

# Type 1 diabetes in schools in Wales - “An Excellent Chance”

March 2016

**DiABETES UK**  
CARE. CONNECT. CAMPAIGN.  
GOFALU. CYSYLLTU. YMGYRCHU.  
CYMRU



**CLINICAL  
CHAMPION**  
**DiABETES UK**  
CARE. CONNECT. CAMPAIGN.

Sara Moran – Diabetes UK Cymru

Dr Justin Warner – Lead Consultant in Paediatric Diabetes (Cardiff & Vale University Health Board), Clinical Lead for the National Paediatric Diabetes Audit for England & Wales, Diabetes UK Clinical Champion for Paediatric Diabetes

Jon Matthias – National Co-ordinator, Children & Young People's Wales Diabetes Network

## Executive Summary

Providing support to children with Type 1 diabetes to enable them to participate in all aspects of school life requires a co-ordinated effort. This report provides evidence that there is an unmet need for an enhanced diabetes educational requirement to support children and young people with diabetes in schools.

Type 1 diabetes is the most common metabolic disorder in childhood, affecting around 1,500 children and young people in Wales. Although Type 1 diabetes occurs at random, there are inequalities in outcomes that are significantly affected by socio-economic status.

Treatment regimens for Type 1 diabetes have become increasingly intensified over the last decade with proven health benefits. To maintain such benefits and reduce the risk of costly long term complications and premature death, frequent monitoring is required.

Schools, local authorities, health services and parents should work together to ensure that the needs of the child are met. The current guidance frameworks for the management of Type 1 diabetes in a school setting differ in Wales and England. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must make additional arrangements for supporting pupils at schools with medical conditions. The legislation does not apply to schools in Wales.

There is a concern that the rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

Evidence gathered from two surveys (one for families and one for healthcare professionals caring for children with diabetes), the experiences of nearly 200 families who have contacted Diabetes UK's bespoke Care in Schools helpline across the UK and a number of physical meetings with family groups across Wales has provided an overwhelming picture of unmet need for children with diabetes during the school day that requires urgent attention.

When families in Wales were asked how often their child's diabetes disrupts their school day:

- 39% stated more than once a day.
- 51% advised that they have had an issue with the care provided by their child's school.
- 36% reported that their child had been sent home early or withdrawn from school because of their diabetes and
- 4% had been forced to move their child to a different school.

Many families report experiencing exclusionary measures that prevent a child with Type 1 diabetes from participating in after school clubs, sports and school trips, which could contravene disability discrimination legislation.

Many schools in Wales appear to rely on high levels of parental involvement:

- 62% of parents have stayed at home from their own work because of issues relating to their child's diabetes and
- 53% have had to leave their own work place during working hours to attend their child's school.

There are issues relating to low awareness, understanding and confidence of school staff in managing Type 1 diabetes:

- 33% of parents have been told by their child's school that they experience a lack of support and information on providing care to a child with the condition.

From the survey of healthcare professionals in Wales:

- 88% of professionals have experienced school staff being reluctant to inject insulin;
- 75% have experienced school staff being reluctant to calculate insulin dosage levels on insulin pumps;
- 63% have experienced school staff being reluctant to perform essential blood tests; and
- 75% reported that school staff have concerns about a child with diabetes participating in activities, school trips and Physical Education (PE) lessons.

Healthcare professionals report that many schools have applied restrictions to crucial elements of insulin treatment, with 83% reporting children with diabetes being prevented from performing diabetes related tasks unless in a designated area.

Variability in provision of care provided in schools is a profound issue. All issues raised by parents and professionals acknowledge different levels of understanding and practice in schools across Wales.

Schools regularly articulate their concerns regarding their legal position in caring for children with diabetes and view the lines of responsibility as unclear.

The Welsh Government's diabetes strategy, 'Together for Health: A Diabetes Delivery Plan (2013)', commits to providing the people of Wales with the following: "Where diabetes does occur, an excellent chance of living a long and healthy life, wherever they live in Wales." In particular, it states a commitment to "ensure children and young people with diabetes have the best possible start in life and are given the opportunity to fulfil their potential."

Following the introduction of 'Together for Health: A Diabetes Delivery Plan (2013)', the Welsh Government committed to the initiation of a consultation process to update 'Access to Education and Support for Children and Young People with Medical Needs (2010)'. This report has been produced to inform this consultation.

## **Recommendations**

- There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. Greater clarity and direction for schools would reduce variability and avoid confusion as to the roles and responsibilities of all involved.
- There is a need for improved and updated guidance for managing chronic diseases in schools. New guidance would need to identify measures to reduce adverse variability in provision and to standardise policies and procedures for schools as much as possible.
- There is a clear need for enhanced support for children with diabetes to be delivered in conjunction with schools and parents. This will improve patient, family and schools'

experience and also allow currently recommended therapies which will impact on improved outcomes.

- Schools, local education authorities, health services and parents should work together to ensure that the needs of the child with diabetes are met and that they are not unduly stigmatised at school because of their condition.
- Paediatric Diabetes Educators for schools are required across Wales to reduce variability in care during the school day and to enhance the understanding and improve the confidence of school staff who are providing this support.

Further information:

- In Wales, Cardiff & Vale University Health Board have realised the need for further investment in a schools Diabetes Educator role and have funded a post until April 2017. Consideration will be given to a jointly funded post between health and education services.
- Diabetes UK Cymru is happy to make available it's Make the Grade bilingual information packs and resources to Welsh Government. Schools are also able to receive a 'Good Care in Schools Award' from Diabetes UK as an acknowledgement of good practice.
- The Children and Young People's Wales Diabetes Network represents all paediatric diabetes teams working in NHS Wales. It has recognised that care in schools is a serious concern throughout Wales. Improving care in schools is one of the Network's priorities. Training videos aimed at schools were launched in January 2016.

## Contents

Introduction .....	7
Understanding Type 1 Diabetes.....	7
Legislation & Guidance: Medical conditions in schools in England & Wales.....	8
Background .....	10
Methodology and Results .....	13
Key findings from surveys in Wales .....	13
Conclusion and Recommendations .....	23
Bibliography .....	25
Appendix A: Respondents to the Family Survey by Local Education Authority.....	26
Appendix B: Family Survey questions .....	27
Appendix C: Paediatric Diabetes Specialist Nurse (PDSN) Survey questions.....	28
Appendix D: Children & Families Act 2014 .....	29
Appendix E: Early evidence of the impact of the Children & Families Act 2014 .....	30

## Introduction

This report provides an overview of the current system of care for children with Type 1 diabetes in schools in Wales. Whilst initially this can be viewed as medical care provided in the day to day management of Type 1 diabetes, providing care for a complex medical condition in a school setting is far from simple and other factors should be noted. These include broader practical and logistical considerations, as well as significantly wider experiences relating to the child and their family's educational, social and economic life.

Providing children with the support they need to participate in all aspects of school life requires a co-ordinated effort. Schools, local education authorities, health services and parents should work together to ensure that they meet the needs of the child with Type 1 diabetes. It is in the interests of both the child and the school to manage diabetes and thus minimise its impact on the child.

This report provides background to the current support expected of schools in Wales and compares this with that expected in England, where recent legislative developments have placed a statutory duty on schools to provide support. It provides an overview of the methodology behind how the information presented was collected, analysed and presented.

