



Safety and inclusion of children with medical conditions at school



ALL PARTY PARLIAMENTARY GROUP FOR DIABETES

Officers of the APPG for Diabetes:

Chair – Rt Hon Keith Vaz MP
Vice Chair – Victoria Atkins MP
Vice Chair – Jim Shannon MP
Co-Secretary – Liz McInnes MP
Co-Secretary – John McNally MP
Treasurer – Baroness Ludford

Special Advisors:

Anna Taylor
Dr Gerry Rayman
Jimmy Desai
Luvjit Kandula
Professor Heather Daly
Dr David Unwin
Vera Labelle
Ben Moody

Contact Us:

Email: diabetes-appg@outlook.com
Website: <https://diabetes-appg.co.uk/>
Twitter: @APPG_Diabetes

The All-Party Parliamentary Group for Diabetes (APPG Diabetes) is a nonpartisan cross-party interest group of UK parliamentarians who have a shared interest in raising the profile of diabetes, its prevention and improving the quality of treatment and care for people living with diabetes.

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the Group. This report was researched and funded by Diabetes UK who provide the secretariat for the APPG.

The secretariat to the All-Party Parliamentary Group for Diabetes is provided by:

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.



Chair's Introduction

There are over 1 million children with long term medical conditions in the UK, ranging from Type 1 diabetes, epilepsy, coeliac disease, chronic migraine, sickle cell disorder, asthma, and many others. All of these children deserve the opportunity to thrive, but currently many do not receive the support they need.

The amendment to the Children and Families Act 2014¹ was an important step forward. It includes a statutory duty from the Department for Education making it law that all schools in England must make arrangements to support children with medical conditions.

This can make an extraordinary difference to the lives of children with medical conditions. If we want all children to learn, be safe and happy at school, we need to create the conditions for all of them to achieve it.

Since children spend a third of their lives at school, being able to manage their condition well whilst there will have a positive impact on their health, avoiding complications that will cost the NHS in the long-term.

Living with Type 2 diabetes myself, I know a medical condition is not something you can take a break from managing.

The APPG has heard from parents and healthcare professionals that far too many schools are not complying with the duty thus putting the safety and inclusion of children with medical conditions at risk.

A recent investigation by the Health Conditions in Schools Alliance showed that only **11.5 per cent**² of the schools asked could demonstrate that they have an adequate medical conditions policy.

It is clear schools need help. Three years after the change in the law, there are still too many schools that do not know about or understand their responsibilities. Children's lives are at risk and their needs and rights greatly override the challenge of change.

Based on the evidence collected, this report illustrates the state of support at schools and the measures that are urgently needed to tackle the widespread variation in support for children with medical conditions.

This is a problem beyond diabetes and demands a united front from all medical conditions to be confronted.

On behalf of the All Party Parliamentary Group for Diabetes and the more than 1 million children living with a medical condition, I urge the Government to take the lead in assuring all children with medical conditions are safe and included at school.

Rt Hon Keith Vaz MP

Chair of the APPG for Diabetes



Rt Hon Keith Vaz MP
Chair



Jim Shannon MP
Vice-Chair



Victoria Atkins MP
Vice-Chair



Liz McInnes MP
Co-Secretary



John McNally MP
Co-Secretary



Baroness Ludford
Treasurer

¹ Department for Education. (December, 2015). Supporting pupils at school with medical conditions. Retrieved from: <https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3>

² Health Conditions in Schools Alliance. (n.d.). Statistics from our 2017 investigation. Retrieved from <http://medicalconditionsatschool.org.uk/>



The problem

Samuel Linton had asthma. In 2007, he suffered a serious asthma attack at school. Despite alerting the teacher to the situation, he was told to wait in the hallway. He was not helped. When his mother arrived at the school, he was grey and his lips were blue. He died soon afterwards.³

Progress has been made in managing children with medical conditions in school with the implementation of the Children and Families Act 2014, but significant improvement is still required.

Julia's son Sam has Type 1 diabetes.

One day, Sam suffered from a hypoglycaemic attack in class⁴. The teacher mistook his changed behaviour for naughtiness and sent Sam out of the class alone to wait in the hallway. He was not helped. Sam became seriously ill and was found unconscious by the school secretary, who called Julia immediately. Julia managed to treat Sam, but eventually had to move him to another school for his safety.

