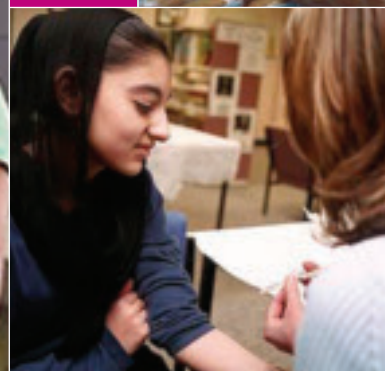
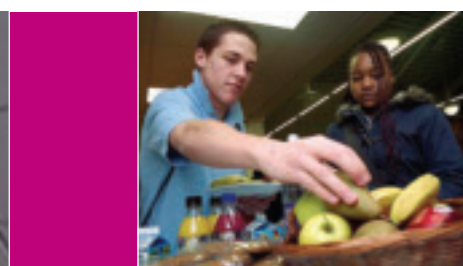


Making Every Young Person with Diabetes Matter



Report of the Children and Young People with Diabetes Working Group

DH INFORMATION READER BOX

Policy HR/Workforce Management Planning Clinical	Estates Performance IM & T Finance Partnership Working
Document purpose	Best Practice Guidance
Gateway reference	7755
Title	Making Every Young Person with Diabetes Matter: Report of the Children and Young People with Diabetes Working Group
Author	DH Diabetes Policy Team
Publication date	April 2007
Target audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, PCT PEC Chairs, NHS Trust Board Chairs, Special HA CEs, Allied Health Professionals, GPs, Directors of Children's Services, Diabetes UK, Royal College of Nursing, Healthcare Commission, British Diabetic Association.
Circulation list	Directors of HR, Directors of Finance, Communications Leads, Emergency Care Leads, Voluntary Organisations/NDPBs
Description	Report of the findings of the working group set up in 2005. The report sets out the current problems, provides guidance and makes recommendations in a number of areas including commissioning, organisation of care, provision of services and workforce.
Cross reference	Diabetes commissioning toolkit
Superseded documents	n/a
Action required	n/a
Timing	n/a
Contact details	Dawn Jones Diabetes Policy Team Room 408 Department of Health Wellington House London SE1 8UG 0207 972 4887
For recipient's use	



Content

Foreword	1
Executive summary	2
Introduction	4
1. Why prioritise children and young people with diabetes?	7
2. Policy context	13
3. Commissioning services for children and young people with diabetes	19
4. Provision of services and organisation of care	24
5. Workforce planning and development	28
6. Audit	32
7. Information and information technology	34
8. Research and development	36
Annex 1: Further guidance for commissioners of services for children and young people with diabetes	
Introduction	38
Health and healthcare needs assessment	39
Generic specification for diabetes care for children and young people: best practice model	40
Primary prevention of Type 2 diabetes in children and young people	43
Diagnosis and initial management	44
Continuing care	45
Other forms of childhood diabetes, including Type 2	47
Annual assessment of the continuing care plan and monitoring for complications	48
Management of complications	49
Structured diabetes education	50
Mental health and emotional well-being: psychological input	51
Support of child and family	52
Early years and school settings	53
Promoting good health and healthier choices	56
Sexual health and pregnancy	57
Transition	58
Benefits	59



Annex 2: The Department of Health's Children and Young People with Diabetes Working Group: Terms of reference	60
Annex 3: Membership of the working group	62
Annex 4: References	65



Foreword



There has been a significant increase in the number of children and young people diagnosed with Type 1, Type 2 and other variants of diabetes. The challenges that this poses both for this country and the rest of the world are becoming clearer day by day.

Caring for children and young people with diabetes is fundamentally different from providing services for adults. It is a complex process that must be focused firmly on the child or young person and their family and/or other carers, supported by the skills and experiences of a wide range of healthcare professionals. The key to achieving good outcomes is to support, engage and empower the individual child or young person with diabetes and their family within a proactive, organised system that results in positive interactions and outcomes.

Service provision has improved in the United Kingdom but some would argue that, despite considerable contributions from individual professionals, it still lags behind much of Europe. Current diabetes care does not always meet the needs of children and young people and there can be wide variations in care delivery and outcomes. These arise not because of a lack of effort, knowledge or even necessarily resources, but because shortcomings exist in the way that care is organised. This calls for a major change in the way services for children and young people are delivered.

This report sets out the findings of a working group established to examine the current challenges and seek solutions to them. It provides guidance and makes recommendations in a number of areas, including commissioning, organisation of care, provision of services and workforce.

We would like to thank the members of the Children and Young People with Diabetes Working Group for developing the guidance contained in this report. It will help diabetes teams to offer a co-ordinated service that supports children and young people in managing their diabetes, enabling them to experience the best possible quality of life.

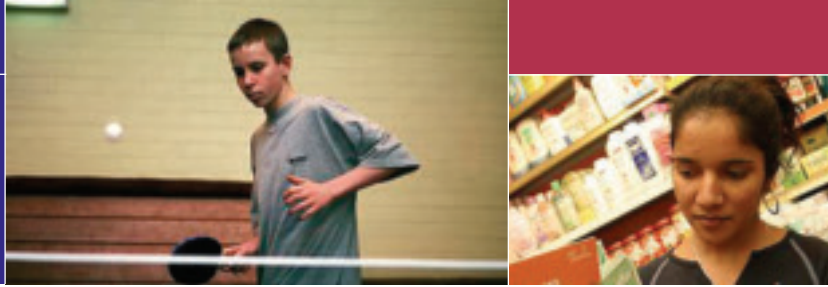
Rt Hon Rosie Winterton MP
Minister of State for
Health Services

Ivan Lewis MP
Parliamentary Under Secretary
of State for Care Services



Executive summary

- 1 The prevalence of Type 1, Type 2 and other forms of diabetes amongst children and young people is increasing.
- 2 The management of diabetes in children and young people is significantly different and more complex than it is for adults.
- 3 Improved management and control of diabetes in children and young people can reduce the incidence and delay the impact of associated microvascular and other long-term complications. It also has shorter-term benefits, including improved academic performance and school attendance, reduced hospital admissions and greater satisfaction with services.
- 4 Cost-effective interventions exist that improve the outcomes for children and young people whilst reducing long-term expenditure.
- 5 Current provision of care for children and young people is variable and does not always meet national standards. The experience of service users is not always positive.
- 6 Current policy for the treatment and welfare of children and young people is wide-ranging and thorough.
- 7 Commissioners and providers of diabetes services will need to have a good understanding of the needs of children and young people.
- 8 Services will need to be designed in response to local needs assessments, in partnership with children and young people, ensuring that they can meet the specific needs of the local population. In every case, however, services should:
 - be developed and delivered in a co-ordinated and integrated way that is focused on the needs of children and young people;
 - meet the *You're Welcome* quality criteria,¹ which help services to be young people friendly;



- offer children and young people a range of options that support self-management, informed choice and individual preferences, and where possible are close to home and based in the community;
- cater fully for those people who cannot access services in line with the locally agreed standard model of care, such as children in care, those in detention, refugees and asylum seekers;
- encourage full participation in school by offering provision outside working hours, and allow 24-hour access to emergency advice from competent staff;
- ensure that transition between young people's and adults' services is negotiated and explicitly planned around the assessed needs of each young person;
- demonstrate that staff have the competences needed to deliver each function;
- have agreed local standards for key outcomes such as timeliness, continuity of care, early years and school settings, monitoring for complications and structured education provision; and
- be quality assured and have arrangements in place for local audit, benchmarking against national standards including the patient experience.