It also explains the complexities of Type 1 diabetes, the treatment options, and how this fits into the daily life of a child whilst at school. Finally, it highlights several key needs, all relating to the management of children with diabetes at school, that research has found to be prevalent across Wales, regardless of geographical area, school type, school year or the age of the child.

## Understanding Type 1 Diabetes

There are around 1,500 children and young people in Wales with diabetes aged 0-17 years (All Wales Registry and National Paediatric Diabetes Audit 2013/14), 96% of these have Type 1 diabetes.

Type 1 diabetes is an auto-immune condition resulting from the destruction of insulin-producing cells of the pancreas. Insulin is a hormone which helps the body to use glucose contained in foods. Without insulin, glucose from food cannot be used, causing blood glucose levels to rise in the bloodstream. This causes tiredness, weight loss, excessive thirst and frequent passing of urine. Other symptoms include difficulty concentrating and negative moods that can lead to irritability and aggressive behaviour.

Although Type 1 diabetes cannot be cured, it can be treated effectively. The aim of treatment is to keep blood glucose levels close to the normal range. This involves:

- Delivering insulin either by at least 4 injections a day or the use of a continuous insulin pump.
- Eating regular meals containing carbohydrate and snacks throughout the day.
- Finger prick blood tests as a minimum before each meal to ascertain current blood glucose levels and thereafter to carry out appropriate treatment (insulin injection or a snack/meal).

- Failure to comply with these requirements puts a child with diabetes at risk of acute life-threatening complications such as Diabetic Ketoacidosis and/or hypoglycaemic coma. Furthermore, long term poor diabetes control increases the lifetime risk of chronic complications such as kidney failure and blindness and a reduced longevity of life. There is also good evidence that getting good diabetes control in childhood will continue to adulthood and reduce the burden placed on the patient, family and health service.

When a child is treated and supported they should feel well, enabling them to concentrate and participate fully in all school activities.

Children with diabetes spend 22% of the waking day per annum in school (equating to 1,300 hours per year). The active management of their diabetes during this time is therefore of prime importance. If diabetes is not managed well, it will limit the ability of a child to learn and concentrate and can also lead to increased absence from school. When families were asked how often their child's diabetes disrupts their school day, 39% of respondents in Wales advised more than once a day, highlighting the need to regularly monitor the condition.

## Legislation & Guidance: Medical conditions in schools in England & Wales

The laws relating to looking after children with medical conditions in school in the UK vary by nation. The following is a summary of the relevant legislation and guidance in England and Wales.

### **Equality Act 2010**

The NHS, local education authorities and schools in England, Scotland and Wales have duties towards children with medical conditions, many of whom are legally defined as being disabled. Fee-paying independent schools are also legally obliged to meet the duties in the Equality Act 2010. The relevant aspect of this act to schools is that governing bodies or proprietors must make reasonable adjustments to ensure that children and young people with a disability are not put at a substantial disadvantage compared with their peers.

Importantly, this duty is anticipatory, which means adjustments must be put in place in advance to prevent disadvantage from occurring. This is particularly relevant to schools in making sure they have enough staff trained so that a child with a medical condition can take part in all aspects of school life. If all the trained staff leave, contingency plans must be in place to train up replacements quickly. The Equality Act also states children with a disability must not be discriminated against, harassed or victimised.

### **England**

Following representations by the Health Conditions in Schools Alliance (a coalition of children and health organisations from the third sector), schools in England now have a legal duty to support and care for all children with medical conditions in schools (*section 100; Children & Families Act 2014*). This provides the legal basis for all children in England to be supported in schools, with accompanying guidance providing detailed, directive and clear instructions on the responsibilities of all parties involved. This is a legal duty in England and the legislation does not apply in Wales.

The Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a duty to support pupils with medical conditions, meaning that in practice schools must make arrangements for supporting pupils at schools with medical conditions (full text of the Act can be found in Appendix D). In meeting that duty, they must have regard to the statutory guidance issued by the Secretary of State. This is entitled 'Supporting pupils at school with medical conditions' and is intended to:

*"...help governing bodies meet their legal responsibilities and sets out the arrangements they will be expected to make, based on good practice. The aim is to ensure that all children with medical conditions, in terms of both physical and mental health, are properly supported in school so that they can play a full and active role in school life, remain healthy and achieve their academic potential."*

The document provides statutory guidance for the appropriate authorities and non-statutory advice for others who may have a role in helping to support pupils with medical conditions. It provides clear instruction on and directs schools to immediately carry out or put in place the following:

- The production, adherence and review of a school's key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.
- Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.
- Procedures for day trips, residential visits and sporting activities.
- Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.
- Staff training and support.
- Unacceptable practice, liability and indemnity issues and complaints.

Following the introduction of the statutory guidance framework, feedback from families indicate that those involved with the provision of care are better able to understand their role and responsibilities in supporting a child with medical needs.

Furthermore, with the statutory guidance now including more directive and clear language, calls to the Care in Schools Helpline appear to suggest that the nature and the complexities of the issues being raised have changed. There appears to be less of a requirement for complicated mediation because those involved are clearer on their roles.

## **Wales**

The current guidance document produced by the Welsh Government in 2010 is entitled 'Access to Education and Support for Children and Young People with Medical Needs'. It has been produced to provide advice to schools and local education authorities on meeting the needs of children and young people with medical conditions. The document provides information for all medical

conditions and includes more specific information on common conditions, such as epilepsy, anaphylaxis and diabetes (Type 1 and Type 2).

Throughout, it encourages schools to adopt good practice recommendations. The guidance references the previous strategic framework, the 'National Service Framework for Diabetes in Wales (2003)'. Key areas of the document are:

- Policies and Individual Healthcare Plans.
- Food and diabetes during the school day.
- Staff training.
- Emergency procedures.
- School trips

Feedback from the survey responses in this report relates to families' experiences of care delivered through this guidance framework.

The new diabetes strategy in Wales, 'Together for Health: A Diabetes Delivery Plan (2013)' replaced the 'National Service Framework for Diabetes in Wales (2003)'. 'Together for Health: A Diabetes Delivery Plan (2013) articulates a refreshed approach to diabetes care and contains specific instructions to support children and young people with diabetes at school. It identifies the need for structured support in the school environment:

*"To support the care for children with diabetes, healthcare staff, schools and family need to be educated to ensure that children have the best possible opportunity to fulfil their potential. Policies need to be put in place to support the management of diabetes in school."*

It also commits Local Health Boards to:

*"Working with education authorities to ensure policies are in place to manage diabetes in schools and to develop management systems to support individual pupils to play a full part at school."*

Following the introduction of 'Together for Health: A Diabetes Delivery Plan (2013)', the Welsh Government committed to the initiation of a consultation process to update 'Access to Education and Support for Children and Young People with Medical Needs (2010)'.

## Background

As a UK-wide third sector organisation, Diabetes UK hosts a range of services for people living with diabetes. Through regular contact with families, children and young people with Type 1 diabetes, Diabetes UK is able to gain an understanding of the issues they face. Below is information on each of the services provided by Diabetes UK to support children and families with diabetes with particular emphasis on their school life.

