

# Services for children and young people with diabetes in the UK: Past, present and future

Peter Swift

**There have been considerable changes in the provision of services and standards of care for children and young people (CYP) with type 1 diabetes over the past 30 years. Although significant improvements have been made, services are inconsistent and the great majority of CYP with diabetes fail to meet the HbA<sub>1c</sub> target of <58 mmol/mol (<7.5%). Fundamental changes in attitudes and organisation, with the implementation of the best practice tariff in paediatric diabetes, should provide more equal access to quality care, improved transitional care, standardised, accredited education and consistent expert psychological and social support to significantly improve outcomes in CYP with type 1 diabetes.**

Over three decades the author has had the privilege of working alongside many healthcare professionals in the NHS to overcome the immense difficulties and complexities of managing type 1 diabetes in children and young people (CYP). Over the timespan of the author's clinical and managerial involvement he has witnessed enormous changes, not only in the organisation of care but also in the technological biomedical aspects of management. Have these changes improved the quality of clinical care of CYP with diabetes, and have they been sufficient to produce significantly positive outcomes?

## In the beginning

In the 1970s there were only a small number of diabetic clinics for children, and few paediatricians acknowledged or accepted a particular interest in diabetes. Although a few nurses (mostly health visitors) helped to manage CYP with diabetes and had done so in Leicester since the 1950s, there were virtually no recognised paediatric diabetes nurse specialists. The great and late David Baum appointed one of the first paediatric diabetes community nurse

specialists in Oxford in the mid-1970s, and in 1979 he made the first attempt at investigating the provision of services for CYP with diabetes through the British Paediatric Association (BPA; now the Royal College of Paediatrics and Child Health [RCPCH]) and the British Diabetic Association (now Diabetes UK). Unfortunately, the response rate was disappointing (201 replies from 1003 BPA members), but some tentative conclusions could be drawn from this selected sample (unpublished):

- Newly diagnosed CYP with diabetes were managed by on-call general paediatric teams (usually without a written protocol).
- More than 50% of CYP with diabetes were later managed in general paediatric clinics.
- About 60% of paediatricians reported that care of the CYP with diabetes was shared between a doctor, nurse and dietitian.
- Around 20% of doctors admitted their training in diabetes was inadequate.
- Transfer to adult services was usually by letter only, and few districts had "adolescent clinics" in liaison with adult physicians.

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## Article points

1. Although there have been significant improvements in the care of children and young people (CYP) with diabetes over the past 30 years, further service developments are needed to improve glycaemic control, screening for complications, mental and psychosocial support, transitional care and the incidence of long-term complications.
2. Improved outcomes will be achieved by fundamental changes in attitudes, organisation and commitment, resulting in more equal access to quality care and better education of professionals, CYP with diabetes and their parents.
3. The implementation of the best practice tariff in paediatric diabetes should help transform services to achieve positive change.

## Key words

- Best practice tariff
- Complexity of management
- Service development
- Type 1 diabetes

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***“Blood glucose monitoring was only described in 1978 by Walford and colleagues, at about the same time as glycated haemoglobin was beginning to be described in diabetes care (Gonen et al, 1977).”***

At that time, clinical management was basic: insulin was given usually once daily (with an increasing use of twice daily); dietary management was predominantly by carbohydrate restriction (with no constraint on fat intake); and monitoring of control was with urine tests (although 24% said they had established some home blood glucose monitoring). Blood glucose monitoring was only described in 1978 by Walford and colleagues, at about the same time as glycated haemoglobin was beginning to be described in diabetes care (Gonen et al, 1977).

Almost a decade later, in 1988, after prolonged debate and consultation, a Working Party of the BPA distributed the first “official” questionnaire survey of diabetes services to all health boards and districts. This identified 360 consultant paediatricians who were providing care for CYP with diabetes (BPA Working Party, 1990). The major findings were that many children were still being seen in general paediatric clinics, most clinicians did not have a particular interest in diabetes, many clinics did not have nurse specialists or dietitians in attendance and too few clinics regularly measured glycated haemoglobin, urinary protein or blood pressure, or examined the retinae.