Introduction

Diabetes takes a severe toll on those who develop it. Life expectancy is reduced, on average, by 23 years in people with Type 1 and by up to 10 years in people with Type 2 diabetes. Mortality rates from coronary heart disease are up to five times higher; diabetes is the leading cause of renal failure; the second most common cause of lower limb amputation; and the leading cause of blindness in people of working age. Women with diabetes have reduced fertility and face additional risks during pregnancy, at birth and to the baby.

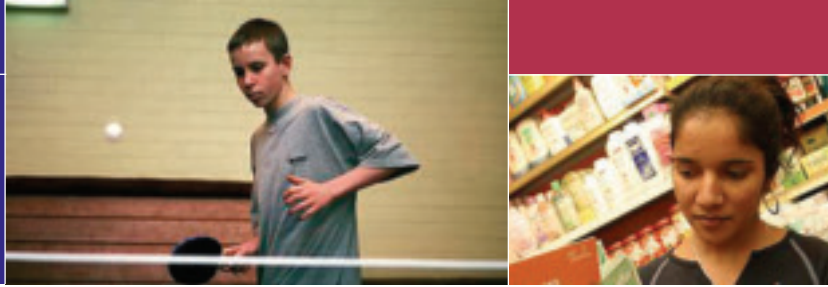
Much of the attention has focused on the explosive growth of Type 2 diabetes and its associated lifestyle factors in adults. However, there is a significant increase in the number of children and young people diagnosed with all types of diabetes. In the UK we have the both the highest number of children diagnosed with diabetes in Europe and the lowest number of children attaining good diabetes control. This is in marked contrast to children with cancer, where mortality and morbidity rates have improved steadily over the last few years.

There are particular concerns relating to the care of young people with Type 1 diabetes. Some 30 to 40 per cent will develop microalbuminuria, leakage of small amounts of a protein, albumin, into the urine, which is an early warning of kidney damage. Twenty-five per cent or more may require laser treatment for retinopathy, a disease of the back of the eye.²

Diabetes can affect children and young people's mental health and emotional well-being. Day-to-day management of food, insulin, physical activity and mood can affect a wide range of their activities and development. These include school attendance and full involvement in extra-curricular activities such as trips and sports. There can also be consequences for social and family life.

Healthcare professionals alone cannot manage diabetes; the challenge is to provide the environment in which diabetes can be jointly managed, promoting self-care and empowerment. The day-to-day experiences of children and young people as well as their families and carers, along with the results of a series of national audits, confirm that current diabetes care does not always meet the needs of children and young people.

Introduction



Consideration must be given to the physical and emotional needs of the developing and growing individual along with the social impact on family, friends, early years and school. Risk-taking behaviour amongst young people is a normal activity, but it can have serious consequences for those diagnosed with diabetes. Unplanned pregnancies for people with diabetes, for instance, are much more likely to result in adverse health outcomes than in the non-diabetic population. A key component of effective care management is establishing and maintaining motivation amongst young people and their families or carers, enabling them to handle the complex juggling act required to effectively manage their condition.

Although the challenges are considerable, many children and young people with diabetes achieve great things in all spheres of life. When faced with a diagnosis of diabetes at a young age, the future may look bleak. The stories of people like Gary Blakie, however, are there to inspire, motivate and show what can be done in everyday life as well as in the sporting arena. Diagnosed with Type 1 at age 12 and now, at 21, representing the UK in international triathlon championships, Gary shows that diabetes need not be a barrier to success and achievement. His and many other stories of significant achievement can be seen at the website [Runsweet – www.runsweet.com/4554.html](http://www.runsweet.com/4554.html) – which is dedicated to showing that diabetes is no barrier to participating and succeeding in sport.

The Children and Young People with Diabetes Working Group was set up in October 2005. The group was set up by the Department of Health and involved a wide range of stakeholders, including Diabetes UK, healthcare professionals, policy makers, purchasers and users of care. The group, chaired by Professor Peter Hindmarsh, was sponsored by both Dr Sheila Shribman, National Clinical Director for Children, Young People and Maternity Services and Dr Sue Roberts, National Clinical Director for Diabetes.

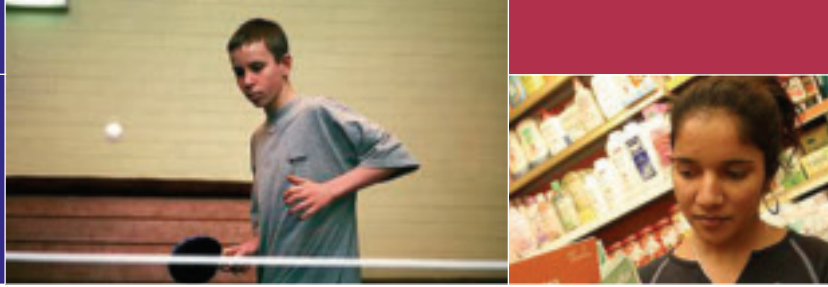
The aim of the working group was to identify what needs to be done to improve care for children and young people with diabetes and to ensure that standards are met. The group debated different options and interventions, and took on board the views of children and young people and their families and carers.

This document is a report from the working group, examining areas for improvement and clarifying standards that need to be met. The report makes suggestions for key outcomes to support quality commissioning and provision.



Audience for and aim of this report

This report is aimed at everyone who has a part to play in improving services for children and young people with diabetes up to age 25. This will include commissioners and healthcare professionals. It provides guidance on a number of areas, including commissioning, organisation and provision of services and workforce.



Section 1: Why prioritise children and young people with diabetes?

Prevalence

The number of people with diabetes of all types is predicted to increase rapidly over the coming years. Type 1 diabetes mellitus is increasing in all age groups but particularly in under-five-year-olds.³ The current estimate of prevalence in the UK is one per 700–1,000 children, yielding a total population with Type 1 diabetes aged under 25 years in the UK of approximately 25,000. Local authorities and primary care trusts (PCTs) might expect between 100 and 150 children with diabetes to live in their area. The peak age for diagnosis is between 10 and 14 years of age.

Type 2 diabetes is also on the increase,^{4,5} probably due to the increased proportion of obese children in the population. Prevalence data are scarce but figures as high as 1,400 cases in the UK have been suggested.⁶ This increase is not evenly spread amongst the population and predominantly reflects the positive correlation between deprivation and diabetes.⁷ Certain communities, such as those of people of South Asian origin, have a higher risk of developing Type 2 diabetes but, and may not have appropriate access to, or effective use of and engagement with, health services. This exacerbates the challenge of providing good care.

Other, rarer, forms include maturity onset diabetes of the young (MODY); its estimated prevalence is 1 to 2 per cent of all diabetes cases in the UK. More children who develop diabetes as secondary to surviving treatment for other conditions, including cystic fibrosis, cancer chemotherapy and thalassaemia, are now being cared for by specialist diabetes teams.

Intervention effectiveness

There is no doubt that improved diabetes control from diagnosis can reduce the incidence of microvascular complications and delay their progression. The Diabetes Control and Complications Trial (DCCT)⁸ demonstrated that any sustained lowering of blood glucose helps, even if the person already has complications. The DCCT also showed that once microvascular complications develop, they can progress very rapidly and other interventions, for example antihypertensive therapy, may be more



beneficial. The Epidemiology of Diabetes Interventions and Complications (EDIC)⁹ study supported the implementation of intensive therapy, as a period of good metabolic control has a delayed protective effect that extends into subsequent years. Establishing good control in childhood and young adulthood is therefore critically important.

