

## Oxfordshire Childrens Diabetes - The Primary Schools Intervention Programme

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### Abstract

Poorly controlled diabetes adversely affects a child's education, with concentration difficulties, alterations in mood, behaviour and fatigue associated with high or low blood glucose levels. Between years 2004-6 we started all toddlers and children on intensive insulin regimens (multiple dose injection or pump) making it imperative that they received support during the school day. This required close monitoring of blood glucose levels and counting carbohydrate intake to adjust rapid-acting insulin dose or pump bolus at every meal. We report our experience of formulating a sustainable structure of support in primary schools based on trained volunteers who partake in the daily 'Individualised Care Plan (ICP)'.

After overcoming multiple barriers, an acceptable system was negotiated with our Primary Care Trust (PCT) and Local Education Authority (LEA). In 2009, the PCT confirmed 3 years funding for a Paediatric Diabetes specialist nurse (PDSN) for schools. In 2010, the first full school year with agreed protocols was in place. By July 2012, our nurses had trained a total of 342 volunteers who provide care for 132 children.

The Oxfordshire Schools Intervention Programme ensures that legal obligations are met. A risk assessment allows the LEA to provide indemnity to their school staff to give injections and do blood tests, after training and competency sign-off by a PDSN. Parents, volunteers and PDSN jointly agree a comprehensive 'ICP' and utilise a hand-held communication record book. Diabetes control improved (age 4-11 years cohort from 2004 onwards: Mean (SD) HbA1c in 2001-4 = 8.38 (1.09)%; in 2005-8 = 7.74 (0.81)%; in 2009-12 = 7.58 (0.69)%; ANOVA  $p < 0.001$ ). This requires 500-1000 hours of DSN time to train/retrain/problem-solve annually (approximately 5-10 days per month). The cost-benefits are discussed.

We advocate that our programme supports each child's ICP, use of intensive insulin regimes in school-day and reassures parents that schools can deliver this safely.

### Problem

When children develop Type 1 diabetes at a young age, they are dependent on an adult to check blood glucose levels and administer insulin for them, as well as deal with any out of range blood glucose levels. Children with Type 1 diabetes spend 6 hours a day during school where they experience fluctuations in blood glucose levels.

Poorly controlled diabetes adversely affects a child's education, with concentration difficulties and alterations in mood or behaviour linked to high blood glucose levels, and the acute cognitive effects of hypoglycaemia. Therefore adults at school need to understand the reasons for the diabetes regimen, and be taught how to manage the various aspects of diabetes care, including blood glucose testing and insulin administration in order to ensure optimum educational achievement.

Schools play an important role in supporting the health and wellbeing of children and a clear legal framework to support this exists, though there is still no compulsion to provide a member of staff to carry out care. Until recently, schools had tended to consider diabetes care as "medical" care and had not been willing to take on this support. We had the task of persuading schools and the local education authority to be more active in managing diabetes in primary school children and in overcoming barriers such as fear and misunderstanding in school staff in order to do so.

### Background

There are 29,000 children with Type 1 diabetes in the UK, around 40% of whom are in the primary school age-group (1). Parents are taught all the practical aspects of diabetes care very quickly, but school teachers and other staff at schools have not historically taken on this care. This is largely because it has been seen as medical rather than self-care. Furthermore this problem of obtaining help in schools has prevented many children's diabetes services from using intensive insulin regimens which require injections or even blood glucose testing in the middle of the day.

However, with the advent of newer insulin analogues, it has become clearer that better glycaemic control is achieved with regimens such as multiple dose injections (MDI) and insulin pump regimens where insulin is required to be given every time a child eats, together with a long-acting insulin once a day. Modern insulin regimens resulting in improved blood glucose control require close monitoring of blood glucose levels (2-7 times a day), counting carbohydrate intake to adjust rapid-acting insulin dose or pump bolus at every meal, using correction doses for high glucose levels and treating hypoglycaemia appropriately.

