to manage medicines as part of their duties is also flagged up, together with the need for them to be indemnified by their employer's insurance arrangements.

The Standard outlines responsibilities for PCTs, including the need for schools to have access to appropriate advice, training and support from local health professionals so that they can make decisions on supporting pupils with their medicines.

• **Standard 5: Safeguarding and promoting the welfare of children and young people.**

Although much of the focus is on the identification and prevention of child abuse and neglect, the Standard makes it clear that safeguarding covers more than the contribution made to child protection in relation to individual children. It draws attention to the duties placed on local authorities and schools' governing bodies, in the Education Act 2002, to safeguard and promote the welfare of children, and to have regard to any guidance issued by the

Secretary of State in considering what arrangements they need to make. These safeguarding responsibilities extend to pupil health and safety, bullying, and fulfilling specific statutory requirements together with other issues, for example, arrangements for meeting the medical needs of children with medical conditions, providing first aid, and other topics about which the Secretary of State has issued guidance.

In this context, the Standard emphasises the need for all schools to have a designated senior member of the leadership team taking the lead responsibility for safeguarding and promoting the welfare of children. The designated person, the head teacher, and all staff who work with children, as well as school governors, should receive training on their responsibilities for safeguarding and promoting the welfare of children and young people.

- **Standard 6: All children and young people who are ill, or thought to be ill, or injured will have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness.**

This Standard addresses the requirements of children, young people and their families when they have an acute illness or injury and also children and young people who have (or are at risk of) a long-term condition which is not disabling. It is assumed here that this Standard will apply to some children with diabetes.

There are a number of highly pertinent recommendations regarding support in schools. These include the need for systems to be developed to ensure that health and social services provide information, training and support to schools and early years settings, in caring for children and young people with medical needs. Moreover, the Standard calls on health and education services to develop joint local protocols for managing the needs of children and young people with a long-term condition that are in line with legislation and guidance. Local protocols should include the identification of a 'named health contact' and a 'named teacher', who are jointly responsible for the reviews of health care plans for each child, which

details the child's health care needs and the support to be provided in schools. These plans should be reviewed by the multi-disciplinary, multi-agency team and the family on an annual basis.

- **Standard 8: Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.**

Local authorities, PCTs, NHS trusts and schools are meant to ensure that disabled children are able to access the full range of opportunities provided by the education service, wherever possible in mainstream settings. It also emphasises the need for an integration of services that truly supports a child's journey, planning and commissioning, including arrangements which encourage multi-agency strategic planning of services for disabled children, possibly through a children's trust.

The Standard recommends that all specialist and mainstream staff whose roles include responsibility for disabled children are competent in the core of skills, knowledge and competencies set out under Standard 3 (Child, young person and family-centred services). It also calls for multi-disciplinary and multi-agency specialist teams to be further developed to meet the needs of disabled children at home and at school, and for appropriate training for all staff in specialist and mainstream settings in health, social care, early years and education.

National healthy schools programme (NHSP)

The Government has set a target that all schools will be participating in the NHSP by 2009 and that 75 per cent of schools will have achieved National healthy school status. The Programme's aims include supporting children and young people in developing healthy behaviours, and to help reduce health inequalities¹⁶.

The Programme has four themes:

1. Personal, Social and Health Education (PSHE)
2. Healthy eating
3. Physical activity
4. Emotional health and well-being, including bullying.

These themes are relevant for children with diabetes at school but the NHSP does not go into specific detail regarding provision of support for children with medical needs at 'healthy schools'. However, the following aspects are worth noting, cited under the minimum types of evidence required to support the theme of emotional health and well-being. The evidence required includes:

- Vulnerable children and young people have individual support plans.
- The school has plans and protocols in place for working with other agencies to support individuals and their families.
- Vulnerable children and young people report feeling supported.

While the 'healthy eating' theme emphasises a number of aspects related to the availability of healthy and nutritious food and drink in schools, it does not explicitly state that appropriate food and drink should be available for children with medical conditions such as diabetes at times to suit their needs.

Every child matters (ECM)

The **ECM** policy forms the over-arching backdrop and basis for much of the current system of regulation and inspection of children's services in England. Spurred in large part by the need to review these services following the death of Victoria Climbié, the Government published a Green Paper in 2003 followed by **Every child matters**: the next steps, and the Children Act 2004.