Research has shown that when Type 1 diabetes is effectively controlled, it can reduce the risks of developing complications as follows:

- new eye disease by 76 per cent;
- worsening of existing eye disease by 54 per cent;
- early kidney disease by 54 per cent;
- more serious kidney disease problems by 39 per cent; and
- nerve damage by 60 per cent.

Macrovascular disease, such as heart attack and stroke, may not affect children with diabetes in childhood, but is very likely in adulthood because of the length of time children live with their diabetes. Effective preventative education and motivation about diet, activity, smoking and weight management should be provided. Early identification and treatment of cardiovascular disease in young adults with diabetes is essential.¹⁰

The second Wanless Report¹¹ stated that, based on the best available evidence, the interventions known to be cost effective using a £20,000 cost per quality adjusted life year (QALY) threshold are:

- tight control of blood glucose and blood pressure for all with diabetes;
- ACE (angiotensin converting enzyme) inhibitors for those with diabetes with one other risk factor not otherwise quantified (for example, for tight control of blood pressure) and multiple risk factor management;
- retinopathy screening for all with diabetes and foot screening for those at high risk; and
- self-care, including patient education.

Section 1: Why prioritise children and young people with diabetes?



One estimate suggests¹² that the cost of blood glucose control per event-free life year gained is around £1,200. DCCT researchers estimate that intensive management doubles the cost of managing diabetes because of increased healthcare professional contacts and the need for more frequent blood testing. However, this cost is offset by the reduction in medical expenses related to long-term complications and by the improved quality of life of people with diabetes. Over a lifetime, DCCT-defined intensive therapy reduces complications, improves quality of life, and can be expected to increase length of life. From a healthcare system perspective, intensive therapy is well within the range of cost-effectiveness considered to represent good value.¹³

Current provision

Service provision has improved in the United Kingdom, but some would argue that it still lags behind the provision available in much of Europe,¹⁴ and includes wide variation in care delivery and outcomes. Not all effective interventions that improve outcomes for children are offered in all areas. In their 2002 survey, Edge et al.¹⁵ found that some participating units (11 per cent) did not have a consultant with a specialist interest in diabetes and 6 per cent were caring for fewer than 40 young people.

The Diabetes UK report, *Your Local Care 2005 – a survey of diabetes services*,¹⁶ found that provision of services in England by PCTs for children and young people was stretched, with an average case load of more than 100 children for every paediatric diabetes specialist nurse (for many existing models of care the Royal College of Nursing (RCN)¹⁷ recommends a maximum ratio of 70 patients per whole-time paediatric diabetes nurse). Despite evidence that 85 per cent of children are not achieving recommended blood glucose concentrations, *Your Local Care* found that only a quarter of PCTs had made improving paediatric diabetes care a priority in their local plans. Half did not have adequate systems for transferring young people to adult care.

In 2006, DiabetesE¹⁸ reported that not all children and young people are able to access specialist advice; only 87 per cent had access to a specialist nurse, 75 per cent to a dietitian, and 48 per cent to a paediatric psychologist/counsellor. It also noted that only 54 per cent of PCTs have management guidelines for children and young people with diabetes, 53 per cent of paediatric specialist teams do not have guidelines for optimising glycaemic control, and 34 per cent of PCTs do not require that all over-12s with diabetes have annual retinal screening.



National Diabetes Audit (NDA) (2004/05)¹⁹ data showed only 19 per cent of 12–15-year-olds with diabetes received eye examinations as recommended by the National Institute for Health and Clinical Excellence (NICE) in the audit year.

Service user experiences and outcomes

A consultation to assess care across the UK in 2005, reported by Diabetes UK in partnership with the All-Party Parliamentary Group for Diabetes and the Hansard Society,²⁰ identified areas for improvement. Although the consultation covered all diabetes services, many comments related to the care that children and young people receive, confirming that there is considerable variation in the standards of service and support across all services that children, young people and parents come into contact with. Comments included:

“There is so much to take in and so little support. There is NO psychological support, and there are NO formal education programmes beyond that provided by the diabetic nurse. I often feel we are at sea, learning about diabetes very much in isolation and when things go wrong we have only our local nurse to turn to. This is not fair on her, not fair on us and certainly not fair on our kids.”

“My daughter is now 14 and has had diabetes for five years. At first she was well controlled and seemed to accept her condition. Now we have times when she refuses to inject, gets angry with everybody and blames us for her condition. In clinic all they seem interested in is getting her A1c down to an acceptable level. When I mention how she feels they just say, ‘Let’s get the A1c down first and we’ll discuss this next time.’ Maybe if they looked at the psychological effect on a teenager it would help with her A1c count.”

“My five-year-old son was diagnosed with Type 1 in June 2005. The care we have received has been superb. Now that I am familiar with the NSF [National Service Framework] and the NICE guidelines I realise how hard our diabetes team work to achieve everything required. They strive to provide excellent inpatient care with a structured programme of visits from the paediatric diabetes specialist nurse, consultant and dietitian. Outpatient clinics every quarter, telephone and on-line support ... support groups etc.”

Section 1: Why prioritise children and young people with diabetes?



“When I go to clinic it doesn’t feel like my consultant really does anything to help me emotionally. The diabetic nurses only ring me once a year. I just wish they’d give us as teenagers more information on what to do when you’re going out, drinking alcohol etc, because it is so hard to deal with it. There’s so many other things to deal with I just sometimes get so sick of it. I sometimes just stop taking my injections, but then I feel really ill. Obviously I know there’s nothing I can do about it but I just wish they’d give me more support because people underestimate how hard it is to deal with diabetes.”

“My daughter has been Type 1 for the last two years; she is now in Year 6 and we are lucky that we have a good school. My daughter’s friends can take her blood level if needed (her hands shake) and one teacher can do her injection if she can’t. When she went back to school her teacher had been to the library and got a book for himself and the classmates to read. She has been on a school trip for a week, with ... good control all week. She has been encouraged to take part in all sports and is in many teams. She can test her blood in the classroom ... Office staff check she has recorded her levels, and the dinner ladies make sure she picks the healthy options.”

The Diabetes UK National Paediatric Diabetes Audit (2002)²¹ concluded that “care currently does not meet nationally agreed standards and this will continue to cause health problems for children with diabetes now and in the future. Children experience both blood glucose levels that are too low which impairs their development and too high which can lead to long-term complications if not addressed ... it appears that only one in seven to one in five of children, depending on age group, are meeting the recommended HbA1c level of below 7.5 per cent ... Further action is needed to prioritise and improve standards of care for children and young people with diabetes to meet national frameworks for diabetes and children and provide the standards of care that children and their parents expect.”

Given this lack of service provision and planning, it is unsurprising that the outcomes and experiences of young adults with diabetes are so variable.



Commissioners and providers will need to determine how they should prioritise diabetes care for children and young people with diabetes based on their local strategic needs assessment. This is further described in Section 3, suggesting the use of outcomes data, service user and stakeholder views, as well as other sources of information, to benchmark existing services.



Section 2: Policy context

National policy has increasingly recognised the importance of services aimed at children and children's health, culminating in the Children Act 2004. Professionals caring for children and young people with diabetes will be aware of the large amount of policy relating to their work that complements the cross-government Every Child Matters programme. All 12 standards in the *National Service Framework for Diabetes* (2001)²² relate to children and young people, as do all 11 standards set out in the *National Service Framework for Children, Young People and Maternity Services* (2004).²³ NICE has published comprehensive clinical guidelines: *Diagnosis and management of Type 1 diabetes in children, young people and adults* (2004).²⁴

Every Child Matters

Every Child Matters (2003)²⁵ and *Every Child Matters: next steps* (2004) paved the way for the Children Act 2004. This provides the legislative spine for developing more effective, integrated and accessible services that are focused around the needs of children and young people and their families. The Government's aim is for every child, whatever their background or their circumstances, to have the support they need to:

- be healthy;
- stay safe;
- enjoy and achieve;
- make a positive contribution; and
- achieve economic well-being.

