

# Diabetes and the child with special educational needs

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## Article points

1. Children with learning disabilities and diabetes require both learning and diabetes management support while in school.
2. This support should not adversely affect the child's learning or health outcomes.
3. The legislation requires schools to ensure reasonable adjustment, so that no child is discriminated against because of his or her disability.
4. Guidelines and resources are available to school policy makers, healthcare staff, and education providers to assist them in supporting the child with diabetes in the special educational needs setting.

## Key words

- Diabetes
- Special educational needs
- School children
- Legislation
- Guidelines

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Approximately 16 000 school-age children in the UK have diabetes (Diabetes UK, 2005). Of these, a small but significant number may have pre-existing learning problems at the time of diagnosis of diabetes, or be diagnosed with diabetes at an early age and then subsequently be identified as having learning difficulties as they grow up. This article outlines the key legislation surrounding diabetes management in this population, and presents a case study to illustrate the difficulties faced by young people with diabetes and learning difficulties.

Diabetes can coexist with conditions that require extra support for the child while in school, and the symptoms of diabetes, such as hypoglycaemia, can affect academic performance. Some conditions, such as Prader-Willi syndrome, can include diabetes as a related condition (Kelner, 1995). Children in the special educational needs setting who already have diabetes, or develop it at a later stage, will require both learning and diabetes management support. This should be provided in a manner that does not adversely affect either the child's learning or health outcomes. The document *Making Every Young Person With Diabetes Matter* (Department of Health [DH], 2007) states that for all children:

*“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.”*

## Current legislation and guidelines

In law, diabetes can be classified as a disability under the Disability Discrimination Act (1995, amended 2005), as the Act states that:

*“A person has a disability for the purposes of this Act if he has 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 Act did not originally cover schools, but the Special Educational Needs and Disability Act, passed in 2001 (Department for Education and Skills [DfES], 2001) extended it to schools. Children with diabetes are covered by this Act, and schools should be aware of this when dealing with pupils with diabetes. The Act requires that schools ensure reasonable adjustment so that there is no discrimination against the child for reasons relating to the his or her disability.

The *National Service Framework for Children, Young People and Maternity Services* (DH/DfES, 2004) states that:

*“Local health agencies, local authorities and schools work closely to ensure that children with complex medical regimens, whether through chronic ill health or disability, receive the specific support they need so that they can attend school – whether a special school or mainstream – on a regular basis. Where support is provided by school staff, they are fully trained by health professionals.”*

Despite support from such legislation and frameworks, schools often remain a contentious issue with respect to diabetes management. These ongoing concerns have led the DH to set up an implementation group to ensure that the recommendations of the report *Making Every Young Person with Diabetes Matter* (DH, 2007) result in action.

At the point of diagnosis of diabetes, if a child or young person has a pre-existing learning disability, there will be a need for enhanced inter-agency communication and co-operation. At this time, families often discuss the current support networks for their child; however, the diagnosis of diabetes may affect the current provision of services to the extent that a complete review of the agencies involved, their current responsibilities, and the distribution of future responsibilities should be conducted in a structured manner.

### The *Every Child Matters* programme

*Every Child Matters: Change for Children* (DH, 2003) is a programme that aims to ensure that all children meet five key outcomes:

- Be healthy.
- Stay safe.
- Enjoy and achieve.
- Make a positive contribution.
- Achieve economic wellbeing.

The agenda for *Every Child Matters* has been implemented nationally, across England, Wales, Scotland and Northern Ireland. Its history lies with the Laming Report of 2003 into the death of Victoria Climbié, where failings in inter-agency communication and decision making contributed to the death of

this young child. One essential step within *Every Child Matters* is that the child's needs become central to any decision-making; consequently, the individual child and family have a far greater input when planning services than under previous legislation.

### Common Assessment Framework

An important tool that can be used to support children in meeting these outcomes is the *Common Assessment Framework for Children and Young People* (DfES, 2006). The purpose of the Common Assessment Framework (CAF) is to allow an assessment to take place in a standardised, universal manner, across all children's services. All local authorities were expected to have implemented the CAF and the associated functions of appointing a lead professional and ensuring information sharing by March 2008. A CAF does not concentrate on one aspect of a child's life, but rather is used to identify strengths and difficulties throughout the child's life.

An example from the perspective of a health professional completing a CAF would be the need to consider educational, emotional and financial aspects of the child's life alongside the immediate health needs. A completed CAF is often held centrally within a local authority, and can be updated as frequently as necessary by any involved agencies.

While *Every Child Matters* does not focus specifically on the needs of the child with diabetes, or with special educational needs, the author would suggest that, as soon as possible after the diagnosis of diabetes in a child with learning difficulties, either an existing CAF is updated or, if no CAF has previously been completed, an assessment takes place to allow identification of the child's needs and services required. This would provide the initial momentum to develop, on an individual basis, the most appropriate support within school settings to allow the child's educational needs to be met while also meeting their diabetes needs.

A case study is presented in *Box 1* to illustrate the difficulties faced by a child with diabetes and autism.

### Page points

1. At the point of diagnosis of diabetes in a child with a learning disability, there will be a need for enhanced inter-agency communication and cooperation.
2. The *Every Child Matters* programme aims to ensure that all children meet five key outcomes:
  - Be healthy
  - Stay safe
  - Enjoy and achieve
  - Make a positive contribution
  - Achieve economic wellbeing.
3. An essential step within *Every Child Matters* is that the child's needs become central to any decision making.
4. The Common Assessment Framework is an important tool for supporting children in meeting the outcomes, and allows an assessment to take place in a standardised, universal manner, across all children's services.

