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 HbA1c 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.

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(201 replies from 1003 BPA members), but some tentative conclusions could be drawn from this selected sample (unpublished):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.
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 which 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 (HbA₁c, 79 mmol/mol [9.4%]) compared with “specialist” clinics (HbA₁c, 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; 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); SCIP (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 \( \text{HbA}_1c \) 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 \( \text{HbA}_1c >102 \) mmol/mol (11.5%).

Although these audit results were not surprising, they were particularly disappointing because it had become clear that \( \text{HbA}_1c \) was the crucial quality indicator of success in diabetes services. \( \text{HbA}_1c \) 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

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

Page points
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significant improvement, 
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significantly improve its 
HbA1c by a fundamental 
reorganisation of care, 
intensifying multidisciplinary 
support and directing 
resources towards education 
of professionals, parents and 
children (Dyrvold 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 HbA1c 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 HbA1c of 57 mmol/mol (7.4%) to 
the worst with a mean HbA1c of 77 mmol/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 HbA1c has not shown a 
significant improvement, and indeed only 
one clinic has published details of how it has 
been able to significantly improve its HbA1c by a 
fundamental reorganisation of care, intensifying 
multidisciplinary support and directing resources 
towards education of professionals, parents and 
children (Dyrvold et al, 2000).

Other European studies, such as in Denmark 
(Svensson et al, 2009), Norway (Margeirsdottir 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, 
perspective 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 HbA1c 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 HbA1c >75 mmol/mol (9%) has declined 
from 40% to 16%, and the proportion of CYP 
with HbA1c <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 HbA1c <58 mmol/mol (7.5%) and 30% have 
an HbA1c >80 mmol/mol (9.5%); most clinic reports 
were paper based (not electronic); and 10% had no 
record of an HbA1c measurement in the past year. 
Some clinics reported fewer than 2% of patients 
than had an HbA1c <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 HbA1c <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 diabetes care (Department of Health, 2012b), which if has accepted the best practice tariff (BPT) in paediatric diabetes in the UK is that the Department of Health.

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. In association with the BPT the author suggests that the increased financial allocation is used in the following ways:

- 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 HbA1c >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 HbA1c of <64 mmol/mol (8%), with greater than 30% of CYP in the clinic having an HbA1c <58 mmol/mol (7.5%) and fewer than 20% having an HbA1c >75 mmol/mol (9%). Such stringent criteria for becoming a DCCD would need to be monitored by some form of peer...
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 neurology.

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 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.”