These five outcomes for every child and young person mean maximising opportunity and minimising risk for every child, and narrowing the gap between disadvantaged children and their peers by enhancing opportunity for all. The *Every Child Matters Outcomes Framework*²⁶ charts the five associated aims for each outcome, plus key targets, and inspection evidence and judgements.



Our health, our care, our say: a new direction for community services

The Department of Health's commitment to children's services was reiterated through the 2006 White Paper, *Our health, our care, our say: a new direction for community services*.²⁷ It echoes the principles of the Every Child Matters vision by setting out a new direction for social care and community health services with four main goals:

- better prevention and early intervention for improved health, independence and well-being;
- more choice and a stronger voice for individuals and communities;
- tackling inequalities and improving access to services; and
- more support for people with long-term needs.

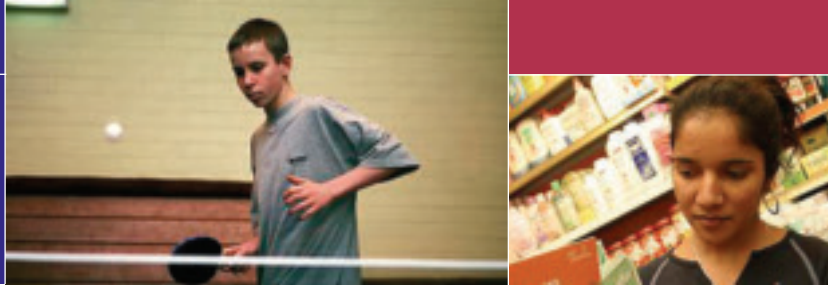
National Service Frameworks (NSFs), Department of Health

The *NSF for Children, Young People and Maternity Services*²³ set out a 10-year programme from 2004 to stimulate long-term and sustained improvement in children's health and well-being. It forms part of the health and social care developmental standards for children and young people's services, which are to be delivered by 2014. Standard 8 sets out an expectation that:

"Children and young people who are disabled or who have complex health needs, receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives."

Key to delivery of this standard will be the effective integrated working envisaged throughout the NSF to facilitate optimum use of practitioner time; prevention and earlier identification of problems; and more focused targeting of specialist services for children who need them.

Section 2: Policy context



Although all of the standards in the diabetes NSF²² relate to children and young people with diabetes, standards 5 and 6 make specific reference to their clinical care:

“All children and young people with diabetes will receive consistently high-quality care and they, with their families and others involved in their day-to-day care, will be supported to optimise control of their blood glucose and their physical, psychological, intellectual, educational and social development.”

“All young people with diabetes will experience a smooth transition of care from paediatric diabetes services to adult diabetes services, whether hospital or community-based, either directly or via a young people’s clinic. The transition will be organised in partnership with each individual and at an age appropriate to and agreed with them.”

Health reform in England – update and commissioning framework, Department of Health (2006)²⁸

This set out the policy framework for commissioning within the wider context of the health reform programme, and recommended a range of measures to strengthen commissioning. These included:

- stronger clinical leadership through practice based commissioning;
- a stronger voice for people and local communities;
- better information to underpin commissioning decisions;
- new incentives for commissioners to attract new service providers and improve service quality;
- more effective levers for commissioners to secure financial stability, including new model contracts; and
- measures to build commissioning capacity and capability.

The next phase of development for commissioning policy was signalled with the *Commissioning framework for health and well-being*, which was published for consultation in March 2007. This framework signals a clear commitment to greater choice and innovation, delivered through new partnerships. Its key aims are to achieve:



- a shift towards services that are personal, sensitive to individual needs and maintain an individual's independence and dignity;
- a strategic re-orientation towards promoting health and well-being, investing now to reduce future ill-health costs; and
- a stronger focus on commissioning the services and interventions that will achieve better health, across health and local government, with everyone working together to promote inclusion and tackle health inequalities.

Joint planning and commissioning framework for children, young people and maternity services, Department for Education and Skills and Department of Health

Effective joint planning and commissioning is at the heart of improving outcomes for children and young people through children's trusts. As part of Every Child Matters, the Department for Education and Skills and the Department of Health jointly published this framework in March 2006.²⁹ The framework aims to help local planners and commissioners to design a strategy for jointly commissioning services in each area which will create a clear picture of what children and young people need, make the best use of resources, and join up services to ultimately achieve better outcomes for children and young people. The framework will sit alongside the Department of Health's *Commissioning framework for health and well-being*, and the Communities and Local Government's *Best Value Performance Indicators* guidance.³⁰ A copy of the framework and supplementary case studies and guidance can be found at:

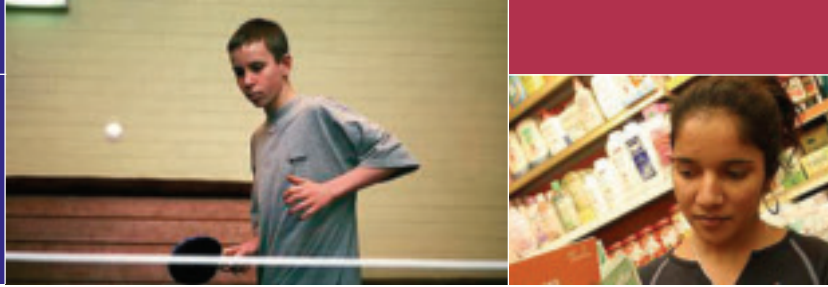
www.everychildmatters.gov.uk/strategy/planningandcommissioning

Diabetes commissioning toolkit, Department of Health

This toolkit,³¹ published in 2006, is aimed predominantly at NHS commissioners of diabetes care, at both PCT and practice level. The toolkit should support commissioners in a number of ways. For example:

- it provides advice on how to carry out a healthcare needs assessment for a local diabetes population in order to understand their specific needs;
- it provides a generic specification for diabetes care, setting out the core elements of quality care and signposting best practice quality markers, such as NSF standards, NICE guidelines and so on;

Section 2: Policy context



- it provides suggestions for indicators that commissioners can use to monitor the quality of their current local services and identify improvements that need to be made; and
- it provides key outcomes that a commissioner could specify when commissioning diabetes care.

In addition, the toolkit may be useful for providers of diabetes services by highlighting quality markers and encouraging local audit. Finally, the toolkit can be used by diabetes networks as it provides a framework with which to look at service improvement and development of models of care.

You're Welcome quality criteria, Department of Health¹

Published in 2005, these are principles to help health services both in the community and in hospitals to 'get it right' and to become young people friendly. The criteria support implementation of standard 4 of the *NSF for Children, Young People and Maternity Services* and build on the Royal College of General Practitioners' initiative, *Getting it right for teenagers in your practice*, which has been supported by the Teenage Pregnancy Unit (Department for Education and Skills) and the Department of Health.

The quality criteria cover nine topic areas:

- accessibility;
- publicity;
- confidentiality and consent;
- the environment;
- staff training, skills, attitudes and values;
- joined-up working;
- monitoring and evaluation, and involvement of young people;
- health issues for adolescents; and
- sexual and reproductive health services.