Sue's son suffers from Postural Tachycardia Syndrome, which causes severe dizziness and can lead to loss of consciousness. One day when ill, the school sent him home by foot and did not inform Sue. He was not helped. Sue only discovered what happened later and fortunately was able to locate and help her son. Eventually she decided to remove him from school for his health.

These incidents occurred after the duty was introduced in 2015 and neither school had taken the necessary steps to comply with it at the time. These children's medical conditions were not taken seriously when they should have been.

How can we ensure children with medical conditions are safe and included at schools? If a duty exists to address this, why are schools not implementing it? What more can be done to ensure the duty reaches its potential?

These are the questions that the APPG has sought to answer.

The Evidence Session

The APPG for Diabetes and the APPG on Epilepsy held a joint evidence session at the House of Commons on Wednesday 1st of March 2017 into the safety and inclusion of children with medical conditions at school.

The meeting was chaired by the Rt Hon Keith Vaz MP and Caroline Ansell MP.

Evidence was heard from parents Louise Taylor, Sue James and Sara Milocco; Professor Helen Cross, from the Great Ormond Street Hospital; Professor Simon Dyson, from De Montfort University; and Thalie Martini, Chair of the Health Conditions in Schools Alliance.

Written evidence and comments were also submitted by over 300 parents, children, schools and healthcare professionals.

The meeting was attended by the APPG for Diabetes members the Rt Hon George Howarth MP, Liz McInnes MP and Victoria Atkins MP; as well as Andrew Selous MP, Andy Slaughter MP, Kevin Hollinrake MP and Baroness Bakewell of Hardington Mandeville.

³ Campbell, Denis (14 October 2013). Children with health conditions need new rules to protect them at school. The Guardian. Retrieved from: <https://www.theguardian.com/education/2013/oct/14/children-medical-conditions-guidance-needed>

⁴ A hypoglycemic attack is when blood glucose levels in the body reach dangerously low levels causing loss of concentration, confusion and can lead to loss of consciousness



Why the duty is important

Duty requirements

The duty is in place to ensure that schools provide appropriate support to children with medical conditions. It addresses the potential negative impact of children's conditions and places a statutory obligation on schools to minimise it.

To avoid unnecessary risks, the duty requires schools to have an individual healthcare plan (IHP) in place for every child with a long term medical condition. The IHP includes detailed information on specific symptoms to watch for and procedures to follow, including the appropriate training of staff.

The duty also requires schools to support children in the case of absences, allowing them to achieve their academic potential, participate in extracurricular activities, and consider the emotional implications of their condition. Non-statutory recommendations exemplify how procedures should be established.

Moreover, the duty is anticipatory. Since its introduction in 2015, all schools in England are now required to have a medical conditions policy, even if they do not currently have any pupils with medical conditions enrolled. This ensures schools are prepared should the situation change.

Thus with the proper support set out in the duty, children with medical conditions are far better supported to lead full and healthy school lives. Without this support, children's safety, academic achievement, social development and wellbeing can be negatively impacted.

The APPG has received significant evidence that illustrates the negative impact of not

having robust medical conditions policies in schools.

Safety

Parents and healthcare professionals that gave evidence to this inquiry expressed concern for children's safety at school. When in an emergency, they want to trust that schools will have the knowledge and right procedures in place to quickly help children and avoid dangerous complications.

Common safety risks mentioned were the unnecessary delay of treatment, leaving children unaccompanied and untreated during an emergency, and leaving unwell children to walk long distances alone, to the medical room.

"I have been called into school and found my child aged seven soaked in urine and no one noticed it, or changed him, until I arrived. His levels were so high that he had wet himself. Another time I found him at school laying under a tree at lunchtime, near two staff members who ignored him. He was having a hypo."

Pippa, mother of a child with Type 1 diabetes

Medical conditions can be life-threatening, yet manageable. In order to reduce how often emergencies take place, daily management of conditions is required. For example, if a child with Type 1 diabetes is supported to monitor their blood glucose and eat when necessary, it is less likely they will suffer a hypoglycaemic attack at school.