## Care in Schools Helpline

Diabetes UK has a Supporter Care Centre, which is a public-facing phone service. Due to the high level of calls received regarding issues with schools, a bespoke helpline was established. Diabetes UK's Care in Schools Helpline, launched in October 2014, is a dedicated helpline to support parents to resolve any issues they are having at their child's school. The helpline provides rights-based information and support to make sure children with Type 1 diabetes are happy and healthy at school and that families are aware of their rights.

The Care in School Helpline is provided by trained volunteers, who can talk families through their options, tell them where to find additional information, draft emails/letters and help families navigate the school's complaints process. The service receives 'one-off' enquiries and cases which require ongoing support. The majority (60%) of parents contact Diabetes UK about issues their child is facing in a local authority run primary school, with 39% from secondary school and a further 1% from sixth form colleges (UK wide data).

Parents regularly contact Diabetes UK for a number of reasons which commonly include:

- Their child has been told they can't go on a school trip,
- Their child isn't allowed to treat their symptoms whilst in lessons,
- Their child's school won't provide any support to their child so they are having to go into school to treat their child.

During its first academic year, the service has supported 179 families, providing them with rights based information and advocacy support (7 cases were recorded in Wales, although 41 cases went without a recorded location). 28% of parents who contacted the Care in School Helpline had never contacted Diabetes UK before.

## Make the Grade campaign:

Diabetes UK launched the Make the Grade campaign in 2014 to make sure all children with Type 1 diabetes get the support and care they deserve at school so that they have the same opportunities as other children.

The UK wide campaign introduced a range of products to support families, schools and healthcare professionals. These include bilingual information packs for parents, schools and healthcare professionals, as well as a school log book, advocacy pack, template documentation and policies for schools to adapt. A Care in Schools Award and Film Competition were also introduced in 2015, providing schools with opportunities to receive recognition for good practice of diabetes care.

To date, Diabetes UK has sent out over 22,000 information packs to schools and parents.

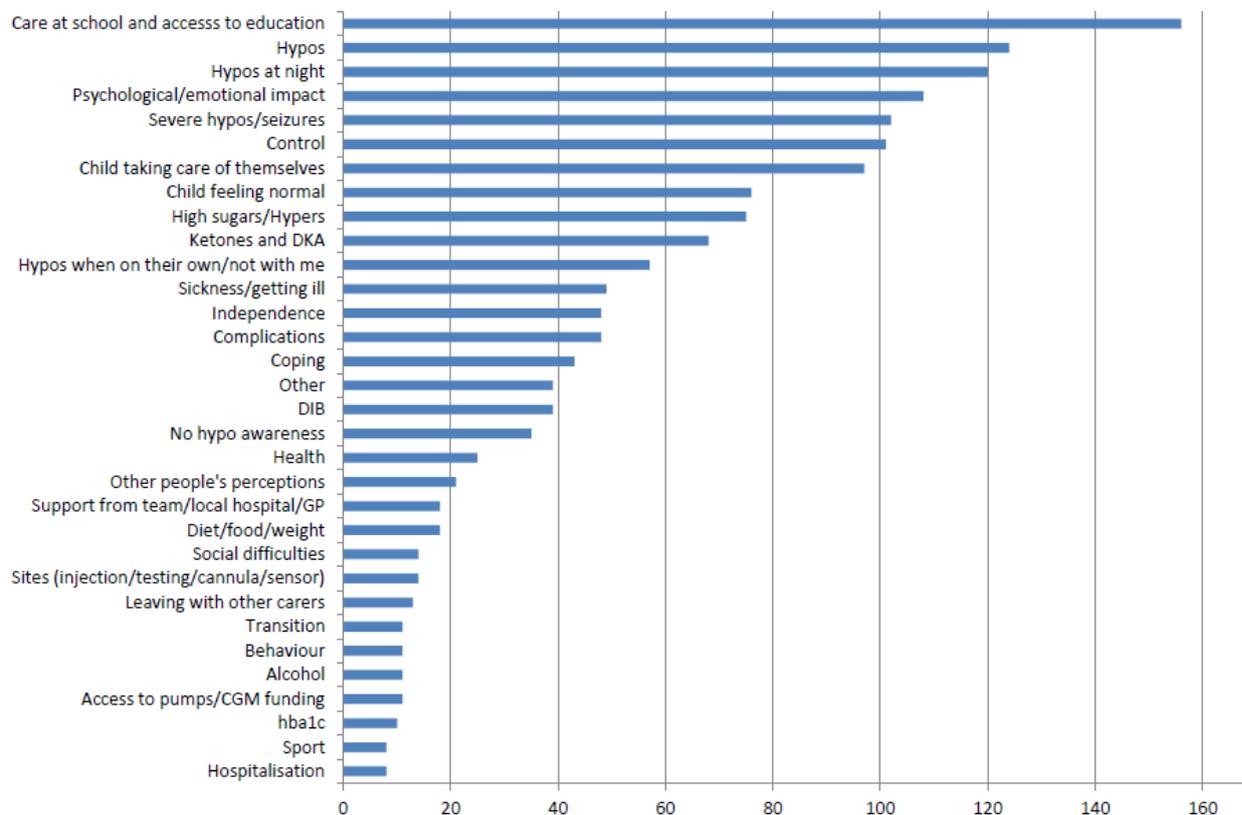
## Family Groups:

Diabetes UK's volunteer-run Family Groups are local networks made up of parents, guardians and the extended family members of children with Type 1 diabetes. They hold regular monthly meetings in person as well as hosting active social media network groups to provide support and information

to each other. There are 7 Family Groups in Wales, each linked to their corresponding Paediatric Diabetes Clinic. Each Family Group is in regular contact with Diabetes UK Cymru and provides a summary of issues raised at meetings.

### Previous Surveys:

In 2014, the Families with Diabetes National Network conducted a survey of parents across England and Wales. When asked their main short term concern about their child was, care in schools and access to education ranked higher than any other concerns (See figure below, Outcomes Survey 2014; Families with Diabetes National Network):



A Diabetes UK survey in 2014 showed variation in the level and quality of support provided to children with Type 1 diabetes in schools. Whilst some schools have excellent policies and procedures in place, some have incomplete, poor quality or no policies and procedures for children with medical conditions. Some children are unable to actively participate in activities and school trips and parents are having to take a key role in managing their child’s diabetes during the school day.

### All-Wales Surveys (2015)

As a direct result of the information and feedback received to date, further research was warranted to understand the extent of the problem in Wales. Diabetes UK Cymru, the Diabetes UK Paediatric Diabetes Clinical Champion for Wales and the Children & Young People’s Wales Diabetes Network therefore conducted specific, Wales-only survey work to ascertain the parental and professional views and experiences of diabetes care in schools.

## Methodology and Results

Diabetes UK designed and circulated a survey amongst families of children with Type 1 diabetes in Wales from September to November 2015 to determine their views relating to the diabetes care provided at school. The Family Survey received 59 responses. The majority have children who attend primary school, although there are also respondents whose children attend nursery, secondary schools and colleges. Responses were received from 12 of the 22 local education authority areas in Wales, equating to approximately 55% of LEA areas (see Appendix A).

