

Accessing Support for Children with Diabetes in School

1. What are the possible causes of schools and Local Education Authorities (LEAs) not being willing or able to provide support/funding for children with diabetes in school?

Having heard many parent's experiences of trying to access support for their child, the most common problem arising is that of parents being told that type 1 diabetes is not a Special Educational Need (SEN) and therefore there is no funding in place for extra support, whether this be for children needing general supervision with snacks and blood tests or for help to administer injections or for an extra trained staff member to ensure safety on a school trip etc. Whilst most parents do not consider their child with diabetes to be disabled or to have "learning difficulties" as such, children with diabetes should be considered under the Code of Practice as having SENs due to medical needs.

Type 1 diabetes, and its treatment, has a substantial effect on a child's health and education because of the wide-ranging impact on the ability to learn and cognitive functions. It is vital for schools to fully understand diabetes and how best to support a child with this medical condition in order for the child to access the full curriculum.

*"The term 'special educational needs' (SEN) has **a legal definition**, referring to children who have learning difficulties or **disabilities** that make it harder for them to learn or access education than most children of the same age.*

If your child has special educational needs, they may need extra help in a range of areas, for example:

- *schoolwork*
- *reading, writing, number work or understanding information*
- *expressing themselves or understanding what others are saying*
- *making friends or relating to adults*
- *behaving properly in school*
- *organising themselves*
- ***some kind of sensory or physical needs which may affect them in school***

http://www.direct.gov.uk/en/Parents/Schoolslearninganddevelopment/SpecialEducationalNeeds/DG_4008600

Several parents, who have very young children, who require a substantial amount of support from school staff to enable them to remain safe, have been told flatly by their LEAs that their child does NOT have SENs therefore will not grant a statutory assessment OR any other support funded by the LEA. Many children with diabetes do not require a statement of special needs in order to be safe at school, but some do. Some children with diabetes children can be supported by invoking School Action or School Action Plus. For younger children these interventions are called Early Years Action and Early Years Action Plus. Some LEAs have to be threatened with legal action before they will help. Many schools are also unwilling to put children with diabetes on to School Action or School Action Plus.

I believe in some areas of the country that when a young child has type 1 diabetes that they are put on School Action or School Action Plus automatically. However this does not always guarantee that the children will get the support needed. Parents in the Lincolnshire area have reported that young children with diabetes are given extra support from teaching assistants which is funded either by the school's own budget or the LEA or jointly. This support can amount to 10 –15 hours a week of extra help which is particularly useful around lunchtime when blood tests, meals and insulin are needed and supervision in the playground. Some younger children will need more support than others. As skills develop, the need for additional support will be reduced for most children. However, the Code of Practice does not insist on schools following this particular pattern and a school can suggest a different type of provision is made which may or may not be adequate!!

Some reasons why diabetes, epilepsy and other medical conditions, may no longer be seen as coming under Special Educational Needs is described in an IPSEA report.

Document from IPSEA

Children with Medical Needs

S312 (2) (b) Education Act 1996, children with medical needs

Under the s312(2) (b) Education Act 1996 children with medical needs which do not in themselves give rise to learning difficulties, but which prevent or hinder them 'from making use of educational facilities of a kind generally provided...' are entitled to be considered for a statutory assessment (statement of special educational needs).

The Original (1994) Code provided clear guidance to LEAs on the duty to assess children for SEN when they have medical condition by:

- (A) giving examples of some of the commonest medical conditions which give rise to SEN "congenital heart disease, epilepsy, asthma, cystic fibrosis, haemophilia, sickle cell anaemia, **diabetes**, renal failure, eczema, rheumatoid conditions and childhood cancers"*
- (B) advising LEAs "where there is clear recorded evidence that a child's medical condition significantly impeded or disrupts his or her access to the curriculum, ability to take part in particular classroom activities or participation in aspects of school life..... the LEA should carefully consider the case for statutory assessment of the child's special educational needs" (15)*

The revised Code when laid before Parliament in 2001 omitted the examples, omitted the guidance on when a medical need might give rise to special educational need and omitted any reference to the LEAs legal duties with regards to assessing children with medical needs.