In the United Kingdom, there are multiple legal and strategic frameworks that exist for supporting care of children with diabetes in schools. These include the common law duty of care, Health and

Safety at Work Act, 1974, the Care Standards Act, 2000, the Education Act, 2002 and the Children Act, 2004. Disability discrimination legislation including the Disability Discrimination Act, 2005 and the Disability Equality Duty, 2005 require every school to have a policy for ensuring that all disabled children including those with diabetes have support and reasonable adjustments to ensure that they are not discriminated against.

In Oxford we started using MDI in toddlers in 2004 and became aware that this cohort would be starting school. Therefore we commenced a process of negotiation with the Local Education Authority (LEA) and the Primary Care Trust (PCT) to produce a diabetes management programme.

## Baseline measurement

In 2004, we started all toddlers on multiple dose injection regime (MDI), then from 2006 started all children on MDI at diagnosis with documented benefits in improving glycaemic control, judged by HbA1c levels. Figure 1 shows the difference in HbA1c during the first year from diagnosis in children in the clinic under the age of 12 years when started on various insulin regimens. In our clinic, MDI produces lower HbA1c levels during the first year which are even maintained below target levels at 12 months. It was therefore imperative that all our young children required support in school to have insulin injections.

We also carried out a study asking parents of primary school aged children about the problems they were facing at school and contrasting this with the head-teachers' responses. Parent reported that children faced multiple problems at school because of the anxieties or ignorance of school staff, including poor management of hypoglycaemia, preventing children going on schools trips. Many parents also reported that they felt pressurised into giving up work to attend the school every day to administer insulin.

Therefore we had good evidence to present to the local health and education providers of the need for improved support for children at school.

See supplementary file: [ds1602.pdf](#)

## Design

The logical place to start was with discussions with the LEA. It took some time to find the right person to negotiate with within education, who had some responsibility for care pathways for other children with medical needs, such as epilepsy and anaphylaxis. We had also used ideas presented to us from the USA (2) and Sweden where systems had been started to provide support to children.

We therefore felt that the best way forward was to train staff within the schools in the basics of diabetes management as well as in the specifics of the care plan for the individual child. We attempted at first for parents to be allowed to provide some of the education for the staff, but this was not felt to be safe. There was a lot of fear and anxiety, particularly around giving injections at school and the main

concern of the LEA was about indemnity if things should go wrong. It took a couple of years before these anxieties were dealt with and an adequate agreement about indemnity was forthcoming.

We eventually negotiated an acceptable system with our PCT and LEA whereby Paediatric Diabetes Specialist Nurses (PDSNs) train up volunteers identified by the school, and, together with the parents, draw up a comprehensive individual care plan and utilise a hand-held communication record book. A minimum of three volunteers are trained per child.

The Oxfordshire Primary Schools Intervention Programme:

1. A primary school-aged child is newly diagnosed with Type 1 diabetes
2. Our Schools DSN will discuss with the parents what support they feel they need at school
3. A care plan is then drawn up with the parents
4. The school Head teacher will have been sent an Introductory document and a meeting with DSN to discuss the process is arranged
5. The Introductory document describes diabetes, and explains the need for testing and insulin during the school day as well as defining the responsibilities of the school, the parents and the diabetes team.
6. The volunteers are trained by the DSN, and the parent agrees to go into the school to supervise until both the volunteer and parent are happy that they are competent (may take several days or weeks)
7. The DSN then goes back into school to certify competence
8. The hand-held Communication Record book is utilised: Parents provide carbohydrate content of meals, insulin doses for meals, correction doses for high blood sugars; and volunteers follow advice, sign for insulin doses given.
9. All equipment provided and updated by parents
10. Annual Evaluation of Schools Intervention Programme including feedback, monitoring risk events and protocols review through Diabetes MDT clinical governance meetings.

## Strategy

PDSA 1-6 The Model of Improvement

Timeline of eventual achievement of a satisfactory outcome in Oxfordshire Primary schools: 2004 - 2012.

PDSA Cycle 1: First attempts

December 2004 - July 2007

- Various meetings with community matron, PCT, LEA health and safety representative, parent representative
- Was told: this should be fine - 'we have an anaphylaxis protocol'
- Several drafts of medical management plans, but still no will to change, and problems with indemnity and with health and safety concerns from the LEA HS representative

The problem is that, despite multiple legislation to support people with disabilities, no-one, unless they are specifically employed by the school for the purpose, can be forced to take on insulin

injections and blood glucose testing. The most useful part of recent legislation is the Disability Equality Duty (2005) which places new responsibilities on schools to actively promote equality of opportunity for all disabled people, and states that prime responsibility lies with school governing bodies.