The Children & Young People's Wales Diabetes Network (CYPWDN) circulated a survey to Paediatric Diabetes Specialist Nurses (PDSNs) to determine their views of care for children with diabetes in schools. PDSNs provide initial training to schools, as well as ongoing support in person or by phone. 40% of the PDSN workforce in Wales responded to the survey.

Both sets of survey questions expand on issues that families and healthcare professionals regularly raise with Diabetes UK. Questions were designed that would result in a combination of quantitative and comparable data, as well as qualitative data where respondents were able to provide as much detail as they could. Questions were agreed between Diabetes UK Cymru, the Diabetes UK Paediatric Diabetes Clinical Champion and the CYPWDN. A full list of questions can be found in the appendix (Appendix B and Appendix C).

Diabetes UK utilised its voluntary Local Group network of adult and family groups as well as social media networks online of almost 7,000 followers to collect responses. They encouraged social media networks to cascade the survey to their extended contacts as part of an expansive approach to obtain as fulsome a response as possible. Working alongside the CYPWDN, Diabetes UK encouraged frontline paediatric staff to inform parents of the survey in their day to day clinical appointments and to complete their own corresponding survey.

In assessing the results, text analysis software synthesized the large volume of text responses and performed quantitative analysis on open-ended questions. This highlights important terms and phrases in qualitative research and allows for open-ended responses to be categorised into the key findings. The ability to analyse what respondents have said has provided an insight into their attitudes and concerns regarding their children's care whilst at school.

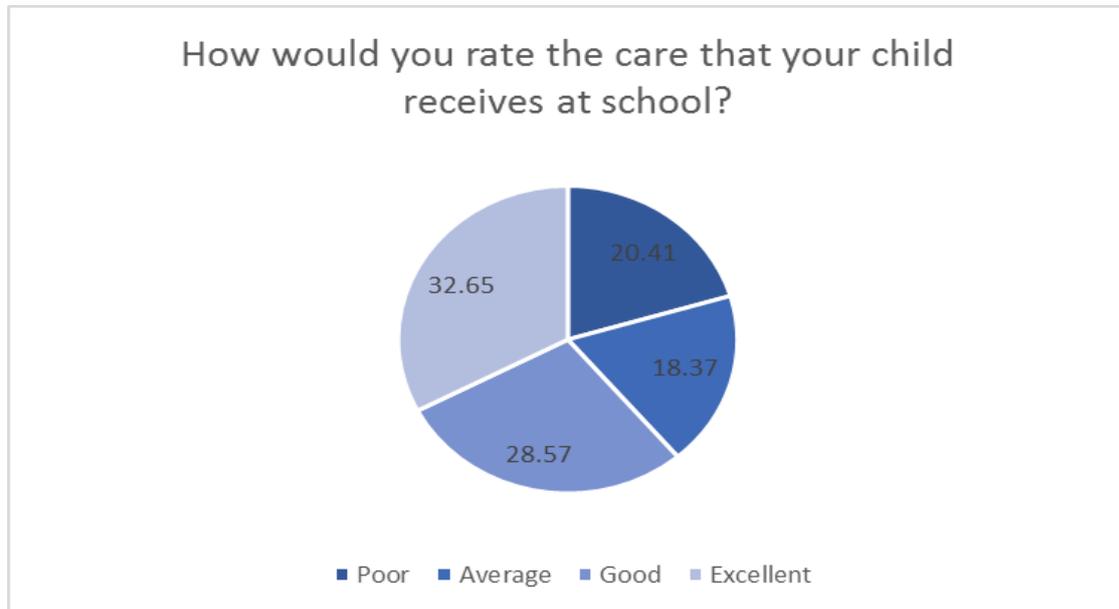
## Key findings from surveys in Wales

Several key themes emerge from both surveys carried out by Diabetes UK Cymru and the CYPWDN. These are regularly cited as issues in feedback from the various services described above. They are discussed in greater detail below.

### **Variability in school care**

The Family Survey shows that while many families across Wales experience good, supportive school environments for their children, the lack of uniformity and application of the current guidance framework appears to be leading to an overtly negative impact on significant numbers of children.

The survey asked families how they would rate the care that their child receives at school. Although just over 60% of respondents rated the care as excellent or good, almost 40% rated it as average or poor (20%).



When asked if they had ever had any issues with the care provided by their child’s school, just over half (51%) of respondents advised that they had an issue. The accompanying responses provide a detailed overview, with several different elements of school life impacting on care. For example, some families have experienced changes to the level and quality of care as a result of routine staff changes made within their child’s school. One mother told us:

*“Initially whilst at nursery, the care was very good, but when a new headmistress started the care standards dropped. There was no continuity of care or understanding of the seriousness of the condition and I had to fight for care. I have rated the school ‘average’ in the previous question, however care is now actually ‘good’ but only because I have fought for this.”*

Some families also described variability between school years within a school:

*“My 7 year old was diagnosed in August 2014. In Year 2 last year he had a class Teaching Assistant and she was amazing. She kept an eye on him and was great with communication etc. Looking back, we were spoilt. This year in Year 3 he has no additional support.”*

Other families have experienced variability between school types. The following family’s experience highlights this:

*“They (the primary school) just didn't deal with anything. She was constantly bullied and nobody was interested in her diabetes. We were told that the classroom assistant was not there for her and that they would not do anything diabetes related! She never went on a school trip without us and was excluded*

*from residential trips. She has now moved to secondary school and they are amazing and cannot do enough for us.”*

There is also clear variability in the policies and procedures in place within schools. A child with a medical condition should have a clear Individual Health Plan (IHP) (sometimes referred to as a care plan) in place. From the survey results, it is clear that there is an inconsistent approach to having a plan in place, that the plan may not reflect reality (for example, the child’s condition or treatment regime) and an unwillingness to deviate from what is in the plan.

### **Child has been sent home early or withdrawn from the school day**

36% of families told us that their child has been sent home early or withdrawn from school because of their Type 1 diabetes. There is a strong consensus amongst respondents that this is due to a lack of understanding by school staff, including school nurses, of the condition:

*“My daughter has learnt not to go to the school nurse if she is feeling low. She has a mobile phone and contacts us herself. This is because if she goes to the nurse, she is inevitably sent home. As she is extremely academic, she is reluctant to miss lessons.”*

*“I have found it safer for my son to contact me for advice from now on. We have insisted he be allowed to call me whenever he needs to.”*

### **Child has been excluded from after-school activities**

13% of families advised that their child has been excluded from after-school activities. One mother advised that:

*“After school activities seem to be run by parents, which I would feel uncomfortable asking them to be trained up. I attend them with my son if he wishes to go.”*

Another respondent, who is a member of staff in a school office, advised:

*“One of our children was offered an out of school active course over the weekend. Her mother was offered a place to attend but unfortunately they didn’t take the offer as the mother couldn’t go.”*

### **Child has been excluded from sports**

Physical activity will nearly always have an effect on blood glucose levels. This is because the body uses up more glucose as fuel when active. Sporting activities therefore need careful consideration and more planning than usual day-to-day activities. One parent explained that whilst her son’s school did include him in an activity, doing so was dangerous because they had not taken this into consideration:

*“We had carefully planned a cycle ride of approximately 5 miles and made adjustments to his insulin basal rates on the pump. The ride was changed to a*

*different location and the miles doubled but no one thought to ask if this was ok or to inform me. They didn't even inform my son of the changes."*