The BPA therefore made the following recommendations, which remain relevant today (BPA Working Party, 1990):

- Every district should have at least one paediatrician with special expertise in diabetes.
- Formal training programmes for trainees should be developed.
- Designated diabetic clinics should be organised in every district.
- Districts where there are three or more paediatricians providing care should centralise resources.
- Clinics should have appropriately qualified nurse specialists in attendance.
- Dietitians with expertise in diabetes and paediatrics should be available for clinics.
- Junior staff should not take primary responsibility as continuity of care is of fundamental importance, and there should be more opportunities for professional education in children’s diabetic clinics.
- Careful arrangements should be made for transfer to adult clinics, and more adolescent/young adult clinics should be organised.
- High priority should be given to the educational content of each clinic visit.

- There is a need to improve 24-hour telephone access.
- Ongoing assessment and audit should be part of improved services for CYP with diabetes.

Around the same time, under the aegis of the World Health Organization (WHO) and the International Diabetes Federation (IDF), Europe, the St Vincent Declaration was signed, “recognising the growing and major problem of diabetes in all ages” (WHO and IDF, 1989). Similar sentiments were expressed by the BPA Working Party (1990), agreeing that adults and children should be enabled to: “have sustained improvements in health experiences and life approaching normal expectations in quality and quantity” (see guidelines by the International Society for Paediatric and Adolescent Diabetes, 2000). This would be accomplished by developing appropriately trained specialist teams, as envisaged in the BPA recommendations.

A later pronouncement from the St Vincent organisation clearly stated what many of us have long understood about the implications of diabetes:

*“There is no disease in which the patient can contribute more to the success of management nor one in where there is such a fine line between invalidity and a life of full normality. These considerations emphasise the importance of educational programmes.”*

Thus by 1990, these surveys, declarations and recommendations provided a platform for improving children’s diabetes services.

### **Further service development**

Subsequent UK surveys in 1994, 1998, 2002 and 2008 demonstrated gratifying concentration of expertise in fewer, better staffed clinics. More paediatricians classified themselves as having a special interest in diabetes, and for the first time, in 2005 it was possible to use the *National Diabetes Paediatric Audit Report* (NDPAR) to analyse glycaemic outcomes in relation to the type of clinic (NHS Information Centre, 2005). This analysis showed that general (non-specialist) paediatric clinics had poorer glycaemic control (HbA<sub>1c</sub>, 79 mmol/mol [9.4%]) compared with “specialist” clinics (HbA<sub>1c</sub>, 74 mmol/mol [8.9%]) (Edge et al, 2005).

The fifth UK paediatric diabetes survey in 2008 (Gosden et al, 2010) resulted in a disappointing

response rate of only 63%, but confirmed the continuing, progressive changes in the provision and (apparent) standards of care over 20 years (Table 1).

These highly commendable improvements endorsed the earlier recommendations. However, a commentary paper on the third survey of 2002 (Betts and Swift, 2003) made it clear that survey results might hide important practical details. For instance, although more “nurse specialists” were attending clinics, some were nurses from the wards who had some degree of interest in diabetes and some were trained in adult diabetes care but were attending children’s clinics. Similarly, many of the paediatric dietitians attending clinics had no experience nor received any training in children’s diabetes, and the provision of mental health services was poor. Betts and Swift (2003) emphasised the need for far more extensive and appropriate training in children’s diabetes for consultants, nurses and dietitians. At that time it was the responsibility of primary care trusts and local diabetes specialist advisory groups to ensure that adequate services were available to all CYP with diabetes; however, in many districts children’s diabetes was not being adequately reviewed and continued to play a minor role compared with other areas, such as cystic fibrosis, oncology and neonatal services.

Gosden et al (2010) exposed significant problems in the 2008 survey: consultants and nurses were still inadequately trained (sometimes with no formal training before taking up posts in children’s diabetes clinics); 9% of children were still being seen in general paediatric clinics; there was only poorly structured *ad hoc* education of parents; and 56% of teams were unable to offer 24-hour advice. Many of these training deficiencies were confirmed by later surveys through the “SWEET EU” programme (Waldron et al, 2011), where new paediatric diabetes consultant posts were still being awarded to applicants with no practical experience in children’s diabetes.