In IPSEA's view this posed a clear risk that LEAs would believe that the law with regards to children with medical needs had been changed (which it had not) and that this in turn would prejudice the educational right of these children. IPSEA wrote to all MPs in advance of the commons debate on the Code. IPSEA's Patron, Baroness Darcy de Knayth, wrote directly on IPSEA's behalf to the minister. As a result, the decision to reinstate clear guidance on children with medical needs in the Code was quickly, and quietly made. But why had it been removed in the first place? IPSEA believes it was done to reduce the number of Statements which an LEA would have to issue and maintain. No explanation was ever given.

<http://www.ipsea.org.uk/newcode.htm>

The Education Act

<http://www.opsi.gov.uk/acts/acts1996/96056-ba.htm#312>

Code of Practice

http://www.teachernet.gov.uk/_doc/3724/SENCodeOfPractice.pdf

It would appear from the first statement that children with medical conditions are excluded from being identified as having SENs. You have to read through three paragraphs, 7.64 to 7.67. Paragraph 7.64 states:

"A medical diagnosis or a disability does not necessarily imply SEN. It may not be necessary for a child or young person with any particular diagnosis or medical condition to have a statement, or to need any form of additional educational provision at any phase of education. It is the child's educational needs rather than a medical diagnosis that must be considered."

It would appear from this statement that SENs (learning difficulties) are highlighted, whilst medical conditions appear to recede into the background. This is partly because the code is mainly concerned with SENs rather than medical diagnoses, however it seems to imply that it is possible to identify children as having either medical needs or SENs. When in fact children with medical conditions, such as, diabetes, epilepsy or asthma etc, are more likely to experience learning difficulties as a direct, or even indirect, result of their condition or the unwanted effects of their medication. The best way to provide a child with the right support would be to recognise that the child's additional needs cannot be separated as such, they are intertwined both the health and educational needs.

The code then acknowledges a relationship between a child's medical status and educational needs at paragraph 7.65. It says that:

"Medical conditions may have a significant impact on a child's experiences and the way they function at school. The impact may be direct in that the condition may affect cognitive or physical abilities, behaviour or emotional state. The impact may also be indirect, perhaps disrupting access to education through unwanted effects of treatments or through the psychological effects that serious or chronic illness or disability can have on a child and their family."

This above is the most important paragraph to point out to the LEA's and schools who keep saying that medical conditions are not SENs and therefore cannot get extra support. Children who have medical conditions should receive the appropriate level of support so that they can function properly in schools and work to the level of their ability and take part in all educational experiences. If they do not have access to medication because adults will not help them and suffer from side effects of the medication because adults will not help monitor them, then obviously their education and health will suffer.

If you get past the Code of practice's opening statement, it becomes clear that you cannot make a distinction between children who have medical conditions and those who have SENs. Instead, a child with diabetes or another medical condition may have a complex interlinked framework of learning, behavioural, emotional and physical difficulties that have come about because of the underlying medical condition. Also the code highlights the fact that these difficulties may affect the child directly or indirectly, depending on the nature or severity of the condition. When there is an impact on education, it can often be complicated by the additional emotional difficulties of having a chronic or long- term condition.

Diabetes at school: a case study

Type 1 Diabetes (insulin-dependent) is a common condition affecting around 20,000 children in the UK under the age of 15. Type 1 diabetes is an autoimmune disease; it is not caused by overeating, poor lifestyle or self-induced, but by a combination of genetic and environmental triggers. The body destroys insulin producing beta cells in the pancreas. Insulin is required by the body to metabolise glucose. Without insulin the body literally starves to death. Before the discovery of insulin, people with diabetes died within a very short time, it was a distressing slow death. Type 1 diabetes is not preventable and there is nothing that a child, or their parents could have done to prevent type 1 diabetes from developing. 80 – 90% of children with diabetes have type 1 diabetes.