### **Child has been excluded from school trips**

13% of families advised that their child had been excluded from going on both day and residential school trips. Most schools will expect a parent to attend with their child to be on hand to provide support and treatment rather than train a member of staff or ensure that a trained member of staff attends. Several parents explained a similar scenario to the following:

*"I have to be with my daughter if she has a school trip. If I or my husband don't go, then my daughter would not be able to go on a school trip. We have 'wasted' days of our annual leave to go on a trip with her."*

*\*Since completing the survey, the family has advised Diabetes UK Cymru that the care provided by the school has improved.*

*"I had to go on a school trip, otherwise she couldn't go. I had to lose a day in work."*

Trips abroad also present difficulties for families with Type 1 diabetes, with families across Wales again experiencing variability in care provided by schools. One family explained:

*"We were told that a health care plan meeting was not needed to go on a trip to France."*

Whilst another explained that:

*"Support was given when my daughter went on a school trip to Rome. We had a full meeting with the teachers before the trip."*

A particularly difficult situation arose for one family, whose daughter was offered places on two separate trips:

*"My daughter is a keen member of the choir and orchestra. The school offered a school trip to Europe with the music department. My daughter (a very keen pupil) asked to go. We did not know how we could cope with the logistics but I am a GP and have DBS clearance. I offered to go to accompany her. We were also willing to pay for her LSA (Learning Support Assistant) from her primary school to go, just so that she felt part of the school and didn't miss out. The head of music phoned us and asked if we knew she wanted to go. We said we did and that we wanted to support her. He said he would look into it and speak to the Local Education Authority. That is the last we heard. The next we knew, the trip was booked and our daughter was not included."*

The same parent goes on to describe a separate occasion:

*"In order for our daughter to go on a school skiing trip, we paid for the whole family (6 of us) to also go to the same resort so that she didn't miss out. Luckily, we were in receipt of DLA which we feel is to be used to support her. However, this has now been*

*stopped so any further trips will mean annual leave for me and funding issues. This is such a shame. There are LSAs who are trained to look after children with diabetes but the school won't fund them to go on school trips (or even let us fund them!)”*

The variability in care provided by schools can be highlighted by comparing the above scenario with another family's experience, where the school was very inclusive. They provided medical forms for the family to complete and provided an opportunity for the parents to speak to the organising teacher. They also purchased a blood tester kit for the child when this was left behind at their hotel.

In addition to families, the majority of PDSNs knew of cases where children were excluded from off-site activities and residential trips:

*“I have not seen them being refused to attend, but when this entails a younger child the parents have been requested to attend too. If the parents are unable to attend, I don't know if the school would refuse to take the child. I haven't come across this as yet.”*

### **Child has had to move schools**

4% of families have had to move their child to a different school to improve the care that their child receives. Whilst this is rare, it is not unheard of. A further small number of parents have advised us that they have considered this option:

*“We have had big issues. I ended up taking her out of school for 2 weeks due to reception telling her to go back to class when her levels had dropped dangerously low. I wouldn't recommend anyone with an illness go to this school.”*

The above cases can again be compared with the following example of good practice:

*“While he was in secondary school and during his first year at college, he has received first class care. He was not treated differently, but he had a very good relationship with the school nurse and he was given privacy to do his injection and test his bloods.”*

From the survey results, it's evident that different families are experiencing different levels of support from their child's school. The level of support directly impacts the level of inclusion or exclusion that a child is experiencing, causing disparity in the system and leaving some children at a distinct educational disadvantage.

### **Parental involvement during the school day**

The majority of respondents have had to attend their child's school during the school day to carry out tasks relating to their child's diabetes, although they do not see this as a negative element of their child's care. However, this will have a detrimental effect on their own working day, as well as a wider economic impact.

For example, 62% of respondents have stayed at home from their own work because of issues relating to their child's diabetes and 53% of respondents have had to leave their own work place

during working hours to attend their child's school but some of those same respondents believe that the care at their child's school is good or excellent. The results suggest that parental involvement is not on a one-off basis, but is a regular and relied-upon routine with them having to provide regular and sometimes daily treatment for their child:

*"The school refuses to allow staff to administer insulin injections to my daughter. As a result, I have to visit the school every lunchtime to inject her."*

*\*Since completing the survey, the family has advised Diabetes UK Cymru that the care provided by the school has improved.*

*"They won't administer insulin, so I have to go into school every lunch time to inject my daughter, who is 6 next week. I also had to go on a school trip, otherwise she couldn't go. Therefore, I had to lose a day in work."*

*"On diagnosis, we as parents had to attend school EVERY day to inject at lunch time from the start of October until the beginning of January."*

As well as attending the school to inject insulin, 62% of parents advised that they are being relied upon to carry out other diabetes related tasks. 26% of these include supervising their child's diet or meal times at school. Some families described how they have had to attend the school in person to provide a small snack to their child because the school has refused to do so.

One parent advised that her daughter's school won't

*"...allow her to have a fast pass to get food as soon as lunch starts. She is questioned regularly by staff when food needs to be eaten."*

In extreme cases, some parents have left or lost their own job because of issues relating to their child's diabetes. One father told us that:

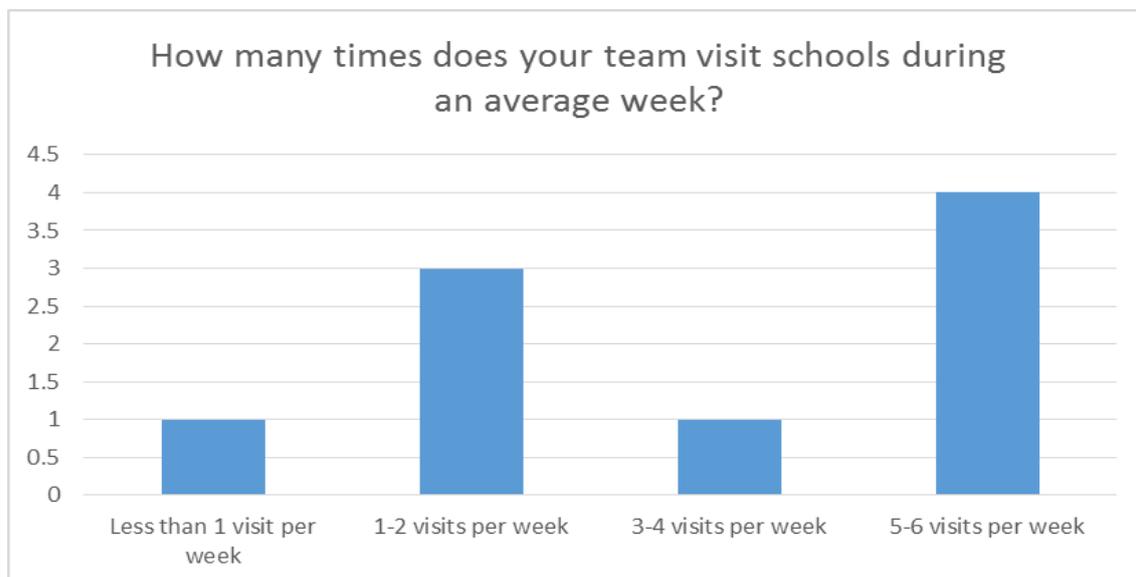
*"My wife doesn't work as she is so worried about anything happening with the children. We have two children who have Type 1 diabetes. She is at their beck and call, should they need her."*

It appears that whilst some schools rely on parental involvement immediately after diagnosis only, some are reliant on parents several months and even years afterwards to provide a high level of support during and/or throughout the school day.