This preventive management also safeguards children's health in the long-term. Parents have told us that their biggest concern is their child's safety at school. Because they know that without the proper support, their child's health will deteriorate. We have sadly heard of some cases where poor management in school has led to complications.



“I started raising concerns with the school in March 2016 that Imogen was being given jacket potatoes most days. This is important because poor nutrition can have an impact on children’s growth, well-being and concentration at school. In June 2016 I withdrew Imogen from school meals as advised by St George’s Hospital as she had not grown in height or weight for 6 months.”

Sara, mother of a daughter with coeliac disease

Academic achievement

Medical conditions have been shown to impact children’s attention, concentration and learning. For example, when a child with migraine is having a crisis, their ability to perform to the best of their ability is significantly reduced. This makes children with medical conditions vulnerable to underachievement.

This impact is often overlooked by schools when children with medical conditions stay within a school’s academic targets. This is not fair. Children are much more likely to fulfil their potential if their individual needs are identified and met, and they should be supported to do so.

For example, introducing measures such as allowing for missed work to be caught up on, deadline extensions and special exam conditions are good practice approaches to minimise the negative impact on academic achievement.

“Despite classroom staff regularly reporting that my son’s blood glucose levels significantly impact his ability to perform, the school continue to state that my son has no educational needs. My son has always been ahead of age related targets; he should be supported to achieve what he, as an individual, is

capable of achieving. He is not able to perform to the best of his ability without support.”

Emma, parent of a child with Type 1 diabetes and coeliac disease

Moreover, children with medical conditions often have more frequent absences due to hospital appointments or illness related to their condition. These absences can increase exponentially if children are also sent home unnecessarily due to recurring emergency incidents the school could neither prevent nor treat.

If not given support, children’s potential can be unfulfilled. Many parents explained how the attendance targets are ‘unfair’ and penalise children because of their condition. Some parents have even told us they have been fined for their child’s missed school days.

“I feel teachers become frustrated when I repeatedly have to ask to leave their lessons. I feel I am seen as a ‘problem’ by the school.”

Leah, child with chronic migraines

Social development

One recurring complaint from parents was that their child has been excluded from participating in extra-curricular activities, such as P.E. or residential trips.

These activities play an important role in social development by taking children outside of their environment and the presence of their carer. To exclude children from these activities is to deny them equal opportunities to grow and develop.

Children with sickle cell disorder, for example, have reported feeling socially



isolated when they are prevented from attending school trips or sport days⁵:

negatively singled out at school because of their condition⁶.

“Anything outside I was not allowed to take part in. I just have to stay back behind in the class. It makes me feel sad you know, everybody is doing something and you are just looking out of the window seeing them enjoying themselves, laughing and running around. And then I am there, pretending to read a book. And I think to myself, why I can’t be like them.”

Child with sickle cell disorder

Wellbeing

The stress of managing a medical condition can impact children’s emotional and psychological wellbeing. Children often develop anxiety, depression, low self-esteem and lack of confidence as consequences of their conditions. Inadequate support in school can make these feelings even more acute.

“I had no help or understanding at school. I have always felt like a failure. I am intelligent but the struggle to keep up at school was too much. I felt doomed to fail from an early age and have never felt adequate. I am still an observer of others achieving their dreams.”

Nicola, person with chronic migraine

Moreover, without proper awareness raising and education about conditions with peers, children with medical conditions can often be the target of teasing and bullying. In a recent Diabetes UK survey of 227 parents, 41 per cent said their child felt bullied or

⁵ Dyson, S.E., Atkin, K., Lorraine, C., Demaine, J. and Dyson, S.M. (2012). School ethos and variation in health experience of young people with sickle cell disorder at school. *Diversity and Equality in Health and Care*, 9, 33-44.

⁶ Diabetes UK. (2017). Annual parent satisfaction survey with schools.



Poor implementation of the duty

From the evidence collected, it appears the duty is being treated by some schools as optional 'best practice' guidance that they can decide whether or not to adhere to. Only **11.5 per cent**⁷ of schools asked could demonstrate that they have an adequate medical conditions policy in place.

Despite the clear mandate, parents and healthcare professionals said often the required policy and plans are either not in place at all, or, when they are, schools refuse to follow them.