Transition: getting it right for young people: Improving the transition of young people with long term conditions from children's to adult health services, Department of Health

This good practice guide,³² published in 2006, shows that the handover from children's and young people's services to adult services should be planned and managed as a process. The guide suggests how this can best be accomplished in the context of the evidence base.

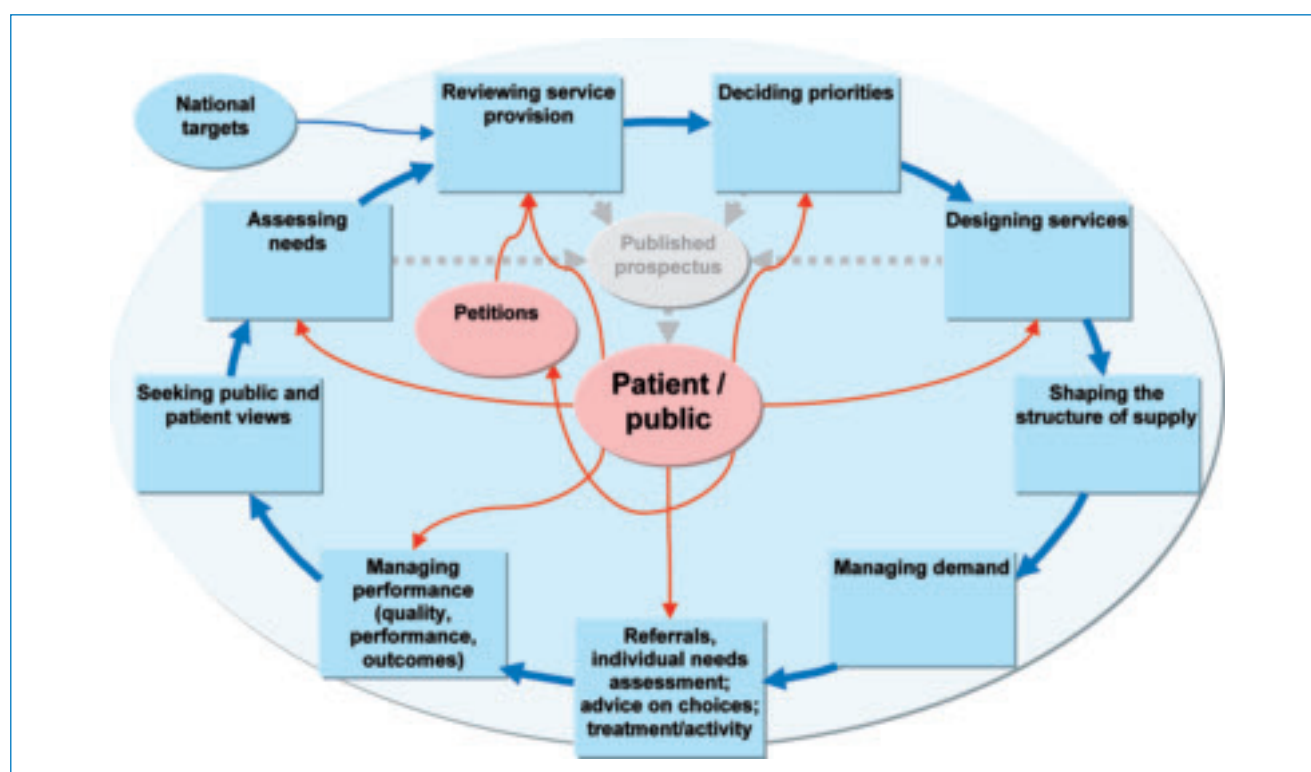


Section 3: Commissioning services for children and young people with diabetes

Introduction to commissioning

There are a number of different definitions of commissioning. The Department of Health commissioning framework²⁸ includes the following diagram describing the different stages involved in the commissioning cycle.

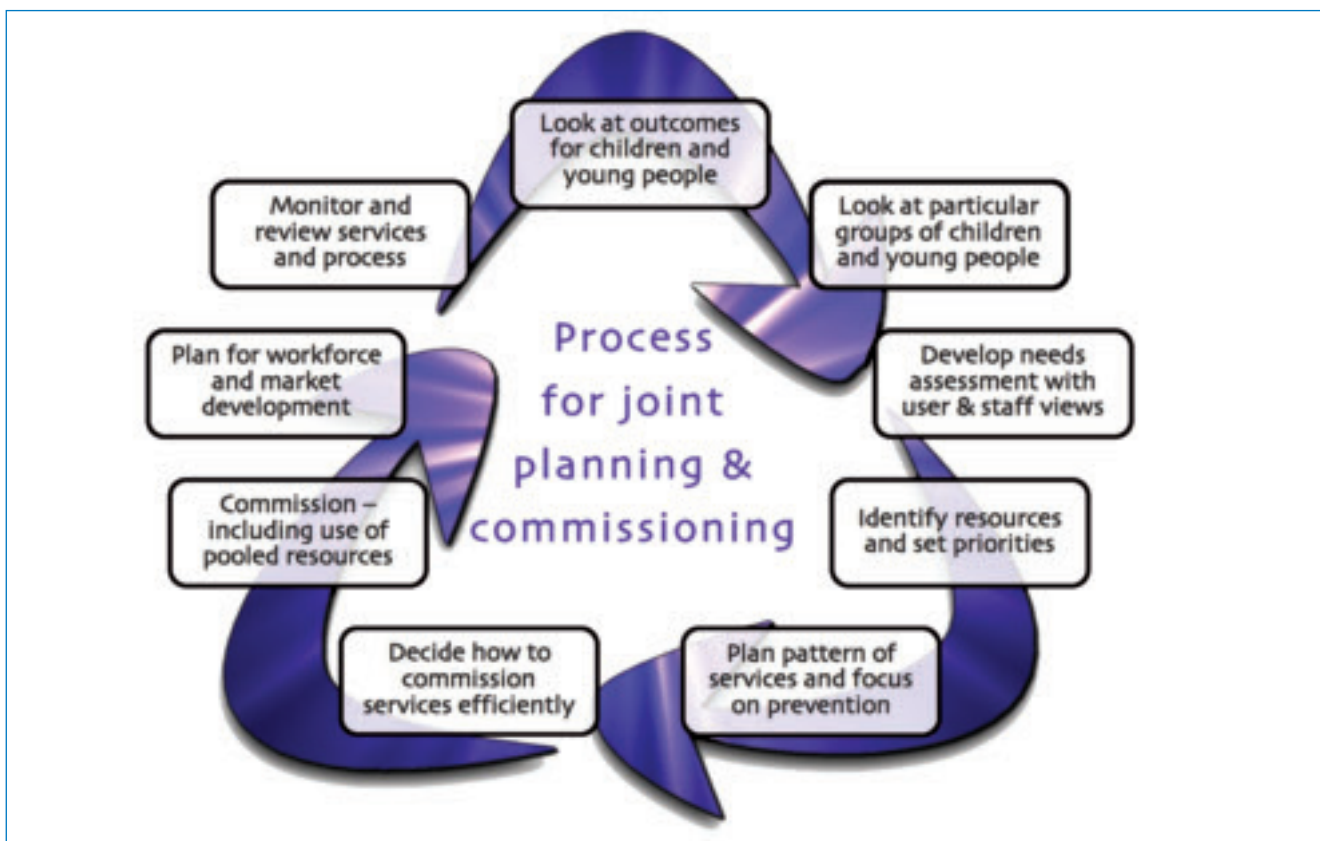
Figure 1: The commissioning cycle for health services





The *Joint planning and commissioning framework for children, young people and maternity services*²⁹ includes the following nine-step cycle for joint planning and commissioning for children, young people and maternity services.