Although type 1 diabetes is a medical condition, it has a direct impact on cognitive functions when the blood sugar levels are out of range. This means that children at school need access to their medication, insulin, and blood glucose testing equipment in order to control this serious medical condition. Young children need help with injections, blood tests and interpretation of the results. All children will need help to monitor hypoglycaemia and moderate or severe episodes will be likely to need treating by a third party, especially if a child is young. High blood sugar effects the concentration levels significantly and is very harmful to the health of the child. In the short term high blood sugar causes frequent urination, blurred vision and difficulty concentrating and can make children feel very unwell. High blood sugar is extremely harmful to the cells in the body, particularly those of the eyes, kidneys, circulatory system and nerves. Not treating high blood glucose levels can eventually lead to a condition called ketoacidosis, which, if not treated can be fatal.

High OR low blood sugars can cause problems with concentration, and short- term memory. This impacts on reading and acquiring new skills. Experiencing untreated, undetected, hypoglycaemia, especially for prolonged periods, means that a child will have not have been able to concentrate and this will obviously have an impact on memory and learning. Prolonged levels of low blood sugar can also cause a child to lose hypo awareness which means they will be in danger of experiencing a severe hypoglycaemic episode with no warning, which will require glucagon and calling the emergency services.

If a child has a moderate to severe hypo they may feel extremely unwell and have a severe headache, their ability to take part in any lessons will obviously be effected. After a moderate or severe hypo event, it can take several hours for a child to be able to function normally again. After a hypo has been treated the blood glucose level needs to be checked again 15 minutes later to see if the blood sugar level has risen to safe levels. During this time a child's ability to function mentally and physically maybe be effected and may remain impaired for some hours. Sometimes a child experiencing a hypo will display disruptive behaviour. Low or high blood sugars can sometimes result in bad behaviour, or a refusal to do something may be mistaken for defiant behaviour. The brain's main fuel is glucose and if the blood sugar is low this affects the brain's function. If a moderate episode of hypoglycaemia is not treated in time this can progress to severe hypoglycaemia which can lead to seizures or unconsciousness. Because of the nature of type 1 diabetes, the condition needs coordinated support that goes beyond basic first-aid training.

Despite the introduction of the Disability Discrimination Act many children with diabetes are still prevented from taking part in educational school trips because of fears over administering medicines or treating hypoglycaemia and by administering glucagon and misunderstandings by staff about the basics of diabetes management.

Children with type 1 diabetes are still facing future medical and educational problems because many children experience a lack of support in school.

One parent said that they had tried to use the DDA to say that their son was being discriminated against because he was being sent home early every Friday afternoon as the school said that there was no one available to look after him. This parent was informed by the Disability Rights Commission that if the Head Teacher could prove that she had acted reasonably, then they wouldn't have a case! All she would have needed to do, was to have said that she had tried to get cover, but couldn't and that as this could be deemed reasonable, then they would have had no case and the parents could not pursue the matter further given that it was unlikely that anyone would have answered an advert for 1 hours cover once a week, to cover the needs of a child with diabetes.

Concentration and attention levels throughout the school day can be affected by the current blood sugar levels.