It is clear children with medical conditions need support at school in order to be safe, included and to thrive. So why is the duty not being followed?

The APPG identified the following causes for the poor implementation of the duty:

1. Poor awareness and understanding of the duty;
2. Lack of monitoring;
3. Lack of collaboration with parents;
4. Limited support and training for schools.

Poor awareness and understanding of the duty

Parents and healthcare professionals have said schools are generally not aware of the existence of the duty and what they are required to put in place. This is reflected in how often the needs of children with

medical conditions are ignored or misunderstood.

Even when schools are aware of the duty, it appears that they often do not understand what implementing the duty involves and what arrangements are needed to keep children with medical conditions safe and healthy.

This invariably leads to poor implementation of the duty, which prevents schools from adequately supporting children with medical conditions.

Lack of awareness of the need

The signs and symptoms of medical conditions are not always evident or taken seriously. A key role of the duty is to enable school leads to make better judgements and accurate assessments of the medical needs at their school. When schools are not aware of their duty, the needs and struggles of children with medical conditions, and their families, can be easily overlooked or misunderstood.

Parents expressed how some schools adopt an 'out of sight, out of mind' attitude when they are not aware of the impact of a child's medical condition and their obligation to minimise it.

"When Akeem has attacks in school, he is given medication but sent back to class in pain. I asked his teacher for a quiet place for him to rest in school before returning to class but this was not provided. The Head Teacher responded that these provisions were only applicable to children with 'serious' health conditions."

Parent of a child with chronic migraines

Moreover, some parents feel their children are judged or are made to justify the

⁷ Health Conditions in Schools Alliance. (n.d.). Statistics from our 2017 investigation. Retrieved from <http://medicalconditionsatschool.org.uk/>



arrangements in place to assist them with their condition. Misunderstandings about children's needs can often lead to further disadvantage.

For example, children with sickle cell disorder can suffer from anaemia with typical symptoms of lethargy and lack of concentration⁸. These children are often labelled as 'lazy' by school staff, who then set unfairly low academic expectations. Without the proper support from school, this low expectation can become a self-fulfilling prophecy.

“One of her teachers is convinced Jade stays away from her morning class on purpose. I believe there is ignorance within the management of schools and colleagues about migraine and how it affects individuals.”

Joy, parent of a child with migraine

Lack of reasonable adjustment

The statutory guidance provides clear expectations of what arrangements schools must put in place to accommodate the needs of children with medical conditions. When schools fail to implement their responsibilities correctly, they can often enforce rigid rules that create further safety risks.

“As my children got older I was more afraid when they were in school than out with friends as teachers were in a position to refuse them glucose.”

Mother of two children with Type 1 diabetes

Parents said schools often don't agree with the reasonableness of adjustments required to minimise the impact of a child's medical condition. For example, allowing a child

with Type 1 diabetes to snack during class or a child with a bowel or bladder condition to take a toilet break.

In some cases, schools appear reluctant to exempt children with medical conditions from school rules for fear of being seen to be giving them 'special treatment'. However, the requirement for 'reasonable adjustments' mean that schools need to be more adaptable for children with medical conditions where the rules may impact on their safety, learning and inclusion.

Lack of monitoring

Despite schools' responsibilities being statutory, there are currently no mechanisms to check a school's compliance with the duty. Consequently, responsible authorities are often not aware of how children with medical conditions are being supported in schools.

As schools are not monitored and medical policies are not scrutinised, adequate implementation of the duty becomes discretionary and is often done incorrectly.

Limited Monitoring

There is no official data on schools' compliance with the duty as no authority routinely monitors the implementation of the duty in schools. Thus the struggles of children with medical conditions remain largely invisible to those with the power to act.

Local authorities are the institution responsible for intervening if a maintained school is not ensuring equal opportunity and achievement for children⁹. However, according to an investigation conducted by the Health Conditions in Schools Alliance¹⁰, less than 1 per cent of local authorities

⁸ Dyson, S.E., Atkin, K., Lorraine, C., Demaine, J. and Dyson, S.M. (2012). School ethos and variation in health experience of young people with sickle cell disorder at school. *Diversity and Equality in Health and Care*, 9, 33-44.