## PDSA Cycle 2 Funding and Responsibilities

We agreed early on with the PCT, against some resistance, that it was essential that the children are given variable-dose insulin according to the carbohydrate quantity of the food, as well as a correction dose for prevailing blood glucose level. This is crucially important for patient safety, as fixed dose insulin would result in hyper- or hypo-glycaemia if the expected amount of food was not eaten. This again was felt to be a problem in that school staff would not know how to do the calculations. Although the LEA was not prepared to allow parents to do any of the training, they accepted that parents would be responsible for communicating the carbohydrate content of the food to school staff, who would have to do very minimal calculations. A Communication Book designed by one of our PDSNs was crucially important for reassurance here.

## PDSA Cycle 3 New insulin regimens already in place September 2007

- Children actually in school but no real system in place
- Involvement of Joint Commissioner
- Request to delay converting children to multiple-dose insulin (MDI)
- Solution - to employ district nurses to go into schools to give injections
- Protocols increasing in length - LEA realised this was not the same as other conditions

The main problems during this phase were the other medical protocols for acute care eg anaphylaxis or epilepsy, where care is only required at times of emergency and not throughout every school day. Further discussions with the LEA resulted in very long guidelines. The PCT said they would not commission MDI in children which we argued was a clinical decision based on the improved control.

## PDSA Cycle 4 Inevitable Progress

- Fight back to PCT Clinical Executive (by now 160 children on MDI and all new ones starting on this regimen)
  - We told them that MDI was a clinical decision and that schools have a duty of care
- September 2008 - another new school year
- Agreed that we could go ahead
  - PCT provided £10,000 for a diabetes specialist nurse for schools for this year
  - Protocols now 28 pages long
  - Trust legal services now involved with LEA to produce risk assessment

PDSN was employed specifically for schools and this allowed us to make the first proper progress. She negotiated with the individual schools and trained many volunteers even before final protocols were agreed. By September 2009, 40 children were having insulin injections at school with carbohydrate counting. The PCT provided

funding for a further 3 years.

We defined responsibilities of all parties very clearly. These meetings allowed improved communication and shared goals between Primary Care Trust, Diabetes Team, Schools, volunteers and Parents. Parents of young children with diabetes were essential members of the team negotiating with the Local Authority. We also worked closely with the Hospital Trust's legal department to draw up a risk assessment to allow indemnity for the volunteers.

## PDSA Cycle 5 Oxfordshire Schools Intervention Programme

- 1st school year with agreed protocols July 2010
- By July 2012, 132 children having insulin injections, pump boluses and blood glucose tests carried out or supervised by school volunteers

After convincing the Primary Care Trust, we developed information for Head teachers, tight guidelines for diabetes care and supervision by school helpers and teachers. In addition, general diabetes education including the recognition and management of hypoglycaemia is regularly given to all school staff including the volunteers by our team of PDSNs and family support by home visits to draw up care plans.

The project has been fully functioning for only two full years. During that time, the insulin pump usage has also increased to around 25% of the clinic, which has required further changes in the protocols and in training plans.

## Schools PDSN volunteer training time

Up to July 2012, to train 342 volunteers for 132 Primary School Children.

Initial training required 342 x3 hours, approximately 1024 hours. During 2011-12 required a further 132 re-training/investigative visits of 528 hours.

A minimum of three volunteers are needed for each child in order to allow for illness and leave. Annually, on average this programme required more than 1000 hours of Schools PDSN training time.

This has been a huge amount of work, and requires several visits to each school at initial stages. Some schools have required that more than three volunteers are trained, and we are going to be looking at the effectiveness of this in the next year. We have now completed the first four locality schools update training sessions, which were well received. We are now in the process of auditing the sessions to see if it is the most efficient and cost-effective way to generate an update for schools.