- **The effects of acute hypoglycaemia on memory acquisition and recall and prospective memory in type 1 diabetes.**
- **Memory Remains Intact in Type 1 Diabetics** Review of 33 studies find that those with type 1 diabetes had significantly lowered performance on the intelligence, speed of information processing, and psychomotor efficiency tests. Lowered performance was also observed on visual and sustained attention, cognitive flexibility, and visual perception.
- **Hyperglycemia Slows Mental Functions in People with Diabetes**
- Int J Clin Pract Suppl. 2002 Jul(129):20-6. Related Articles, Links. **The effects of glucose fluctuation on cognitive function and the functional costs of hypoglycaemia and hyperglycaemia among adults with type 1 or type 2 diabetes.** Cox D, Gonder-Frederick L, McCall A, Kovatchev B, Clarke W. University of Virginia, Charlottesville, USA. Publication Types: * Review * Review, Tutorial PMID: 12166601 [PubMed - indexed for MEDLINE] It is traditionally believed that while acute hypoglycaemia has detectable negative consequences, such as unpleasant symptoms and cognitive-motor disruptions, acute hyperglycaemia is not associated with such consequences. However, recent research with adults affected by either type 1 or 2 diabetes mellitus demonstrates that relatively mild hyperglycaemia is associated with unpleasant symptoms and cognitive disruptions. Both hyperglycaemia and hypoglycaemia can be associated with patient experiences of physical, affective, and cognitive symptoms, as well as cognitive-motor disruptions. These effects can lead to impaired functioning and quality of life. Because these effects are different across patients, their significance can be difficult to appreciate. There is ample evidence that acute hypoglycaemia is a problem for both adults with type 1 and those with type 2 diabetes, and that mild and moderate hypoglycaemia reduce one's mental efficiency relative to euglycaemic performance. There is growing evidence that transient hyperglycaemia has similar negative effects. At relatively mild levels of extreme blood glucose--either hypoglycaemia or hyperglycaemia--cognitive efficiency may decay by a third. The impact of this effect will depend on the task the patient is dealing with at the time. If the person is engaging in a relatively dangerous task, such as driving a vehicle, significant consequences could follow.

- Both hypoglycaemia and hyperglycaemia have been demonstrated to have not only acute, but also chronic effects in patients with type 1 as well as those with type 2 diabetes. Although hypoglycaemia occurs at a lower rate among patients with type 2 diabetes than among those with type 1, the number of patients with type 2 diabetes is so large that even this low rate results in many persons being affected.
- J Pediatr Endocrinol Metab. 1996 Jul-Aug;9(4):455-61. **Acute hyperglycaemia impairs cognitive function in children with IDDM.** Davis EA, Soong SA, Byrne GC, Jones TW. Department of Diabetes/Endocrinology, Princess Margaret Hospital for Children, Perth, Western Australia. Publication Types: * Clinical Trial * Randomized Controlled Trial PMID: 8910814 [PubMed - indexed for MEDLINE] OBJECTIVE: The effects of acute hyperglycaemia on cognitive function in children remain controversial. This study was designed to investigate the suggestion that acute hyperglycaemia impairs cognition in IDDM children. DESIGN: To examine this question we studied 12 randomly selected children with IDDM (6 boys, 6 girls, mean age 12.4 years). Cognitive performance was assessed on two occasions at least six months apart (7.4 +/- 1.4 mths, range: 6.3-11.1 mths) under randomized conditions of hyperglycaemia (20-30 mmol/l) on one occasion and euglycaemia (5-10 mmol/l) on the other. Target glucose levels were achieved using a modified clamp technique with subjects and psychologist blinded to the glycaemic level. Cognitive tests chosen to assess performance skills were subtests from the Wechsler Intelligence Scale for Children-3rd Edition (WISC-111). RESULTS: No significant learning effect was present. However, there was a reduction in performance IQ at hyperglycaemia compared with euglycaemia (106 +/- 4.3 vs 112 +/- 4.5 IQ points respectively, $p < 0.05$). Under hyperglycaemic conditions the mean decrease in percentile score for performance IQ was 9.5%. Of the 12 children tested, 8 had a decrease in IQ when hyperglycaemic, which was independent of duration of diabetes and long term metabolic control assessed by HbA1c. CONCLUSION: Acute hyperglycaemia results in impairment of complex cognitive function in children with IDDM. This may have important implications for school performance.
- Diabetes Care. 1999 Aug;22(8):1318-24. Comment in: * Diabetes Care. 1999 Aug;22(8):1239-41. **Conventional versus intensive diabetes therapy in children with type 1 diabetes: effects on memory and motor speed.** Hershey T, Bhargava N, Sadler M, White NH, Craft S. Department of Psychiatry, Washington University School of Medicine, Washington University, St. Louis, Missouri, USA. tammy@npg.wustl.edu Publication Types: * Clinical Trial * Randomized Controlled Trial PMID: 10480777 [PubMed - indexed for MEDLINE] OBJECTIVE: Severe hypoglycemia may impair medial temporal-mediated cognitive skills, such as the ability to recall past events explicitly (delayed declarative memory). The objective of this study was to determine whether delayed declarative memory deficits are present in a group of diabetic children with an increased risk of severe hypoglycemia. RESEARCH DESIGN AND METHODS: Nondiabetic children ($n = 16$) and children with type 1 diabetes who had been randomly assigned to either intensive (IT) ($n = 13$) or conventional (CT) ($n = 12$) diabetes therapy at the time of diagnosis participated in the study. All episodes of severe hypoglycemia were prospectively ascertained. All children were tested on memory tasks that have been closely linked to medial temporal functioning and on reaction time measures. RESULTS: Our results demonstrated that the IT group had a threefold higher rate of severe hypoglycemia, performed less accurately on a spatial declarative memory task, and performed more slowly, but not less accurately, on a pattern recognition task than did the CT group or