**Box 1. Case study.**

J was diagnosed with autism at 4 years of age. For him, the condition resulted in an inability to communicate effectively with those around him. Educationally, he was able to attend a mainstream primary school, and with an educational statement in place he received support from a learning assistant on a one-to-one basis. He was supported initially during Key Stage 1 by speech therapy services and an educational psychologist within the school, but continued to make progress so that by the time he had progressed to Key Stage 2 (KS2) his ongoing support was provided via the school.

Soon after progressing to KS2, J was diagnosed with diabetes, after a short history of symptoms. He was well at the time of diagnosis, and after discussion with J's parents and demonstration of various devices to J, he commenced subcutaneous insulin.

At this point, J was unable to perform his own blood glucose testing. As part of the planning for his return to school a meeting was convened between family, healthcare staff and school senior management to establish a suitable course of action to ensure that school staff would be able to support J with this task. A skills-based training package was developed using the blood glucose monitor manufacturer's guidelines for use. Along with appropriate health and safety precautions (the use of gloves when testing, availability of sharps bin, clinical waste bags) and support from the local school health advisor, training was provided to J's learning assistant, as her role was specifically to support J, the diagnosis of diabetes being another area of support that required new skills.

Educationally, J progressed well, and transition planning for his move to secondary school education obviously included a great deal of discussion about his diabetes needs. He had progressed from twice-daily premixed insulin to three injections a day, but his glycaemic control was variable, with HbA<sub>1c</sub> up to 9.5%. Hypoglycaemia was a complicating matter, and J's behaviour towards food and drink resulted in difficulty in using the common forms of glucose drink, requiring suitable alternatives to be identified.

In line with guidance from NICE (2004), discussion occurred around the use of multiple injection therapy. The decision for this to progress was made in the months before the move to secondary school.

Because of J's autism, and solely on the basis of his learning needs, J's secondary school education was to take place at a school providing special educational needs support for children and young people up to 18 years of age. School staff involved in this transition discussed the support that would be required for multiple injection therapy to be implemented, and a core of staff, including on-site registered nurses and learning support staff, were trained in the preparation and administration of injections. The registered nurses would provide support to the learning assistants, as the majority of the nurses' workload comprised the provision of support to those youngsters with very complex health needs.

This transition in J's life has taken place within the last year, and it appears to have been successful. His parents report that he enjoys the greater flexibility of multiple injection therapy, and is appearing to thrive within his new school.

**Conclusion**

Although the case study described is an isolated example of multi-agency coordination to meet an individual child's needs, the legislation required to support such interventions is in place. This can be clearly identified through the *Medical Conditions at School Policy Pack* (Medical Conditions at School Partnership, 2007), which has been developed by the charitable sector to give school policy makers access to up-to-date, valid information on long-term medical conditions in childhood.

It is suggested that prompt and clear communication with the education providers is essential to ensure that the needs of a child with pre-existing special educational needs are identified, and the effects of the diagnosis of diabetes are fully supported by education professionals who will already have developed an understanding of the child's unique learning needs. ■

Department for Education and Skills (DfES) (2006) *Common Assessment Framework for Children and Young People: Supporting Tools*. Available at: [www.everychildmatters.gov.uk/delivering-services/caf/](http://www.everychildmatters.gov.uk/delivering-services/caf/) (accessed 09.01.09)

Department of Health (DH; 2001) *National Service Framework for Diabetes: Standards*. DH, London

DH (2003) *Every Child Matters: Change for Children*. DH, London

DH/DFES (2004) *National Service Framework for Children, Young People and Maternity Services*. DH, London

DH (2007) *Making Every Young Person with Diabetes Matter*. DH, London

Diabetes UK (2005) *Children with Diabetes at School: What All Staff Need to Know*. Diabetes UK, London

Disability Discrimination Act 1995 (c.50) (1995) Available at: [www.opsi.gov.uk/acts/acts1995/ukpga\\_19950050\\_en\\_1](http://www.opsi.gov.uk/acts/acts1995/ukpga_19950050_en_1) (accessed 09.01.09)

Disability Discrimination Act 2005 (c.13) (2005) Available at: [www.opsi.gov.uk/Acts/acts2005/ukpga\\_20050013\\_en\\_1](http://www.opsi.gov.uk/Acts/acts2005/ukpga_20050013_en_1) (accessed 09.01.09)

Kelnar CJH (1995) *Childhood and Adolescent Diabetes*. Chapman & Hall, London

Lord Laming, Chair (2003) *The Victoria Climbié Inquiry: report of an inquiry by Lord Laming*. Available at [www.victoria-climbié-inquiry.org.uk/finreport/finreport.htm](http://www.victoria-climbié-inquiry.org.uk/finreport/finreport.htm) (accessed 13/01/2009)

Medical Conditions at School Partnership (2007) *Medical Conditions at School Policy Pack*. Available at: [www.medicalconditionsatschool.org.uk/](http://www.medicalconditionsatschool.org.uk/) (accessed 09.01.09)

NICE (2004) *Type 1 Diabetes: Diagnosis and Management of Type 1 Diabetes in Children, Young People and Adults. Clinical Guideline 15*. NICE, London