The **ECM** green paper identified the five outcomes that are most important to children and young people:

1. be healthy
2. stay safe
3. enjoy and achieve
4. make a positive contribution
5. achieve economic well-being.

The five outcomes are universal ambitions for every child and young person, whatever their background or circumstances. The outcomes are mutually reinforcing. For example, children and young people learn and thrive when they are healthy, safe and engaged.

The Children's plan

This plan published in 2007, is a ten year strategy to improve services for children. The Secretary of State for Children, Schools and Families, explains:

'Our aim is to make this the best place in the world for our children and young people to grow up'¹⁷.

The plan is underpinned by five core principles:

1. Government does not bring up children, parents do
2. all children have the potential to succeed according to their efforts and abilities (rather than background and circumstances)
3. children and young people need to enjoy their childhood
4. services need to be shaped by and responsive to children, young people and families
5. it is always better to prevent failure than tackle a crisis later.

The plan emphasises the vital role that schools play in promoting physical and mental health, and emotional well-being, highlighting their duty to promote the well-being of pupils in the Education and Inspections Act 2006, and draws attention to new school level indicators that will be developed to measure a school's contributions to pupil well-being.

Among a range of other issues, the plan stresses the importance of good health for children and young people announcing that a **Child health strategy** would be produced jointly by the DCSF and the DH in 2008. The strategy has not been published at the time of writing, however it is an ideal opportunity

for the Government to detail how schools, PCTs and local authorities will work together to support children with long-term conditions at school.

Children's trusts

The *Children's plan* says that it seeks a step change in outcomes for children and that it will set high expectations for children's trusts. Children's trusts are local-area partnership arrangements for bringing together key agencies, some of which are under the Children Act 2004 'duty to co-operate'. The aim is to deliver integrated and more outcome-focused services for children, young people and their families.

Updated draft guidance on the 'duty to co-operate' was published for consultation on 3 April 2008¹⁸. A significant proposal is that in future all schools should be strongly supported by their children's trust and schools need to have a real involvement in the strategic work of the children's trusts¹⁹. Schools can expect to be supported to raise standards and give practical effect to their new duty to promote the well-being of all their pupils. Equally the DCSF says that schools must be able to help shape the planning and commissioning of local services and play a central part in the work of the children's trust board. By 2010 the Department expects that all schools will be providing access to a range of extended services shaped by consultation with parents, children and young people. The essential features of a children's trust are:

- Outcome-led vision - a focus on improved outcomes, informed by the views of children and their families.
- Integrated front-line delivery - professionals working together around the needs of children, not constrained by organisational boundaries.
- Integrated processes - better assessments, information sharing and improved referrals mean children get the services they need quickly.
- Integrated strategy - joint commissioning of services and pooling of budgets and resources to drive multi-agency working.
- Inter-agency governance - setting a clear framework for strategic planning, resource allocation, and accountabilities²⁰.

The draft guidance does not specifically discuss

support in schools for children with medical needs. However, it refers to the need for the arrangements to focus rigorously on prevention and the early identification of children with additional needs; to involve and empower parents; and to drive effective integrated working between all professionals working with children and young people.

In emphasising the importance of good physical mental and emotional health as a key outcome in its own right and as having a crucial influence on each child's future, the draft guidance states that it is essential that all partners in the children's trust, including schools, work together to promote good health and prevent ill health for all local children and young people whether they are well, sick or belong to a vulnerable group such as children in care or disabled children.

The Centre for Excellence and Outcomes in Children and Young People's Services (CfEO) is being set up to identify, co-ordinate and disseminate knowledge and evidence about how outcomes and services for children and young people are improving.

Children's well-being – draft guidance 2008

At the time of writing, the Government was consulting on draft guidance to advise schools on their duty to promote pupil well-being that came into force in September 2007 (under the Education and Inspections Act 2006)²¹. It explains that well-being is defined in law in terms of the five *ECM* outcomes.

Support for children with medical needs is not explicitly mentioned in these proposals but it does offer scope for the issue to be given greater recognition.