### **The role of the PDSN in care at schools**

PDSNs are responsible for providing training to at least 2 (ideally 3) members of staff within a school. There is usually a minimum requirement of having 2 trained members of staff to be able to provide cover for annual leave or sickness absence. The training will be tailored to the child's treatment regime and is usually arranged between the PDSN and school directly on school premises. Thereafter, the PDSN will provide training updates and ongoing support in person or remotely. However, PSDNs are finding this role increasingly time-consuming, with all children with diabetes now requiring treatments that impact on the school day. This includes intensive insulin regimes and increasing numbers going on to continuous insulin pump infusions.

The PDSN Survey asked how many visits to schools their team makes during an average month. The results can be seen below, with the majority of PDSN teams visiting schools more than once or twice a week and most teams carrying out 5-6 visits per week.



In addition to physical visits to schools, PDSN teams are contactable by phone for both schools and parents. 44% of PDSNs receive 1-2 calls per week from parents regarding school issues, 33% receive 3-5 calls and 22% receive more than 6 phone calls per week. A third of PDSNs surveyed advised that almost all calls from schools identified training needs for educational staff.

### **School's staffing: Capacity issues**

The survey results indicate that there are not enough trained adults to provide an adequate level of care for children with Type 1 diabetes in a school setting, despite the high level of support provided by the PDSNs described above. Many parents advise that senior staff members at their child's school, such as a Head Teacher or Deputy Head Teacher, are very reluctant for any staff to be responsible for diabetes management. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to identify hypoglycaemic symptoms or to accompany their child to inject at meal times. The training of supply teachers also presents difficulties for some families.

In turn, schools have advised parents that they experience significant issues relating to the provision of diabetes care and support. 29% of respondents' schools cited staff training issues as the predominant barriers in provision. One family explained:

*"I have been told by school that their staff are not medically trained and therefore they shouldn't have to inject the insulin. However, there are staff trained in carbohydrate counting and injections in the school, as they have previously had a Type 1 pupil."*

*\*Since completing the survey, the family has advised Diabetes UK Cymru that the care provided by the school has improved.*

One mother described a recent situation that occurred at her son's school, where he does not have additional support and relies on his teacher for treatment:

*"I had recently spoken to the Head Teacher and made him aware that my son's teacher has to treat him straight away if he feels unwell and that she has to almost disregard the other 29 children to treat him. He assured me that the teacher is prepared to do this and realised the importance etc. Today, my son was told that although he felt unwell at 11:45ish, it was nearly lunch time so she'd sort him out then. By that time, she tested him and he was dangerously low (2.8). I've spoken to the Head Teacher again tonight but surely this is unacceptable? It's frightening to think what could have happened."*

One family advised:

*"There is only the teacher with the class. I believe they need an additional adult to recognise signs/symptoms of a high/low blood sugar, as it affects learning drastically. Also, to be able to treat a hypo immediately, as it's unreasonable to ask a teacher to treat a diabetic hypo whilst managing a class of 30 children."*

Once more, the above families' situations can be compared with the following examples of good practice elsewhere in Wales:

*"The school my son attends have been extremely helpful. They make sure that all staff that will work with him have been fully trained to administer his insulin."*

The above scenarios can be further compared with one PDSN team member advising that:

*"All schools [have] concerns but with support have been very willing [to support the child]. The delays occur due to lack of PDSN time in that the practical training to give injections can only be done at lunch time and, due to the geographical area, at one school per day. Verbal education and training is more flexible as it can happen before, during or after the school day."*

Another PDSN supported this assertion, explaining that:

*"Time isn't being allocated to staff for provision of support - it all needs to happen during their break and this feels unfair. Teachers want to be teachers, not medical staff."*

### **School staffing: Confidence and understanding of the condition**

Issues relating to families' concerns about staff training and knowledge levels are not due to lack of training from PDSNs, rather that the member of staff is not confident or a staff member who did not receive the training has been tasked with caring for the child with Type 1 diabetes.

Families regularly encounter varying levels of understanding and/or confidence about Type 1 diabetes from teachers and members of school staff that they meet. 32% of parents have been told by their child's school that they experience a lack of support and information on caring for children with Type 1 diabetes. A further 21% of parents stated that their child's school has advised them that they have a lack of contact with healthcare professionals and so struggle to provide adequate care.

Two separate families who have tried to engage their child's school with their Type 1 diabetes explain:

*"They maintain they have no problems. They do not give children with diabetes the care they need and staff are not aware how serious the condition is."*

*"The school, teachers and so-called nurses at the school clearly have little idea of what diabetes is and what is involved with the condition. They are totally ambivalent over the illness."*

It seems that neither family are alone in describing challenging scenarios. Another two families explain:

*"We would not dream of sending our daughter on long trips due to total lack of understanding of most staff."*

*"(...) at times, it is a struggle to make staff understand that I have to talk to the carer during school hours."*

Many of the parents who responded to the survey spoke of a general lack of knowledge, understanding and compassion. This is supported by yet another family's case that:

*"Several times my daughter has had issues with teachers complaining about school time lost due to diabetes appointments. The school seem more concerned with targets than with children's health."*

### **Impact on educational attainment: Exams**

During exam times, many parents advised that their child has been offered a private room to be able to treat their diabetes during the exam, if necessary. Diabetes UK receives regular calls from supporters advising that exam conditions are an issue with schools. Some parents describe situations such as this one, where their child has suffered additional stress and concern at what is already a difficult time:

*"When doing exams, we were assured by the Head of Year that all examination overseers would be aware of her, her condition and what actions can be taken in the event of a hypo. When phoning to check the day before, no one knew anything about special considerations."*

In direct contradiction to the scenarios described above, one family advised that:

*“We have been lucky to have the school this involved and willing to provide that care. We don’t expect it to be perfect, we make mistakes ourselves. That has given them the confidence to work with us.”*

### **Treatment: Equipment and medication**

Almost 90% of PDSNs have experienced school staff being reluctant to inject insulin, whilst 75% of PDSNs have experienced school staff being reluctant to calculate insulin dosage levels on insulin pumps. This corroborates the experience of Diabetes UK, which receives regular phone calls from parents and schools regarding this issue.

The majority of PDSNs have experienced schools being reluctant for children to test glucose levels or receive insulin in a public area of the school or for children to participate in normal school activities. It is presumed with support from PDSNs that these reservations were overcome in the majority of cases.