- control subjects. In addition, both groups of type 1 diabetic children were significantly impaired on a motor speed task compared with their nondiabetic peers. **CONCLUSIONS:** These results indicate a selective relative memory impairment associated with IT that is consistent with the effects of severe hypoglycemia and medial temporal damage or dysfunction. If larger prospective studies determine that severe hypoglycemia is the mediating factor for this memory impairment, extreme caution in imposing overly strict standards for glucose control in young patients with type 1 diabetes would be indicated because of the increased risk of hypoglycemia associated with IT regimens.
- **High Blood Sugar, As Well As Low, Slows the Mind** on Tuesday, December 28 @ 13:41:30 EST Virginia researchers say a temporary rise in blood sugar levels in people with diabetes can inhibit their ability to think quickly and solve problems. Dr. Daniel J. Cox stated that, "most people with diabetes are aware of problems when their blood sugar levels drop too far." However, patients also often report not feeling well when their blood glucose levels are high." But lacking "a clear theory as to why that happens, patient complaints were typically being ignored," he said. While laboratory studies have shown that mental performance declines when blood glucose is artificially raised, "this is not a realistic environment," the researcher added. Cox, at the University of Virginia Health System in Charlottesville, and his colleagues therefore conducted a field study with 196 subjects with type 1 diabetes and 34 with type 2 diabetes. The team instructed the participants to complete tests assessing verbal and mathematical skills using hand-held computers immediately before routine self-monitoring of blood glucose, three to four times daily. Approximately half the subjects made more errors and had slower responses when blood glucose exceeded a certain point, the researchers reported. Cox pointed out that to avoid a drop in performance associated with low blood glucose, people often load up on carbohydrates before "cognitively sensitive procedures," such as exams. "But they in fact could be doing themselves a significant disservice," he said, and would perform better by avoiding both high and low extremes of blood glucose levels. Roughly 55 percent of the people in the study showed signs of cognitive slowing or increased errors while hyperglycemic, suggesting that the consequences of hyperglycemia vary among individuals. However, among those whose cognitive performance deteriorated when blood sugar levels rose, the negative effects consistently appeared once levels reached or exceeded a certain threshold. Diabetes Care, January 2005

There are some examples of how the LEAs and school can work together to support a young child with diabetes.

Including Me Council for Disabled Children

http://www.standards.dfes.gov.uk/eyfs/resources/downloads/including_me.pdf

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Jackie Jacombs Sept 2007