The guidance says that, in considering their contribution to pupil well-being, schools will need to pay particular attention to the needs of vulnerable children. However, children with long-term medical conditions are not included in the cited list of examples. Nevertheless, the document does draw attention to the fact that, under equalities legislation, schools are required to promote equality of outcomes for different groups and to ensure that none of their policies are discriminatory. It also emphasises that the disability equality duty requires

a more proactive approach, and includes a requirement for schools to monitor the impact of their policies and practices on disability equality.

The final guidance will be aimed at offering advice to schools on what is meant by well-being and their role in promoting it, together with the support they should expect from the local authority and other partners. Obviously children with long-term conditions should be explicitly identified as a vulnerable group, so that their needs are properly considered across the five *ECM* outcomes, and the cycle of self-evaluation in school formally takes account of progress in supporting these children.

A separate consultation is expected later in 2008 on proposals for improving the data and evidence about schools' contribution to well-being, linked to proposals for developing new school level indicators of well-being that will be reflected in Ofsted's new inspection framework from 2009 (see pages 30–32 for further discussion of Ofsted's role).

Disabled children's review

Following a review in 2006 of what more can be done to improve the outcomes of disabled children and young people and their families, the Government published a document in 2007 setting out further actions to be taken²². Focus is placed on three key areas:

1. Empowerment - offering parents and disabled children choice and the power to take decisions about their own care and influence local priorities, to improve service quality and responsiveness.
2. Responsiveness - prioritising disabled children locally and nationally, with early intervention, coordinated and timely support, easier access for families to holistic support, and prevent conditions deteriorating.
3. Service quality and capacity - boosting provision of services which are vital for improving outcomes for disabled children and their families.

Entitlements

The Government stated that better support and improved provision of services for disabled children and families needs to be underpinned by clear

entitlements that are well understood, with minimum standards as part of a 'core offer'. While acknowledging the need for local flexibility and innovation, it said that such entitlements will ensure disabled children are not disadvantaged by how well local areas are accommodating national standards and local priorities. The need for co-ordinated planning and commissioning to ensure best use of resources across health, social services and education boundaries was also explicitly recognised as a key element.

Moreover the Government decided to introduce a national disabled children indicator (NI 54) as part of the new set of priority public service agreements (PSAs) so that commissioners and service providers have sufficient incentives to focus on the needs of disabled children (see pages 28–30). The disabled children's national indicator will look at parents' general experiences of services for disabled children and young people. It is intended to be a core part of performance management arrangements aimed at improving the quality of services for disabled children, which is also a priority of the Child health and well-being public service agreement (PSA12)²³.

A funding package of £340 million for the period from 2008/11 was announced alongside the outcome of the *Disabled children's review*. This raises the question of whether any specific funding could be available through this stream to assist schools in improving support for children with medical needs – at present; this does not appear to be the case.

The DCSF has commissioned the National Centre for Social Research to help develop the methodology for the survey that will underpin the indicator. At the time of writing, a decision on the form of the indicator was due to be taken in Autumn 2008, with the intention that the indicator will be measured for the first time at local level in 2009/10.

Disabled children and data collection

A significant recommendation arising from the *Disabled children's review* is the need to develop a clear picture of the disabled children population at local level to improve planning. It is intended that

local authorities and PCTs will improve their data collection and national and local agencies will work together to develop more coordinated data sets.

Presently there are no official figures of the number of children in primary and secondary schools who have a long-term medical condition (apart from statistics on children who have special educational needs but these do not include children whose medical condition does not give rise to an SEN. At the time of writing, the DCSF was looking at how to collect information on pupils' disabilities in future. However, according to a reply to a Parliamentary Question, it also has to balance the need for additional data with the burden that its collection places on schools²⁴.

The DCSF commissioned the Thomas Coram Research Unit to undertake a survey of all Directors of Children's Services in England to collect and analyse data on the numbers and characteristics of disabled children and the services provided to them²⁵. They found that most authorities experienced difficulties in providing information for the survey. This was because social care, education and health differ in their definitions and criteria for categorising disability. Consequently there is a lack of reliable data, both nationally and locally, on the numbers and characteristics of disabled children and their use of local services.