Figure 2: Process for joint planning and commissioning



The principles of effective commissioning feature in both figures. As a minimum, the commissioning process might involve an assessment of local needs, design of a local specification to meet those needs, procurement of services to deliver the local specification and proactive monitoring.

Whichever approach is adopted, commissioning should be specific to the needs of children and young people with diabetes and should also link to wider children and young people's initiatives. These include:

- local needs assessment;
- involving children and young people and their parents and carers in planning and commissioning services;

Section 3: Commissioning services for children and young people with diabetes



- Children and Young People's Plan (CYPP) and children's trusts;
- pooled budgets and resources;
- improvement and performance management cycle; and
- children's services inspection.

This should include a local interpretation of the over-arching *NSF for Children, Young People and Maternity Services*, extending beyond individual PCT/local authority boundaries, with transparent commissioning of services along the complete pathway of care.

Who is involved in effective commissioning for children and young people?

In different localities, commissioning for children and young people with diabetes may be carried out at a number of levels and using a variety of arrangements. These include PCT commissioning, practice based commissioning and through children's trust arrangements (which involve joint commissioning with the local authority and other key stakeholders). Some commissioners will lead on diabetes across all ages including children and adults, whilst others will focus on commissioning services for all children and young people.

What should effective commissioning involve?

Commissioning diabetes care should be a strategic process involving service users, carers, clinicians and partner organisations, and taking account of the local vision for health and social care in the whole community. Commissioners will be able to use the commissioning process to address variations in care, and any needs assessment should take account of local patterns of deprivation.

For children's services, both local and regional components of the service need to be commissioned to ensure a comprehensive service is delivered. What is provided locally and what is provided regionally will vary from place to place, although commissioners will wish to ensure that care is delivered as locally as possible. Local components might include access to a children and young people's specialist multidisciplinary diabetes care (CYPSD) team, and routine care including diagnosis, initial management, continuing care and annual assessment. Regional components should include resources to maintain the network, provide professional training and enable audit and quality assurance.



Commissioners will need to agree monitoring arrangements with service providers, which should include specific quality assurance indicators. The best practice specification at Annex 1 makes suggestions for the content of these indicators. Once these arrangements are in place, specific responsibilities and a timescale for actions should be agreed to allow periodic reviews of progress.

Commissioners will wish to discuss their needs with existing and alternative providers to see what contribution they might make to the delivery of the overall service. Commissioners should consider opportunities to bring in new providers, and ensure that the commissioning process enables all organisations to bid (through capacity building, for example).

Annex 1 provides more in-depth guidance, detailing the features of a local needs assessment, and providing a generic specification for a diabetes service for children and young people. This will be of use to both commissioners and providers and builds on the diabetes commissioning toolkit published by the Department of Health in November 2006.

Commissioning levers

Commissioners have a number of levers available to them to support the process of service redesign and improvement. Payment by Results (PbR) provides commissioners with national currencies, enabling providers to be paid a set price (or tariff) for the services they supply, rather than being reliant on historic budgets and the negotiating skills of individual managers. The national tariff therefore enables commissioners to focus their negotiations on the quality rather than the cost of services. The current tariff is not yet fully comprehensive, however, and a number of key services for children and young people with diabetes (such as drop-in clinics, education sessions) do not yet have a national tariff. Commissioners and providers may therefore decide to negotiate local tariffs for diabetes services outside the scope of the national PbR tariff, relating to, for example, care outside hospital, provision of telephone or other support, work with schools and structured education provision.

Section 3: Commissioning services for children and young people with diabetes



Further information on diabetes and PbR is available on the National Diabetes Support Team (NDST) website

www.diabetes.nhs.uk

Information on PbR is also available on the Department of Health website

www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Financeandplanning/NHSFinancialReforms/index.htm

Further information

Further details, including service models and examples of good practice, are available on the Diabetes UK website

www.diabetes.org.uk/Professionals/Shared_Practice/

Further examples are available on the following databases:

www.childretnsfcasestudies.dh.gov.uk/children/nsfcasestudies.nsf

www.everychildmatters.gov.uk/resources-and-practice/

www.diabetes.nhs.uk/



Section 4: Provision of services and organisation of care

Although there are some fundamental principles of delivery linked to national policy which should not be varied, for example the move towards care closer to home, local services should interpret care guidelines flexibly to meet users' needs. Currently, provision is largely centred in district general hospitals. Outcomes for service users can be variable, and increasing workforce capacity may be difficult. New, locally sensitive arrangements for delivering equity of outcomes may therefore be required, with appropriate methods of ensuring quality assurance. Whatever model is chosen, clear and easy access to specialist care will be required as children with diabetes often have complex needs

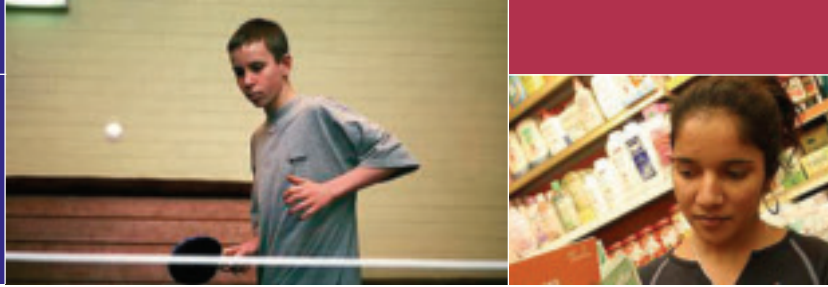
Children's services will now be provided according to the *Guide to Promote a Shared Understanding of the Benefits of Managed Local Networks* (Department of Health 2005)³³ which suggests that:

"managed local networks will operate at many different levels and scales of operation; across PCTs, across primary care, community and acute care, within a health or local authority district, or across a number of local authority boundaries. The exact nature and optimal size of networks depends on their rationale and purpose. Managed local networks are fundamentally about enabling services to be formed or linked across boundaries (whether physical or financial) with the overall aim to ensure an optimal patient journey through and across services."

They differ from other types of partnerships as they have clear governance and accountability.

The preferred option to provide even and optimal support for children with diabetes is a combination of local provision of care through local diabetes services (not necessarily based around district general hospital structures) and regional networks providing oversight, direction, support and combined use of resources. This follows examples provided by paediatric oncology, neonatology and cystic fibrosis, endorsed by the Royal College of Paediatrics and Child Health (RCPCH).³⁴ Developing these regional networks involves collaboration between those commissioning children's diabetes services. It will

Section 4: Provision of services and organisation of care



be necessary to identify 'viable' local diabetes services which are then commissioned to provide children's diabetes services and which receive regular support from the network. The regional network will include clinicians and patient representatives from each local service, PCT and/or children's trust commissioners, local diabetes networks, the voluntary sector and representatives from the strategic health authority (SHA).

Each area should consider such arrangements and work collaboratively with local and regional stakeholders to agree organisational working arrangements that meet local needs and deliver most effectively in the local context. Components to be provided locally and regionally will be clearly and explicitly defined. Those organising local service delivery will need to integrate closely with regional networks to ensure the most effective and appropriate use of resources.