However, a number of consultants and their teams were exploring better ways of managing childhood diabetes. In the UK, eight randomised controlled trials (RCTs) have been designed to examine specific education interventions: DEPICTED (motivational interviewing); FACTS (family communication); CHOICE (carbohydrate counting/insulin adjustment); CASCADE (solution-focused therapy); DECIDE

(inpatient versus outpatient stabilisation); KICK-OFF (carbohydrate counting/insulin adjustment); SCIFI (pump versus multiple daily injections); EPIC (age and maturity information packs). These RCTs will provide valuable information but they are not service redesign models so cannot provide all the solutions to the problems within our current service provision (see page 38 for an overview of this research).

### Glycaemic outcomes in perspective

By 2008, the sixth annual NDPAR (NHS Information Centre, 2010) was still unable to capture reports from more than 50% of clinics. Additionally, it revealed a mean HbA<sub>1c</sub> of 70 mmol/mol (8.6%), with only 16% children under the target of 58 mmol/mol (7.5%) and a staggering 9% of CYP with HbA<sub>1c</sub> >102 mmol/mol (11.5%).

Although these audit results were not surprising, they were particularly disappointing because it had become clear that HbA<sub>1c</sub> was the crucial quality indicator of success in diabetes services. HbA<sub>1c</sub> is the only tested biochemical outcome marker that reflects long-term prognosis in type 1 diabetes. Many publications have described concerns about poor glycaemic outcomes and the huge variability between different centres, both within countries (Scottish Study Group for the Care of the Young Diabetic, 2001) and between countries (de Beaufort et al for the Hvidoere Study Group on Childhood Diabetes, 2007). In the first Hvidoere Study in

#### Box 1. Changes in diabetes care for children and young people over the past 20 years (Gosden et al, 2010).

- Number of paediatricians caring for children and young people with diabetes (1988, 360; 2008, 196)
- Paediatricians with special interest (1988, 32%; 2008, 98%)
- Designated paediatric diabetes clinics (1988, 63%; 2008, 91%)
- Clinics with <40 patients (1988, 77%; 2008, 1%)
- Clinics with paediatric diabetic nurse specialists in attendance (1988, 61%; 2008, 94%)
- Clinics with paediatric dietitian in attendance (1988, 37%; 2008, 93%)
- HbA<sub>1c</sub> not regularly measured (1988, 9%)
- HbA<sub>1c</sub> not available in clinic (2008, 25%)

### Page points

1. The overall Hvidoere mean HbA<sub>1c</sub> has not shown a significant improvement, and indeed only one clinic has published details of how it has been able to significantly improve its HbA<sub>1c</sub> by a fundamental reorganisation of care, intensifying multidisciplinary support and directing resources towards education of professionals, parents and children (Dyrlov et al, 2000).
2. This poor set of results has also been highlighted in another NHS assessment of outcomes, the *Atlas of Variation in Healthcare for Children and Young People* (Department of Health, 2012a), which illustrates the enormous variation in outcomes across the country.
3. Although such variation occurs in all diseases and all conditions and is sometimes reflected in the variable amount of expenditure on child health, this situation must be viewed as totally unacceptable for diabetes in the NHS.

1995, all three UK centres had poor HbA<sub>1c</sub> results (Mortensen and Hougaard, 1997; Swift, 2004). Subsequent studies confirmed the wide differences in results between centres, ranging from the best centre with a mean HbA<sub>1c</sub> of 57 mol/mol (7.4%) to the worst with a mean HbA<sub>1c</sub> of 77 mol/mol (9.2%) (de Beaufort et al, 2007). Over 15 years, some clinics have maintained their excellent results while others have remained below average. The overall Hvidoere mean HbA<sub>1c</sub> has not shown a significant improvement, and indeed only one clinic has published details of how it has been able to significantly improve its HbA<sub>1c</sub> by a fundamental reorganisation of care, intensifying multidisciplinary support and directing resources towards education of professionals, parents and children (Dyrlov et al, 2000).

Other European studies, such as in Denmark (Svensson et al, 2009), Norway (Margeisdottir et al, 2010), Germany and Sweden (Hanberger et al, 2008), have reported important national improvements in their glycaemic outcomes, and clinics in the USA and Poland are producing enviable results (Rosenbauer et al, 2012). These often appear to be associated with a far greater emphasis on more organised, comprehensive care in hospitals and in clinics, with attention given to more intensive and consistent training of healthcare professionals. In both Denmark and Norway the introduction of a national register with annual structured audit of results seems to have activated a quest for better results.