Conclusion and recommendations

There is a vast amount of policy and guidance relevant to children with long-term conditions. However, its implementation is woefully inadequate. This perhaps explains to some extent why basic data is missing. The Government and local services should know the number of children at school with long-term conditions, and the number of children with a disability. Yet the situation is compounded by the fact that education, health and social care services do not have a common definition of disability. Developments in policy for integrating services for children through Children's trusts are very welcome, providing they explicitly recognise children with long-term conditions as a vulnerable group needing schools to provide support, and that there's a clear mechanism for holding trusts to

account. Similarly guidance for schools on children's well-being should also recognise children with long-term conditions as a vulnerable group.

- The National healthy schools programme should be revised. That is no school should be 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.
- Disabled children and their families need to have clear entitlements that are easily understood as part of the 'core offer'. These should explicitly include entitlements to proper trained support in schools for children with diabetes and other long-term conditions.
- 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.
- The guidance on children's well-being should be amended so that children with long-term conditions are specifically included as potentially vulnerable that the issues is considered during self evaluation.
- There needs to be a clear means of scrutinising the role and performance of children's trusts, including the support that the trusts and related schools provide for children with diabetes and other medical needs.

9. Performance measurement and inspection

If the adage “what gets measured gets done” is true, this means that the needs of children with long-term conditions will only count if their needs are formally recognised.

For local authorities and health services, alongside all the policy, standards and guidance, there is a panoply of accompanying mechanisms and indicators to measure and assess their performance. This includes performance in relation to children's health and well-being, though whether children with long-term conditions are included is far from clear. With specific regard to schools, Ofsted (an independent agency) conducts inspections that are required to cover the five **ECM** outcomes.

Public service agreements (PSA)

Thirty PSAs were produced as part of the Government's Comprehensive spending review 2007. Particularly relevant is PSA 12 – to improve the health and well-being of children and young people. This PSA sets out the Government's vision for improving the physical, mental and emotional health of all children for the next three years. The focus is on prevention, early intervention and enabling children, young people and their families to make healthy choices. The key indicators on which progress will be monitored include:

- Reducing childhood obesity.
- Improving emotional health and well-being, and child and adolescent mental health services.
- Improving services for disabled children.

Improved health outcomes for children and young people are also supported by PSA 14 - to increase the number of children and young people on the path to success. And PSA 18 - to promote better health and well-being for all.

National indicators for local authorities and partnerships

These indicators are now the only measures on which central Government will performance manage outcomes delivered by local government, working alone or in partnership. They replace all other existing sets of indicators; 185 indicators have been published to date, with a full set of 198 expected.

The indicators relate to the PSAs and performance against each one will be published annually by the Audit Commission, as part of the comprehensive area assessment. The following are particularly relevant:

- No.50 - Emotional health of children (new).
- No.54 - Services for disabled children (new).
- No.55 - Obesity in primary school age children in Reception (existing).
- No. 56 - Obesity in primary school age children in Year 6 (existing).
- No. 57 - Children and young people's participation in high-quality PE and sport (new).
- No.70 - Hospital admissions caused by unintentional and deliberate injuries to children and young people (new).
- No 140 - Fair treatment by local services (new).

Local area agreements (LAAs)

As from June 2008, the new LAAs form the only mechanism for setting targets shared between local government and their delivery partners (including PCTs) and central government. Each LAA will have a set of up to 35 local improvement targets, complemented by 16 statutory targets on educational attainment and early years, selected from the 198 national indicators.

According to the DCSF, children's trusts are meant to have a critical role in the process of identifying improvement priorities for the children and young people's theme of new LAAs, and in feeding these into the wider Local Strategic Partnership which will negotiate improvement targets with central government.

The intention is that the Children and young people's plan (CYPP) will provide a basis for discussion on the children and young people's theme. The LAA should inform the CYPP and vice versa, with the LAA containing the priorities and associated targets, and the CYPP setting the strategic context for the authority's targets and the strategies for achieving them.

Comprehensive area assessment (CAA)

Health and social care related services and activities in England will come within a new assessment system, the CAA, from April 2009.