Most PDSNs also report that said schools have applied restrictions to crucial elements of insulin treatment, such as blood glucose testing. We heard from parents who were very concerned that their child’s school had lost blood glucose kits and stored hypoglycaemic treatment within reach of other students. One mother described a recent situation where the school failed to provide the opportunity to resolve an issue in a clear and transparent way:

*“We had an incident where two other children messed with my son’s meter kit. One child pricked the other on the thumb. Yesterday, the Head Teacher completely washed her hands of the situation after speaking with the parent of the other child. I had to go in to do his bloods, stay for after school club and he had to go behind a screen to test. I walked out in tears. Today, they are back to doing things exactly the same as before and are looking out for him again!”*

This again can be compared with a different school’s approach:

*“In secondary school, they have been very supportive on the rare occasion things have gone wrong (even popping to the shop to buy replacement batteries for his pump when his spare ones failed!).”*

### **Child privacy when managing their condition**

Some schools provide a private room for children to test their blood glucose levels and to inject insulin. This is because both tasks often require injections into areas of the body usually covered by clothing, such as the stomach area or upper leg. Yet again, we have seen a variability in experiences from school to school, with some parents advising that their child’s school does not provide

adequate room for injecting and others advising that their child is given privacy to do their injections and to test their blood.

### **School's confusion over their legal position**

Among the PDSN Survey results, the professionals raised concerns that schools regularly articulate their concerns regarding their legal position in caring for children with diabetes:

*"[Schools raise the issue of] not being covered legally in the event of an error. The lines of responsibility are very unclear."*

## **Conclusion and Recommendations**

This report provides an overview of the care in schools provided to children with Type 1 diabetes in Wales based on the views of a range of parents and healthcare professionals directly involved in the provision of support within a school environment.

The survey results suggest that the current guidance framework in Wales has not resolved the issue of variability, which can be found at every level and in every aspect of care for a child with Type 1 diabetes. The results show that children are routinely experiencing exclusion from the school day, after-school activities, sports, school trips and in extreme cases, are having to move schools. The high level of parental involvement in their child's school day indicates an over-reliance on families to perform diabetes-related tasks and highlights issues in school staff capacity. The survey results further show that this can be linked to levels of staff confidence and aptitude in managing Type 1 diabetes in schools, resulting in different children experiencing different practices around their treatment and medication regimes and the wider practical aspects of their care.

Support is not received in equal measures by children with Type 1 diabetes and differs greatly from child to child and from school to school. This can be expected to some degree in the treatment and care of a long term, individualised condition, but the degree of variability is surprising. As shown in the survey results, many families across Wales experience good and supportive school environments for their children, however, the evidence clearly outlines the need for uniformity. The application of the current guidance framework appears to be leading to an overtly negative impact on significant numbers of children, as evidenced above. Early evidence from the implementation of the new statutory guidance in England suggests that this variability has been reduced with a more directive guidance framework.

The large range of feedback gained through the surveys from families and professionals provides a picture of what a good supportive school environment should be for every child. One PDSN response to Diabetes UK has been included below in full to illustrate this:

*"In general, I feel that having named staff responsible for the diabetes management and the staff getting allocated time for training and carrying out the procedures are crucial for success. This along with good communication and a good relationship*

*between school and home all help in ensuring diabetes is managed well at school. An understanding Head Teacher definitely leads the way in making their staff feel supported and able to volunteer to help with diabetes managements at school. The Head Teacher is very much the gatekeeper of what can occur in school and if the Head doesn't want staff involved in supporting the child's diabetes management then we really struggle to avoid the need for parents to be permanently on call for blood glucose testing and insulin administration."*

The following recommendations need careful consideration and implementation to ensure all children and young people in Wales receive an 'excellent chance' to prosper and succeed.

- There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English system. Greater clarity and direction for schools would reduce variability and avoid confusion as to the roles and responsibilities of all involved.
- There is a need for improved and updated guidance for managing chronic diseases in schools. New guidance would need to identify measures to reduce this and to standardise policies and procedures for schools as much as possible.
- There is a clear need for enhanced support for children with diabetes to be delivered in conjunction with schools and parents. This will improve children, young people, their family and their schools' experience and also allow currently recommended therapies which will impact on improved outcomes.
- Schools, local education authorities, health services and parents should work together to ensure that the needs of the child with diabetes are met and that they are not unduly stigmatised during the school day from their condition.
- Paediatric Diabetes Educators for schools are required across Wales to reduce variability in care during the school day and to enhance the understanding and improve the confidence of school staff who are providing this support. Cardiff & Vale University Health Board have led the way in funding the first Paediatric Diabetes School Educator in Wales. This now requires partnership working between Health and Education to implement an all-Wales approach to ensure consistency across Wales.

## Bibliography

Welsh Government (2013) *Together for Health – A Diabetes Delivery Plan*. Available at <http://gov.wales/topics/health/nhswales/plans/diabetes/?lang=en> (Accessed 12<sup>th</sup> January 2016).

Welsh Government (2010) *Access to Education and Support for Children and Young People with Medical Needs*. Available at <http://gov.wales/topics/educationandskills/publications/guidance/medicalneeds/?lang=en> (Accessed 12<sup>th</sup> January 2016).

National Paediatric Diabetes Audit (2015) *National Paediatric Diabetes Audit Report 2013-14. Report 1: Care Processes and Outcomes*. Available at <http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-paediatric-diabetes-audit-n-0> (Accessed 12th January 2016).

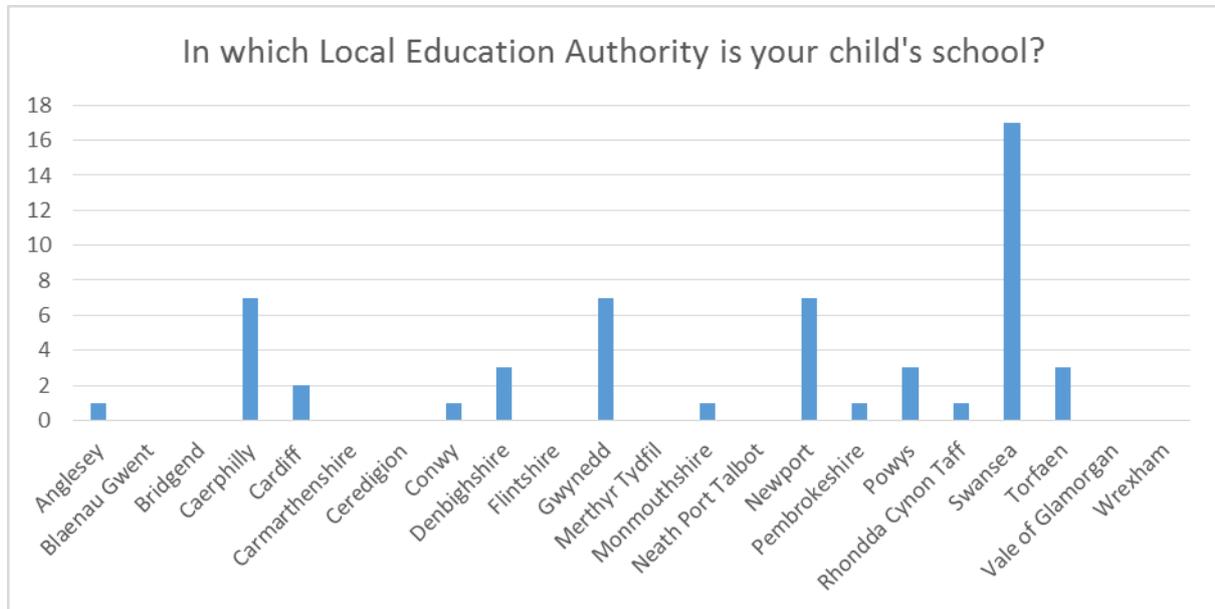
Department of Education (2014) *Supporting pupils at school with medical conditions*. Available at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/306952/Statutory\\_guidance\\_on\\_supporting\\_pupils\\_at\\_school\\_with\\_medical\\_conditions.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/306952/Statutory_guidance_on_supporting_pupils_at_school_with_medical_conditions.pdf) (Accessed 12th January 2016).