## PDSA Cycle 6 Evaluation

Until all data have been collected, the Schools Intervention is subject to regular review of problems and feedback from parents and school staff through our diabetes governance meetings, this includes updates of protocols involving our multidisciplinary team members (five Consultants, eight Specialist Nurses, three dieticians and our Clinical Psychologist).

Clearly, school staff have been nervous about starting with the injections, especially when they have not known anything about diabetes previously, but generally the system works very well, providing parents with peace of mind that their children are obtaining the care they need to thrive and develop and learn at school.

We have since worked with the Local Education Authority to review and refine this programme and are now developing further guidelines. Responsibilities have been tightened up and parents are not allowed to be more involved in the process and can let PDSNs know when volunteers are competent.

## Results

Over the last two years there has been considerable progress within Oxfordshire's primary schools using multiple daily basal/bolus insulin regimens and increasingly using insulin infusion pumps. We therefore provide some interim results until our final analysis of primary and secondary endpoints have completed for three year analysis (see attached figures). The Ratio was 2.6 trained volunteers per child.

Glycaemic control has also improved over the whole period of the project in this age-group (from 4-11 years of age).  
 Mean (SD) HbA1c from 2001-2004 = 8.38 (1.09)%.  
 In 2005-8 = 7.74 (0.81)%  
 In 2009-12 = 7.58 (0.69)%; ANOVA  $p < 0.001$ .

Parents have increased confidence: informal feed-back from parents shows that the system is working well and their children are generally being cared for very well in school.

There have been a small number of problems, including three needle-stick injuries when staff have re-sheathed pen needles against the instructions in the training protocols. There have been very few occasions when the wrong doses have been given. Only one school has refused to carry out the agreed care, and in this case the parent is happy to go into school for the insulin injections.

See supplementary file: ds1816.pdf

## Lessons and limitations

Our successful strategy for support in schools has been adopted by overcoming a multitude of barriers including finding the right person to talk to in the Local Education Authority. It proved essential to work through a lot of misinformation and fear about insulin injections in young children at school and the project has taken several years, but as results demonstrate improvements in glycaemic control with the use of intensive regimens.

The Health and Safety representative had the role of protecting the school staff from unfamiliar and dangerous activities. This has resulted in very long protocols and management plans which we are now planning to review to shorten.

The Indemnity aspect also took time and many discussions to sort out, including those with the hospital trust's legal department. The risk assessment was very helpful for this.

Unfortunately the School Nurses were not able to take on any extra work and were not helpful in this process. It took some while for us and the PCT to realise this during which valuable time was lost.

1. With more resource and time, Schools PDSN could complete an expanded assessment that would include written input from the parent and teacher on how well the child was managing in school and other suggestions for working with the child.

2. Although quality of life is not usually part of a PDSN or school nurse's health assessment, it could be included as there is some evidence that a supportive school environment improves quality of life. We should have included some audit questions for parent and child experience of the project.

3. The annual updates for the school personnel have proved difficult and we are going to change how we do this, to more centralised training.

Our clinical intervention establishes a safe school environment for diabetes care as a priority and following this other health indicators such as parents' satisfaction and schools confidence of caring for children were improved. This is definitely sustainable given adequate funding in the system for enough nursing time to carry out the training. This is increasingly true as disability legislation catches up and now schools must produce documented evidence on how the needs of pupils with diabetes are being met within school at least every three years and demonstrate that the previous plan was evaluated at least annually. This will definitely help children with diabetes at school.

## Conclusion

It is critically important that diabetes control is optimised during the school day, as improvement of diabetes control is facilitated when all teachers and carers understand diabetes care. Parents need confidence and reassurance that their child is supervised adequately when at school. Educational progress and quality of life are optimised when blood glucose levels are controlled.

We have demonstrated improved glycaemic control over a period during which school staff have been trained to manage the diabetes tasks for primary school aged children in Oxfordshire. This successful programme was achieved through training school volunteers. From 2010 to 2012 with funding from the PCT our PDSNs had trained a total of 342 volunteers who are providing care for 132 children, including performing and supervising blood glucose testing and performing and supervising insulin administration using insulin pens or pumps. The key is that parents, volunteers, school teachers and Diabetes Team all participate to develop an agreed 'Individual Care Plan.'

## References

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## Declaration of interests

Nothing to declare

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