Each area's CAA will have four elements: an assessment of the risks to outcomes being delivered in areas (including LAA targets) and the effectiveness of their management; a scored use of resources judgement for each local authority in the partnership; an annual scored 'direction of travel' judgement for the local authority; and publication of performance data for each area against the set of national indicators. The CAA will include evaluation of the quality of public engagement, including how well vulnerable and marginalised groups of people have been involved.

A critical issue will be how useful the assessment reports are to local people, including whether they cover matters such as the adequacy of provision of services in schools for children with diabetes and other long-term conditions.

The inspectorates involved include the Audit Commission, the new Care Quality Commission and Ofsted. The intention is that the inspectorates will provide CAA findings in ways that mean local people can access information about services where they live. The stated aims of the CAA include:

- Strengthen accountability to citizens and communities by adding to the best value duty so that authorities, where appropriate, must secure the participation of citizens in their activities.
- Provide citizens and communities with timely information and better opportunities to hold delivery partners to account.
- Develop a small set of national indicators measuring citizens' perspectives.
- Ensure that inspectorates have a strong focus on citizen experiences and viewpoints in their work.

As the CAA will focus on the strength of strategic partnership working in delivering outcomes, it is meant to help drive more effective co-operation and integration within the children's trust and other partnerships.

The joint area review (JAR)

This is a three-year programme running until December 2008 in England: all 150 local authority areas will have one joint area review during this time. A JAR is intended to judge the contribution that the

council and its partners in the local area are making to improve outcomes for children and young people. JARs are meant to gather evidence during on-site fieldwork investigations into the contributions local services make to improving outcomes for some of the most vulnerable groups of children and young people, and those groups of children and young people who are not doing well enough or who are at risk of underachieving. It has not been possible to investigate whether the JAR programme is looking how well children with long-term conditions are supported in schools – this is clearly an area that would merit further exploration.

PCT performance measurement Annual health checks

PCTs are currently assessed by the Healthcare Commission according to how well they have performed in up to 24 core standards and existing national targets for NHS healthcare providers. The results are published annually in the Commission's annual health check.

Core standards are intended to describe a level of service which is acceptable and which must be universal – compliance with the core standards is not optional. Developmental standards are aimed at driving continuous improvement over time (NSFs should be considered as part of the developmental standards).

While these standards relate to the provision of NHS health care, they are intended to recognise the need to develop services in a co-ordinated way, taking full account of the responsibilities of other agencies in providing comprehensive care. The standards are currently divided according to specific domains: safety; clinical and cost effectiveness; governance; patient focus; accessible and responsive care; care environment and amenities; and public health.

One of the core indicators within the public health domain (C22) emphasises co-operation with local authorities and other organisations, and a key aim of the developmental standard (D13) is the need for PCTs to take the leading role in tackling health inequality issues.

Vital Signs

The NHS Operating Framework for 2008/9 requires PCTs to have developed an operational plan by the end of March 2008 that describes local targets, how they have been agreed and how they will be achieved; defines success; details milestones; and details their proposed LAA content on health outcomes. PCTs are not expected to submit their operational plan to DH, but they are meant to consider how the plan is shared with the local community. The national priority areas where PCTs are expected to plan for delivery in 2008/09 include improving access; and keeping adults and children well, improving their health and reducing health inequalities.

Within this Framework, the Government has introduced a new approach, known as 'vital signs'²⁶. PCTs will monitor progress against the specified national priorities using the indicators set out in Tier 1 and Tier 2 of the 'vital signs', limiting central performance management to the tier one national priorities and, beyond that, only to those areas or organisations where performance is weak.

Tier 1 consists of 'must do's'; Tier 2 are 'could and should do's', whilst Tier 3 indicators are for benchmarking purposes, and to 'help PCTs make choices on local priorities and inform the process of engagement with the local community.' The indicators for local use listed under Tier 1 include: patient reported unmet care needs; patients with diabetes in whom the last HbA1c is 7.5 or less from quality outcomes framework; and parents' experience of services for disabled children.

The DH will monitor progress against all elements of the 'vital signs' at least once a year. Report cards, based on the 'vital signs' will be produced for PCTs to ensure that patients and the public can monitor PCT improvements alongside the local NHS contribution to their LAA. The Department of Health also expects that the Healthcare Commission will build the national priorities (tiers 1 and 2) into its inspection regime.