⁹ Education Committee, *The role of School Governing Bodies*, 25 June 2013, HC 365-II

¹⁰ Health Conditions in Schools Alliance. (n.d.). Statistics from our 2017 investigation. Retrieved from <http://medicalconditionsatschool.org.uk>



know how many schools in their area comply with the duty. Without monitoring, there can be no intervention in schools.

Priority during inspections

Ofsted is the school standards and regulatory body. Its inspection statutory guidance states that inspectors must consider how well the school meets the need of pupils with medical conditions, yet the Ofsted handbook, which guides inspectors on what to look for, does not reference the duty.

If supporting children with medical conditions is not something schools can be held accountable for, it is hard for parents to demonstrate the importance of complying with the duty.

“I would urge Ofsted to review, as standard practice, whether or not schools not only have a good and comprehensive medical conditions policy which is known about and is put into practice but also that schools have a member of staff who ‘champions’ the needs of students with long term medical conditions such as diabetes. Ofsted is the one body with the authority to make this happen.”

School Head Teacher

A number of schools that received either a ‘good’ or ‘outstanding’ rating on their last Ofsted inspection were identified by Diabetes UK to having potentially put children’s safety or inclusion at risk.

One example of this is related to a mother of a child with Type 1 diabetes. When her son was excluded from a school trip because of the school’s unwillingness to support his condition, she took her son’s school to tribunal and won. While this was happening, the school received an ‘Outstanding’ grade at an Ofsted inspection, with a special mention that ‘all

statutory requirements and arrangements for safeguarding were met’.

While simply checking for the existence of a medical conditions policy would be a positive start, it will ultimately not be enough. Evidence shows that often the duty is not adequately followed or implemented even if a policy is in place.

It is vital that Ofsted inspectors also have the tools to understand the needs of children with medical conditions and to assess whether they are being met at school.

Complex complaints pathways

Concerns have been raised by parents about the complaints procedures when faced with a lack of support for their children. Many parents have shared the issues that they have faced when finding where to ask for help.

Emma’s story is representative of this. Since 2015, Emma has attempted to contact all authorities to hold her son’s school to account and failed.

“His school did not have a medical conditions policy in place when he was diagnosed in 2015. The school was not even aware of the duty. I had to fight to get a healthcare plan in place. However, even after a number of life threatening incidents, the school still refused to follow the plan. Oliver has been excluded from extracurricular activities and the school has indicated this will continue.”

Emma, mother of a child with Type 1 diabetes and coeliac disease

Emma’s complaint to the school resulted in them stating she should move her son to another school. After complaining to the local authority, they visited her son’s school, but she was not allowed to contribute to their investigation and subsequently the report. Emma then



contacted the Department for Education, but she was told that they were unable to intervene. When she contacted Ofsted, they advised her that they do not deal with issues for an individual child.

Ofsted's complaints system only responds promptly to individual cases where safeguarding is the concern, which does not include complaints relating to academic achievement, social development or wellbeing. Non-safeguarding concerns require a larger amount of complaints and are typically investigated at the school's next inspection. As it is unlikely that any one school has a large amount of children with medical conditions, their complaints might take years to be investigated, if at all.

Lack of collaboration with parents

Despite the statutory guidance stating that schools must listen to parents' views and consult them on their child's needs, many parents have said that schools are reluctant to accept their input.

Communication with parents is key to achieving good care for children with medical conditions. Every child with a medical condition is different and parents are best placed to know what their individual needs are.

When communication fails, so does support in school. Often the needs of children with medical conditions are not taken seriously and parents are not able to request an appropriate adjustment from the school without appearing overly demanding. This prevents the school from adequately implementing the duty and properly supporting the child.

“The partnership working between the family, the education and healthcare professionals has proved to provide the best possible outcomes for this child. Education

has to be age and maturity specific and individualised to this child and family throughout her journey.”

Margot Carson, Healthcare Professional

When any attempt at collaboration fails, and without mechanisms to hold a school to account, parents are often required to make personal sacrifices to keep their children safe and included. This allows the school to continue to not comply with their responsibilities and prevents the school from adequately implementing the duty.