The most exemplary improvements in outcomes have been reported by the DPV (Diabetes-Patienten-Verlaufsdaten) Initiative; over 14 years, prospective data have been collected from 305 clinics in Germany and Austria, representing up to 30 708 CYP with diabetes (Rosenbauer et al, 2012). Overall, the HbA<sub>1c</sub> in children and adolescents has decreased, from 69 mmol/mol (8.5%; 1995–97) to 60 mmol/mol (7.6%; 2001–05); the proportion of CYP with HbA<sub>1c</sub> >75 mmol/mol (9%) has declined from 40% to 16%, and the proportion of CYP with HbA<sub>1c</sub> <58 mmol/mol (7.5%) has increased from 25% to 45%. At the same time the incidence of hypoglycaemia has also decreased (Gerstl et al, 2008). These major improvements could not be statistically related to the many changes in insulin regimens, but were more likely associated with “improvements in resources, organisation

and attitudes of diabetes care teams and patient education” (Rosenbauer et al, 2012).

In contrast to these results, although our most recent NDPAR for 2009–2010 has shown a 25% increase in clinics registered (NHS Information Centre, 2011), there has been no improvement in glycaemic outcome over 7 years: only 14.5% of CYP have an HbA<sub>1c</sub> <58 mmol/mol (7.5%) and 30% have an HbA<sub>1c</sub> >80 mmol/mol (9.5%); most clinic reports were paper based (not electronic); and 10% had no record of an HbA<sub>1c</sub> measurement in the past year. Some clinics reported fewer than 2% of patients had an HbA<sub>1c</sub> <58 mmol/mol (7.5%), whereas other clinics reported 37% of patients had attained target levels; some clinics reported no patients with multiple episodes of diabetic ketoacidosis, whereas other clinics reported the figure was higher than 30%. In the foreword to the report, the academic sponsors commented that: “shockingly, 96% of children and young people may not have received all of the key processes recommended by NICE [the National Institute for Health and Clinical Excellence]”. This poor set of results has also been highlighted in another NHS assessment of outcomes, the *Atlas of Variation in Healthcare for Children and Young People* (Department of Health, 2012a), which illustrates the enormous variation in outcomes across the country. It shows that the percentage of children not achieving an HbA<sub>1c</sub> <86 mmol/mol (10%) varies across districts from 0–58%, with a huge variation in the incidence of diabetic ketoacidosis. Although such variation occurs in all diseases and all conditions and is sometimes reflected in the variable amount of expenditure on child health, this situation must be viewed as totally unacceptable for diabetes in the NHS.

### Why have our results been so disappointing?

Although there have been revolutionary changes that have occurred over three decades in diabetes management and evolutionary shifts in the provision of services in the UK, the outcomes in terms of glycaemic control, screening for complications, mental health and psychosocial support, transitional care and by inference the incidence of long-term complications have not significantly improved. Why has the UK lagged so far behind many other countries, and is it possible to change this situation?

An important factor is that society as a whole has not acknowledged the seriousness of the disease, perhaps because children with diabetes generally look healthy and show no overt complications for many years. Diabetes can also be viewed rather negatively, because it is often confused with type 2 diabetes, which is linked to poor lifestyle and obesity. Even within paediatric endocrinology, diabetes was not given significant focus for many years, and treatment continued to be provided by general paediatricians with no paediatric diabetes specialist nurse support.

In the author's view, these approaches have undoubtedly had a huge impact on the attitudes of NHS managers, which are prevalent today, that diabetes is not of any special consequence and resources should not be different from those for general paediatrics. Furthermore, diabetes nurses are potentially seen as less important, non-acute nurses who can readily be moved back into the wards at times of understaffing.

These attitudes have undermined the fact that diabetes is a life-threatening disease with significant physical and emotional consequences; its modern management is exceedingly complex and difficult, with potentially seriously disabling long-term complications.

### The way forward

An important advance in the care of CYP with diabetes in the UK is that the Department of Health has accepted the best practice tariff (BPT) in paediatric diabetes (Department of Health, 2012b), which if implemented appropriately should help to transform services in highly positive ways. In association with the BPT the author suggests that the increased financial allocation is used in the following ways:

- Resources are ring-fenced for the sole purpose of improving local paediatric diabetes services in a smaller number of Designated Centres for Children's Diabetes (DCCD). These would become true centres of excellence. Real service design improvements will not be made unless diabetes expertise is concentrated in the larger paediatric units with fully staffed, fully trained, full-time multidisciplinary diabetes teams totally committed to consistent, standardised, accredited diabetes training, education and care. Children from surrounding districts should be referred to the DCCD for initial management, ongoing education and supervised continuing care.