School management and inspection

Consideration of how support can be improved for children with diabetes within schools must take account of how schools are managed and inspected. As a result of Government policy changes over the last

few years, some state schools have become more autonomous, although they are still subject to statutory duties such as those set out in section 3.

How schools are run

Ultimately the employer is responsible for ensuring that a state school fulfills its statutory obligations, including aspects such as health and safety, the duty of care, the disability equality duty and the duty to promote pupil well-being. School governing bodies are responsible for determining the aims and overall conduct of a school. Specific duties of governing bodies include the appointment of head teachers, setting staffing levels, setting and agreeing the school budget, and monitoring health and safety.

According to the National Governors Association website, the governing body has strategic responsibility for planning within the school while implementation and management is the role of the head teacher and staff. In practice, much will depend on the extent to which responsibilities are delegated and carried out by employers, such as local authorities, school governing bodies, and head teachers.

Those responsible for the duty not to discriminate in school education vary depending and on the type of school. For any school, the body that has responsibility under the duties is called the 'responsible body'.

The DCSF website for school governors outlines the respective roles and responsibilities for health and safety matters in schools²⁷. Statutory health and safety responsibilities in community schools, community special schools and voluntary controlled schools fall on the LA (as the employer) and on the head teacher and staff (as employees). The governing body, as the management body, should ensure that school staff and premises comply with the LA's health and safety policy and practices. In foundation schools, foundation special schools and voluntary aided schools, statutory health and safety responsibilities fall on the governing body (as the employer) and on the head teacher and staff (as employees).

In practice, the employer may delegate specific actions to meet statutory obligations to head teachers who may in turn delegate these matters to other members of staff. However the employer retains the ultimate

responsibility no matter who carries out the task. In terms of health and safety, school employees have a responsibility to cooperate with others by carrying out instructions and reporting unsafe practices. The head teacher, who has delegated responsibility for running of the school, has a particular role in ensuring that the governing body's health and safety policies and associated procedures are put into practice. The DCSF website for school governors also sets out a range of topics for governing bodies to consider relating to health and safety. These include pupil health: according to the website, this may include a range of issues such as support for children with medical needs, policies on water consumption by children etc. The website also signposts to current guidance on managing medicines in schools.

Widening roles

As outlined previously, current Government policy is for schools to play an increasingly important role within children's trusts about local needs and priorities. Moreover, Government policy is to encourage schools to become 'extended schools', as one of the key ways of delivering *Every child matters (ECM)* outcomes. An extended school is meant to work with the local authority, local providers and other schools to provide access to a core offer of integrated services, including swift and easy access to targeted and specialist services. Swift and easy access (SEA) is about schools working closely with other services to identify and support children and young people with emotional, behavioural, health or other difficulties as early as possible. The types of services covered may include speech and language therapy; family support services; and intensive behaviour support. Clearly there is an opportunity here to include support for children with long-term conditions.

Teacher training

Teacher training is another important part of the jigsaw, as it can and should provide opportunities for teachers to gain an understanding of long-term conditions, such as diabetes, that may affect children in their care.

It has not been possible to explore this issue in detail, however, in broad terms, the Training and Development Agency for Schools (TDA) is the national agency and recognised sector body responsible for the

training and development of the school workforce. It is meant to play a central role in supporting the workforce to help children and young people meet the *ECM* outcomes.

Monitoring and inspection

School inspectorates have a key role in contributing to the Joint area reviews through monitoring how well schools are meeting the outcomes defined in *ECM*.

Ofsted school inspections consist of evidence gathering aimed at assessing how well a school is performing. Inspections are short and focused, and may take one or two days. Inspectors study the schools self-evaluation form (SEF), and use this, the school's report on performance and assessment (PANDA), where one exists, and the report from the previous inspection to prepare a pre-inspection briefing about the school.

Inspectors are meant to carry out a range of activities in order to check how well the service meets the needs of children and young people. They should consider the *ECM* outcomes and evaluate how well the service performs against them, focusing on those most important and relevant to the service provided. On examination of the Framework for the inspection of schools in England from September 2005, it is clear that most focus understandably is placed on the outcome to enjoy and achieve. The least is placed on being healthy and staying safe, therefore school performance in relation to the needs of children with long-term conditions is arguably a weak aspect of inspection.