Several parents have shared stories of how they have had to resort to taking part-time work at their child's school or giving up work altogether. Some situations, such as schools expecting parents to go into school to treat their child when ill, are not only impractical but also unsafe.

“For almost eight years, I attended to my son's school every lunch time to check his blood glucose levels and monitor him administering his insulin injection. I have had to go on school trips with him. I have had to go into school to treat him during hypos. I have worked night shifts to accommodate being able to ensure he is supported.”

Julie, parent of a child with Type 1 diabetes

Limited support and training for schools

There are concerns about how to implement the statutory guidelines and how schools can cope with the pressure of adapting to this change on top of other pressures that they are currently facing.

“The duty came in on the same date as a new national curriculum; the abolition of NC levels; universal free infant school meals; performance related pay for teachers; and the



reconstitution of governing bodies. The volume of change at the same time was unprecedented and led through necessity to some aspects being paid lip-service rather than given the full attention they needed.”

Stephanie, Head Teacher

While local authorities have a legal responsibility to ensure that schools can meet the duty, evidence from the Health Conditions in Schools Alliance¹¹ shows the support offered is limited. Only 4 per cent of local authorities who responded offer training specific to the statutory requirements and less than 11 per cent have shared a sample medical conditions policy or the statutory guidance with the schools they are responsible for.

Another issue highlighted was the possibility of no staff volunteering for the extra medical responsibilities. Teachers' contracts do not include a requirement or expectation to administer medical procedures¹². According to the duty itself, no teacher can be forced to support children. The teacher must be willing.

The final barrier raised during this APPG evidence session was the variability in access to school nursing services. The School and Public Health Nurses Association has stated there is only about one school nurse for five schools¹³, and this number is at risk of declining further.

However, while nurses can help in emergency situations and managing a child's condition, they cannot influence their inclusion, peers' acceptance or teachers' understanding. A school-wide change is required.

“Schools are under severe pressure with limited funding and staffing, but their first obligation is to ensure the safety of children, so this policy should form an essential part of all inspections. Not all schools appreciate this or prioritise it.”

David, parent of a child with Type 1 diabetes

¹¹ Health Conditions in Schools Alliance. (n.d.). Statistics from our 2017 investigation. Retrieved from <http://medicalconditionsatschool.org.uk>

¹² Campbell, Denis (14 October 2013). Children with health conditions need new rules to protect them at school. The Guardian.

¹³ Roxby, Philippa. (13 April 2013). Why are school nurses important? BBC News. Retrieved from: <http://www.bbc.co.uk/news/health-22106939>



The way forward

It is clear from the evidence submitted to the APPG that a change in the law has helped some, but not the majority of children with medical conditions. There are a number of steps that, if taken, could ensure that far more children receive the support they need to be happy, healthy, safe and achieve their potential whilst at school.

Evidence shows that when schools have adequate information and support, the barriers to preventing good care are removed, schools recognise the duty's potential, becoming examples of good care.

The strength of the duty

It is clear schools are constantly under a lot of pressure and any type of change can appear daunting. It is also unrealistic to expect school staff to become specialists in every medical condition and its wide ranging needs. Fortunately, the duty does not expect them to.

The duty is designed to give schools the correct processes to guide school staff through all situations, mitigating risk and enabling good care. It takes away the paralysing fear of the unknown. When collaborating with parents and writing healthcare plans, schools can have the appropriate information and be reassured that they are doing what is necessary to keep the child safe and included.

“I know that my child is safe in school because he has a care plan put in place. This enables staff to be aware that my child has a medical condition that requires medical

treatment daily and the potential of having to act in an emergency.”

Samantha, parent of a child with Type 1 diabetes

The support of willing teachers or school nurses alone is not enough to make a difference to the experiences of children with medical conditions at school.

Policies are designed to create a better place of learning for all children instead of focusing on individual adjustments¹⁴. A medical conditions policy helps to embed the principles of inclusion in a school's culture. It also builds stronger relationships with parents and healthcare professionals, which will benefit any child who is newly diagnosed or joins the school.

Research into the experiences of children with sickle cell disorder at school has shown that a policy that operates in the background has a more transformative effect in improving school support than simply teacher awareness¹⁵.