- The smaller hospital units should not have primary responsibility for diabetes; their units should have diabetes nurses or educators to attend clinics and provide community continuity and should attend clinics run by the outreach teams from the DCCD.
- The DCCD should have ultimate responsibility for both inpatient and outpatient services for a specified population (perhaps at least 0.5 million), and should organise regular mandatory educational programmes for individual patients and groups. To reduce variation in standards, there should be a standardised approach to both professional and patient education and training across the country.
- Nationally there should be a more formalised agreed approach to the problem of transition from paediatric services to young adult services. Staff from both services should work together for a period of time during the transition.
- In the case of individual poor glycaemic control (e.g. an  $HbA_{1c} >75$  mmol/mol [9%]), the child and parents should be referred for further periods of intensive re-education and greater psychological and social investigation and support to help motivate them towards improved control.

### DCCD criteria

The ultimate justification for being a DCCD is:

- To have a fully trained and experienced interdisciplinary team (experience must be gained by supervised contact before taking primary responsibilities).
  - To have available standardised, comprehensive, accredited, structured educational materials.
  - To provide 24-hour access to expert advice (perhaps in cooperation with geographically adjacent colleagues).
  - To have readily available help from mental health experts.
  - To have appointed an administrative officer to type correspondence, to manage a patient database and to keep electronic national audit data up to date.
  - Specifically for the centre to demonstrate year-on-year improvements in glycaemic control, working towards a target median  $HbA_{1c}$  of  $<64$  mmol/mol (8%), with greater than 30% of CYP in the clinic having an  $HbA_{1c} <58$  mmol/mol (7.5%) and fewer than 20% having an  $HbA_{1c} >75$  mmol/mol (9%).
- Such stringent criteria for becoming a DCCD would need to be monitored by some form of peer

### Page points

1. Within paediatric endocrinology diabetes was not given a significant focus for many years, and was treated by general paediatricians with no paediatric diabetes specialist nurse support.
2. Attitudes have undermined the fact that diabetes is a serious, life-threatening disease with physical and emotional consequences; its modern management is exceedingly complex and difficult, with potential long-term complications.
3. An important advance in the care of children and young people with diabetes in the UK is that the Department of Health has accepted the best practice tariff, which if implemented appropriately should help to transform services in highly positive ways.



**“Only fundamental changes in attitudes, organisation and commitment in the UK leading to major service redesign based on more equal access to quality care, availability of a standardised, accredited educational model and consistent expert psychological and social support will significantly improve outcomes in CYP with diabetes.”**

**Tabitha Randell gives her views on “Developing a best practice tariff in paediatric diabetes: Can we improve services and outcomes for children and young people with diabetes in England?”, pages 23–6.**

review (which may have already been instituted in some areas). Perhaps an inspectorate would be appropriate (possibly overseen by the RCPCH). The whole system would be subject to comparative review by regional, national and international networks.

These proposals are certain to be controversial, especially for those working in smaller units, but it follows the pattern of care for other specialties such as cystic fibrosis, oncology and neonatology.

### Conclusion

Evidence has been provided to illustrate the considerable evolutionary changes that have occurred in the provision of services for children with diabetes over the past three decades. These changes have occurred at a rather slow pace and there is little evidence that the changes have resulted in better outcomes.

Over the past 10 years the pace of change in the management of type 1 diabetes in children has quickened and has become far more complex and more demanding. Its modern management requires far greater professional experience, expertise and organisational commitment to improve the education and motivation of parents and CYP in order to improve glycaemic control. Better glycaemic control will delay and even prevent the devastating long-term vascular complications and premature mortality. However, concentrating excessively on the pharmacotechnological aspects of diabetes to the exclusion of a more holistic approach, dealing with psychological and social well-being, team cohesion and goal setting, will not produce the required results (Skinner and Cameron, 2010).

Only fundamental changes in attitudes, organisation and commitment in the UK leading to major service redesign based on more equal access to quality care, availability of a standardised, accredited educational model and consistent expert psychological and social support will significantly improve outcomes in CYP with diabetes. ■

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