As well as having discussions with senior management and communicating with parents and pupils, inspectors may also look at school records. These could include care plans, accident books, medication details, and health and safety logs. Ofsted also has responsibilities for inspecting schools regarding minimum evidence for the National healthy schools programme.

However, the priorities for inspection vary between schools. From conversations with Ofsted (June/July 2008) it is understood that Ofsted inspectors would ask schools whether they are meeting the

requirements of anti-discrimination legislation and how school governors are monitoring the effects. They would also commonly expect to see health plans, for example, and to check the number of disabled children at a particular school. However, inspectors would not necessarily track individual cases unless they are alerted to a child's circumstances, for example, through discussions with parents and/or pupils. Some inspectors may ask to see children with medical needs but this varies between schools.

At the time of writing, the DCSF was consulting on guidance regarding schools' role in promoting pupil well-being. A separate consultation is expected later in 2008 on proposals for improving the data and evidence about schools' contribution to well-being, linked to proposals for developing new school level indicators of well-being that will be reflected in Ofsted's new inspection framework from 2009.

Conclusion and recommendations

Current performance measurement and inspection of local authorities, PCTs and schools does not give clear attention to the needs of children with long-term conditions. This stems from the fact that official policy does not explicitly recognise children with long-term conditions as a vulnerable group. Inspection is of course key to ensuring that schools have proper policies for supporting children with diabetes and other long-term conditions, and whether these policies are implemented, regularly reviewed and updated. In reality, the varied circumstances of schools and the relatively short period for individual inspections means that attention to these issues cannot be taken for granted. Consequently, it is vital that the requirements for inspections are tightened up in this respect. The development of new school indicators for Ofsted that take effect in 2009 offers an opportunity to remedy this.

- The system of performance measurement for PCTs should be reviewed to ensure that it includes their performance in supporting schools to help children with long-term conditions.
- The concept of swift and easy access to services through extended schools should incorporate co-ordinated provision of support for children with

diabetes and other long-term medical needs.

- 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 ensure that schools have similar requirements to those providing services in child-minding, 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.

“If my son was unhappy at school I don’t think I could cope. His school has been amazing since he was diagnosed. The teachers are very supportive and are embracing my son and his diabetes. They treat him as one of their own.” Tessa, Mum of Jack, age 10, Type 1 diabetes, Wakefield

For every child with diabetes who does not receive appropriate support, their health and well-being is put at severe risk and the whole family suffers.

The fact remains that schools have statutory obligations that they are required to meet (see pages 16–19). These include requirements under the DDA, common law duty of care, health and safety, and duties to promote and safeguard children’s welfare and well-being. In view of this it is staggering that support for children with diabetes and long-term conditions appears to be an entirely voluntary matter for schools.

Certainly official policy, guidance and legislation can be improved to explicitly recognise children with long-term conditions as a vulnerable group whose well-being needs to be properly supported. For instance the Education and Inspections Act 2006 can be strengthened so that the needs of these children do not continue to be overlooked at their peril. The broad duty to promote pupil well-being in the Act needs to be amended to explicitly include the well-being of children with long-term conditions.

Ultimately, though, implementation is the crux of the matter, so effective monitoring and enforcement is essential. This means Ofsted inspections need to ensure they take account of school provision for children with diabetes and other long-term conditions. This underlines the need for official policy to recognise children with long-term conditions as a vulnerable group.

Last but not least, the number of children with Type 1 diabetes is increasing significantly every year. Therefore many more teachers and head teachers are likely to meet children with the condition. Some may even become parents of children with diabetes. Clearly it is not an issue that is going to disappear. As such, professionals in education, health and local

government must work together to ensure every child with diabetes grows up to be a healthy adult with the same life chances and opportunities that all our children are entitled to.

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The charity for people with diabetes

Macleod House, 10 Parkway, London NW1 7AA

Telephone 020 7424 1000 **Fax** 020 7424 1001

Email info@diabetes.org.uk **Website** www.diabetes.org.uk

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