Local diabetes services

Work undertaken as part of this programme indicated that local diabetes services will need to provide:

- access to a CYPSP team with appropriate training and competences; likely to include doctors, nurses, dietitians, as well as school and social support, consistent with other local children's services;
- links to local diabetes networks, children's networks, children's services departments and their partners in children's trust arrangements (including education), primary care and adult diabetes services to promote effective care;
- routine care including diagnosis, initial management, continuing care and annual assessment;
- access to routine and integrated psychological support and local counselling;
- support for data entry, register and audit, reporting appropriately in terms of quality assurance and performance monitoring arrangements, and participating in the National Diabetes Audit (NDA);
- responses to recommendations arising from results of audit data (network, national and international) and other data such as user feedback to improve services;



- agreement of explicit responsibilities with the regional network and efficient delivery of these;
- agreement of explicit responsibilities with primary care teams, including arrangements for shared access to records and 24-hour access to specialist diabetes advice. Primary care teams are unlikely to care for sufficient numbers of children and young people with diabetes to develop the necessary specialist competences; they are also unlikely to have adequate capacity to meet their needs; and
- assurance that, as pump therapy becomes more common amongst children, local services have the appropriate skills and competences.

Regional networks

The remit of the networks is to support strategic development, improvement based on audit outcomes and quality assurance, and to provide a forum, in collaboration with the children's trusts, PCTs and SHA, for shared learning for all professionals caring for children with diabetes in the region. Such benchmarking will inform future service design. The networks will have a significant support and training function for local services, working alongside them to allow the majority of clinical care to be delivered locally.

Specifically, the networks might provide:

- a forum for review of case load, outcome measures and overall performance of commissioned local children's diabetes services;
- specific support for services, such as addressing local difficulties with intensive treatment, substance use and/or specialist psychological leadership;
- an educational forum for sharing good clinical practice, crisis limitation and managed clinical care; and
- robust information on numbers of children and the incidence of new cases (Type 1 and other forms), plus audit data regarding clinic attendance, HbA1c targets and surveillance of complications/related conditions to inform further development of NSF guidelines.

Section 4: Provision of services and organisation of care



In order to facilitate these activities, commissioners would need to commission jointly an appropriate network infrastructure, which might include:

- a network co-ordinator;
- a network data manager and data entry facilities; and
- support services provided by the regional network.



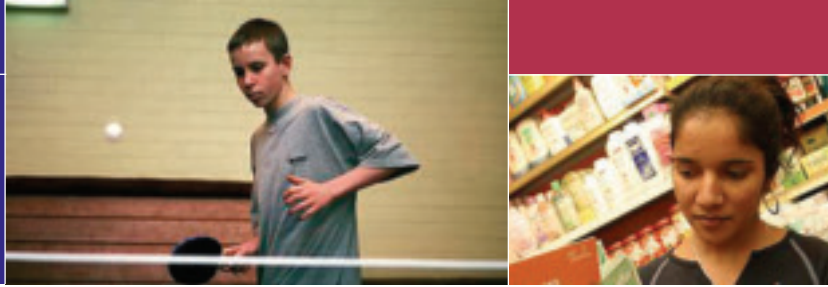
Section 5: Workforce planning and development

Children and young people with diabetes and their families or carers need to be confident that staff providing care and support have the necessary skills to deliver safe and effective care to agreed standards. This can be achieved by ensuring that all staff coming into contact with children and young people with diabetes have a level of competence and experience relevant to their role and that this competence is maintained and developed through continuing professional development (CPD). Achieving this will be challenging, as the workforce needs to have not only the skills and competence to support diabetes management effectively, but also the more generic skills associated with working with children, young people and families. These more generic skills are described in the Common Core of Skills and Knowledge developed as part of the Every Child Matters programme and are grouped under six main headings:

- effective communication and engagement with children, young people and families;
- child and young person development;
- safeguarding and promoting the welfare of the child;
- supporting transitions;
- multi-agency working; and
- sharing information.

There is no single route through which the workforce will be commissioned but whatever the local arrangements, it is important that the workforce is commissioned as part of the local model of care to ensure it is delivered effectively. A model of care, in this context, refers to how all the major components of diabetes care for children and young people are organised and delivered, either regionally or locally; these are described in previous sections.

Section 5: Workforce planning and development



Workforce planning has traditionally been based on identifying the number of professional staff required to deliver a service and making predictions of future requirements. The new emphasis on commissioning the workforce in the context of models of care, however, means that workforce planning needs to be undertaken in a different way as well. Increasingly, National Workforce Competences are being used as a common currency for undertaking workforce planning and this is the approach taken here. This report recognises that this will not be a comfortable concept for many clinicians and professional groups, and there will be an expectation to set out requirements as to numbers of staff. However, as a national document, it focuses on important principles and the 'how to', leaving the 'numbers' for local services to determine based upon their local needs and the model of care delivery.

A possible model for taking this competence-based approach to workforce planning is given here.

- Carry out a robust needs assessment and use this as a basis for defining the local model of care. Ensure that all the major components of care are identified within the model, and use this to identify the workforce competences required for its delivery. The model should reflect the competences needed to deliver direct clinical care, as well as the following:
 - prevention;
 - education;
 - psychology and psychological support; and
 - audit and research.
- Compare what competences are needed with what is currently available to produce a gap analysis.
- Develop a workforce strategy to identify how this gap will be met in order to deliver the model. This can then be used as advice to providers on workforce requirements. This should include training and CPD, which will need to be commissioned as part of the workforce package.



- Produce an implementation plan that clearly identifies who is responsible and what the timescales are.
- Evaluate and review within a specified timescale.

This should take place in a structured way across the health community and should be supported by commissioners, providers, clinicians, service users and managers working together, with the whole process underpinned by the following principles.

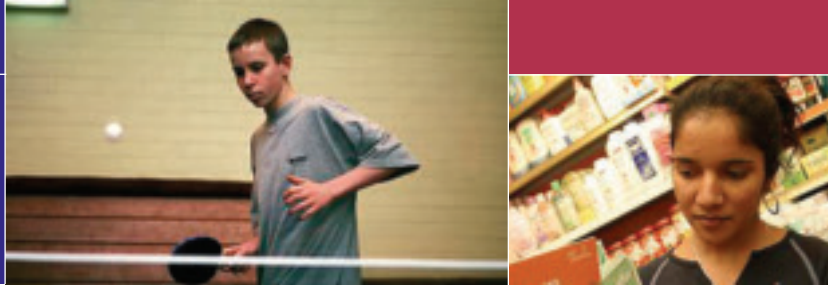
- The service user should be at the centre of any workforce planning.
- New models of service delivery will require new ways of working and the development of new roles, but these should be introduced only as part of an agreed model of care.
- People are the most important resource available to diabetes services and, as such, all staff should be valued and developed.
- All staff should have access to appropriate training and CPD and should be supported in this.
- The roles of unqualified staff need to be valued as much as those of qualified staff.
- Specialist staff will have an important role in the education and training of non-specialist staff, and this needs to be recognised, supported and resourced.

Resources

A number of resources are available to help support individuals and organisations in workforce planning and development. The list below, whilst not exhaustive, may be a useful starting point:

- National Diabetes Support Team, *Levels of Care: A New Language for Service Planning and Design*
www.diabetes.nhs.uk/downloads/levels_of_care1d.pdf

Section 5: Workforce planning and development



- The RCN has produced a number of documents including *Paediatric diabetes: RCN guidance for newly appointed nurse specialists; Specialist nursing services for children and young people with diabetes; and Services for children and young people: preparing nurses for future roles*
www.rcn.org.uk
- The British Dietetic Association has produced *A Workforce and Training Framework for the Delivery of Diet and Lifestyle Pathways, for Long-term Conditions: Diabetes Perspective*. Available by contacting info@bda.uk.com
- National Workforce Projects has produced a *Workforce Planning Toolkit* and a *Resource Pack for Workforce Planning for Long Term Conditions*
www.healthcareworkforce.nhs.uk/longtermconditions.html
- More information on competences and how they can be used
www.skillsforhealth.org.uk
- Further information on the Common Core of Skills and Knowledge
www.everychildmatters.gov.uk/deliveringservices/commoncore/
- A National Diabetes Workforce Strategy, to be published later in 2007.