Welsh Assembly Government (2003) *National Service Framework for Diabetes in Wales*. Available at [http://www.wales.nhs.uk/documents/DiabetesNSF\\_eng.pdf](http://www.wales.nhs.uk/documents/DiabetesNSF_eng.pdf) (Accessed 12th January 2016).

Families with Diabetes National Network (2014) *Outcomes Survey*. Available at [http://www.cypdiabetesnetwork.nhs.uk/files/6414/2796/7833/Outcomes\\_Survey.pdf](http://www.cypdiabetesnetwork.nhs.uk/files/6414/2796/7833/Outcomes_Survey.pdf) (Accessed 12th January 2016).

## Appendix A:

### Respondents to the Family Survey by Local Education Authority



## Appendix B: Family Survey questions

The Family Survey asked the following questions:

- Is your child at nursery, primary, secondary school?
- In which Local Education Authority is your child's school?
- Have you had any issues with your child's school providing care for their diabetes (past or present)?
- How would you rate the diabetes care your child receives at school?
- Have you ever had any of the following occur? (Multiple choice)
  - Attended school during the school day to administer insulin
  - Attended school during the school day to supervise diet/meal times
  - Attended school during the school day to carry out other diabetes-related tasks
  - Left your own place of work during working hours to attend the school
  - Stayed at home from work because of issues relating to your child's diabetes
  - Left or lost your job because of issues relating to your child's diabetes
  - Moved your child to a different school
  - Child has been sent home early/withdrawn from school
  - Child has been excluded from school trips
  - Child has been excluded from after school activities (clubs etc.)
- On average, how frequently does diabetes disrupt your child's day at school?
- Has your child's school ever told you that it has experienced any of the following difficulties in managing children with diabetes? (Multiple choice)
  - Shortage of trained staff
  - Shortage of staff willing to volunteer to care for your child
  - Lack of contact with healthcare professionals
  - Lack of support and information on caring for children with diabetes
- How can the care that your child currently receives at school be improved?

Free text boxes were provided for further comment.

## Appendix C:

### Paediatric Diabetes Specialist Nurse (PDSN) Survey questions

The PDSN Survey asked the following questions:

- How many times does your team visit schools during an average week?
- How many calls do you estimate you receive from parents regarding issues with schools per week?
- How many of those calls require additional training and support for school staff?
- In your experience, which of the following has caused school staff to raise issues regarding diabetes care? (Please tick all that apply)
  - Reluctance to inject insulin using an injection pen
  - Reluctance to calculate doses for an insulin pump and input numbers
  - Reluctance to perform blood tests
  - Fear of hypoglycaemic episodes
  - Concern about children administering own insulin
  - Concern about children doing blood tests/injecting insulin in classroom or public area
  - Concerns about hypo treatment, especially giving a child snacks and/or sweets
  - Concerns about a child with diabetes being able to participate in activities, school trips and PE lessons
  - Other – please list
- Have you seen children who have been affected in any of the following ways? (Please tick all that apply)
  - Refused a place in a preferred school
  - Refused permission to engage in normal activities e.g. PE lesson
  - Refused permission to engage in off-site activities, including day trips and residential trips
  - Discouraged from taking part in school activities
  - Prevented from testing blood, injecting insulin or other diabetes-related activity unless in a designated area
  - Other – please list

Free text boxes were provided for further comment.

## Appendix D: Children & Families Act 2014

### 100 Duty to support pupils with medical conditions

- (1) The appropriate authority for a school to which this section applies must make arrangements for supporting pupils at the school with medical conditions.
  - (2) In meeting the duty in subsection (1) the appropriate authority must have regard to guidance issued by the Secretary of State.
  - (3) The duty in subsection (1) does not apply in relation to a pupil who is a young child for the purposes of Part 3 of the Childcare Act 2006 (regulation of provision of childcare in England).
  - (4) This section applies to the following schools in England—
    - (a) a maintained school;
    - (b) an Academy school;
    - (c) an alternative provision Academy;
    - (d) a pupil referral unit.
  - (5) In this section  
“the appropriate authority for a school” means
    - (a) in the case of a maintained school, the governing body,
    - (b) in the case of an Academy, the proprietor, and
    - (c) in the case of a pupil referral unit, the management committee;
- “maintained school” means
- (a) a community, foundation or voluntary school, within the meaning of the School Standards and Framework Act 1998, or
  - (b) a community or foundation special school, within the meaning of that Act.
- (6) The Education Act 1996 and this section are to be read as if this section were included in that Act.

## Appendix E:

### Early evidence of the impact of the Children & Families Act 2014

In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must make additional arrangements for supporting pupils at schools with medical conditions. The legislation does not apply to schools in Wales.

Whilst the implementation of the legislation is in its infancy, early indicators document a clear increase in schools' engagement with medical conditions. Diabetes UK has seen a marked increase in the number of healthcare professionals who are nominating a school in their area for Diabetes UK's Good Care in Schools Award.

Comparative evidence gathered annually by Diabetes UK shows that the situation in England is improving year on year:

Indicators	2013	2014	2015
1. Percentage of parents who are satisfied with the diabetes care provided to their child at school	67%	71%	72%
2. Percentage of parents who state that an individualised care plan is in place at school which meets their child's needs.	51%	66%	85%
3. Proportion of schools that have access to Type 1 diabetes training	66%	66%	73%
4. Proportion of schools with appropriate policies and procedures in place to provide children with Type 1 diabetes with consistent, individualised care (including IHP that cover extracurricular activity)	7%	58%	71%

\*Figures from 2013, 2014 and 2015 annual surveys of parents and schools conducted online by Diabetes UK.

The following case study highlights the beneficial and direct impact that the introduction of a statutory duty has had in practice:

*On a forthcoming residential trip at a primary school, an 11 year old child with Type 1 diabetes was told that their parent would also have to attend to provide care for them. The school advised that the child would have to stay in a separate room away from their peers, which the parent felt was very unfair.*

*The parents contacted Diabetes UK's Care in Schools Helpline for assistance. The volunteer who supported the parent explained the need for a thorough Individual Healthcare Plan (IHP) for their child, which the school should have in place. The IHP would need to be adapted and updated to include additional provisions in relation to any school trips.*

*They discussed the need for the school to undertake a risk assessment in advance of the trip, where they could highlight potential issues. The risk assessment should also describe what steps the school would take and what measures they would put in place to help mitigate these risks.*

*The Care in School Helpline wrote to the School Governors citing their responsibilities under section 100 of the Children & Families Act 2014 to support the child on the trip without the need for a parent having to accompany them. As a result, the school acknowledged that they had not complied with their statutory duties. They acknowledged that they had treated the child unfairly and that the child should be treated equally. The parent felt that the school had made improvements and were now better informed of their responsibilities. The child enjoyed the residential trip along with their peers.*