The policy legitimises the needs of children with medical conditions and creates a commitment from schools to support it. Without it, these children's needs will remain invisible and misunderstood, putting their health, development and wellbeing at risk.

“Having a policy gives ‘authority and status’ to diabetes and individualises care which ensures each child is treated appropriately. It gives each child a safe pathway so teachers know how to treat and act. It gives the family and child ownership and empowerment of their own care.”

Sophie, Healthcare professional and parent of a child with Type 1 diabetes

¹⁴ Kirsten Stalker (2015) Understanding and responding to the experience of disability, *European Journal of Special Needs Education*, 30:3, 422-424.

¹⁵ Dyson, S.M., Atkin, K., Culley, L.A., Dyson, S.E. and Evans, H. (2011) Sickle cell, habitual dys-postions and fragile dispositions: young people with sickle cell at school. *Sociology of Health & Illness*, 33, 465-483.



Examples of good practice

When schools comply with and implement the duty adequately, good support for children with medical conditions is achieved.

The APPG heard of many good examples from schools that have complied with the duty and were able to support children with medical conditions.

One of these examples came from Head Teacher Stephanie. She shared how her school has been proactive in both meeting the needs of children already at her school as well as planning for others who might join. The school has taken a number of actions since 2014 including: writing a new policy in line with statutory requirements; listening to parents and pupils about their experience of care and acting on the responses; raising awareness among pupils; intensive staff and governors training on the new responsibilities and key information about the main conditions, which now forms part of annual September induction day.

“There is an ethos of shared responsibility in the school, which means that all adults and peers are aware of children’s specific needs and risks. Our approach is always ‘How we can’ rather than ‘why we can’t’”.

Stephanie, Head Teacher

The policy and healthcare plan gives schools confidence and gives parents peace-of-mind. It is not a daunting ask. With the right support, a child’s likelihood of success is dramatically increased. It is worth the investment.

“It is vital that schools have a procedure in place so that they know exactly what to do in case of emergency. My son unfortunately suffers frequent hypos and once after he accidentally took too much

insulin his primary teacher managed to prevent him going into coma. Thankfully we had spent a lot of time explaining what to do if he suffered a severe hypo. Sadly many schools do not have this knowledge.”

Debbie, parent of a child with Type 1 diabetes



Recommendations

The duty to support children with medical conditions is clearly not yet known, understood or implemented by enough schools.

It is not acceptable to expect individual parents to have to advocate and argue for their child's rights. There is a greater role for the government and education bodies to play to ensure the law is adequately implemented and enforced and that children receive the necessary support.

Schools need to be better informed about what is expected of them, what adjustments are required, and then reassured that the procedures they have put in place are correct.

From the evidence submitted to this inquiry, the APPG makes the following recommendations:

Department for Education

- 1) The Department needs to take leadership on raising awareness of the duty with all schools in England in the coming autumn school term, ensuring they understand what arrangements must be in place.
- 2) The Department needs to circulate awareness information through its website, social media platforms and quarterly digital bulletin, making sure it reaches all schools in England.
- 3) The Department should amend the duty to include a requirement for all schools to publish their medical conditions policies on their website, ensuring they are readily accessible to parents and school staff as required in the statutory guidance.

Ofsted

- 1) Ofsted should update the inspectors' handbook to reference the statutory

guidance, in order to better guide inspectors to check that schools are complying with their statutory obligation.

- 2) Ofsted should update inspectors' training to ensure that they understand the impact medical conditions can have on a child's safety, development and wellbeing.
- 3) Ofsted must include the monitoring of medical conditions policies and their effective implementation as part of all routine inspections.

Local Authorities

- 1) Local authorities should promote the statutory duty on their websites.
- 2) Local authorities need to monitor the schools in their area that are complying with the duty and support schools that fail to comply.
- 3) Local authorities need to commission specific training on medical conditions and the requirements of the statutory duty.

Past publications:

Industry Action on Obesity and Type 2 Diabetes (2017)

Levelling up: Tackling Variation in Diabetes Care (2016)

Taking Control: Supporting People to Self-Manage their Diabetes (2015)



ALL PARTY PARLIAMENTARY GROUP FOR DIABETES