Section 6: Audit

In September 2003, the National Paediatric Diabetes Audit moved into the National Diabetes Audit (NDA), which is part of the National Clinical Audit Support Programme (NCASP) and provides an infrastructure for the collation, analysis and feedback of local clinical data to support effective clinical audit across the NHS. It does not provide local clinical information technology (IT) systems for collection of audit data, however, which need to be in place to support data submission.

The information provided from the audit analysis supports the monitoring of performance against agreed clinical standards and constructive service comparisons. Diabetes UK, the RCPCH and the RCN continue to be involved in the development of the NDA, ensuring that the interests of people with diabetes and healthcare professionals working in paediatric diabetes services are represented.

Participation in national clinical audit is already used in some areas to inform and support commissioning of diabetes services for children and young people and to drive service improvements. This includes needs assessment and performance monitoring. Furthermore, participation in NDA can also be used in developing service-level agreements for children and young people's diabetes services. In conjunction with this, NDA data are used for audit purposes in service provision and as part of assessing the achievement of required standards of care for a good service.

Participation in national audit is crucial to quality improvement and is part of effective service provision. Teams should regularly review their performance in order to inform service planning and design.

In order to achieve this, it is essential that services are supported by an appropriate information system, which also enables participation in national clinical audit. Encouragement of full participation in the NDA across primary and secondary care organisations provides a view of progress in implementing the Diabetes and Children's NSFs and meeting NICE guidelines for the whole population with diabetes, including children and young people. This supports effective commissioning and performance monitoring of service provision. Adequate IT support facilitates participation in national clinical audit. Where possible, consideration should be given to IT system

Section 6: Audit



compatibility between paediatric, young people and adult services to support smooth transition of care.

www.icservices.nhs.uk/ncasp/pages/audit_topics/diabetes/paediatric-new.asp



Section 7: Information and information technology

The information needs of children, young people and their carers, including parents and school staff, should be met fully. Information is essential in actively engaging, empowering and supporting effective self-care.

Information technology plays a pivotal role in achieving a quality service for diabetes. Modern care delivery packages are already available and consideration should be given to how these can be integrated into the Spine (the national IT database of key information about each patient's health and care) and how information can be generated for the NDA and for national quality assurance and improvement schemes. An IT system should:

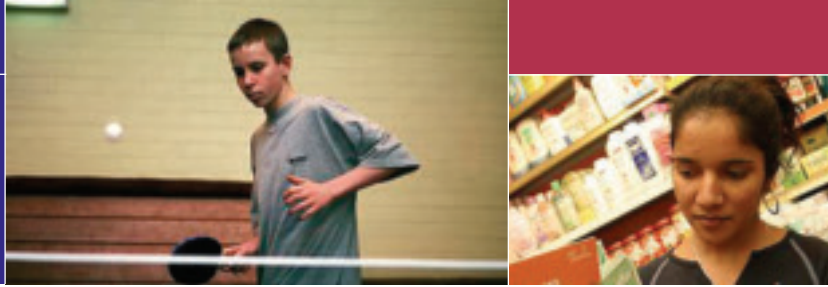
- harmonise working practices to ensure the consistent use of the best solution for any particular problem;
- provide easy access to services and information for service users and parents; and
- allow clinicians at different sites to record and share service user information.

Functionality

An ideal information service might include the following.

- A telephone help-line will be available to service users and primary care staff 24 hours a day, 7 days a week. The clinical team who staff the help-line will have access to all the on-line tools and information necessary to give the best advice to the patient. In time, this service could be supplemented by electronic telemonitoring systems.
- As well as access to support through the help-line, service users and parents will be able to book regular reviews with their lead professional (either on-line or through the help-line) at a time that suits them best.

Section 7: Information and information technology



- Clinicians and service users will have on-line access to shared protocols, guidelines and information relating to the condition. These materials will be available in formats appropriate to their intended audience. As well as textual materials, there will be interactive tools to guide clinicians, parents and service users through specific condition-related crises, as well as to support long-term care pathways.
- Staff at any location, including at primary care level, will be able to read and add entries to the electronic health record of any of their service users, and also receive electronic notifications of changes to the record of any patient for whom they are the lead clinician, or in whom they have a special interest. As well as clinical observations and the current management plan, the record will include details of encounters and advice given, also of pathology, imaging and drugs. Service users and their parents, if authorised or entitled, will have access to their own records along with explanations of the terms used, and be able add notes and observations to it.
- Decision support trees will be provided for the service user and/or parent to use for sick days, hypoglycaemia and dental visits and for health professionals who provide care during surgery or in the initial phases of diabetic ketoacidosis (DKA) management.



Section 8: Research and development

NICE identified the following areas for future research.

- Evaluation of the effectiveness of age-specific structured education programmes for children and young people with Type 1 diabetes, their families and other carers, and an investigation into the most effective way of training healthcare professionals to provide such education.
- Evaluation of the effectiveness of multiple daily injection regimes, continuous subcutaneous insulin infusion (insulin pump therapy), metformin combined with insulin treatment, and invasive versus non-invasive continuous glucose monitoring systems in children and young people with Type 1 diabetes, and the effectiveness of insulin glargine in young children with Type 1 diabetes.
- Evaluation of the effectiveness of training in flexible, intensive insulin management to enable children and young people with Type 1 diabetes to adjust insulin doses to match carbohydrate intake.
- Investigation of the effectiveness of different concentrations of rehydration fluid, the rate of rehydration, the use of albumin infusion and the dose of insulin infusion in the management of diabetic ketoacidosis.
- Evaluation of the effectiveness of behavioural and social interventions for managing anxiety and depression, eating disorders, behavioural and conduct disorders, and non-adherence to therapy in children and, especially, young people with newly diagnosed and established Type 1 diabetes.
- Evaluation of the effects of persistent hypoglycaemia and recurrent diabetic ketoacidosis on neurocognitive function, learning, attendance at school, and educational attainment in children and young people with Type 1 diabetes.

Research is also needed to examine the reported different international outcomes attributed to cultural or attitudinal issues and the role of family support.

Section 8: Research and development



There is a need to establish a much greater understanding of the prevention and management of Type 2 diabetes in children and young people.

Professionals should have access to research findings in order to provide effective care, and where possible should be encouraged to contribute to high-quality research.



Annex 1: Further guidance for commissioners of services for children and young people with diabetes

Introduction

Commissioners will need to consider four key questions when commissioning diabetes care for children and young people:

1. Where are we now?

Commissioners need to commission services based on a thorough assessment of local needs and existing service performance reviews.

2. Where do we want to be?

The following tables signpost best practice quality markers that all services will need to strive towards, such as National Service Framework (NSF) standards, the National Institute for Health and Clinical Excellence (NICE) guidelines and national targets .

3. How do we get there?

The following tables do not provide explicit advice about what local services need to do to deliver these priorities and meet the needs of their local population, as this will be a matter for local determination. However, the generic specification should provide a useful framework for people undertaking service redesign. The tables will help local commissioners and providers to design possible local options to assist this process. The supporting database, including examples of good practice, will also inform service planning.

4. How will we know when we are there?

The generic specification and tables include suggested quality assurance indicators that can be used by local services as measures of effective practice.



Health and healthcare needs assessment

The diabetes commissioning toolkit³¹ includes advice on one approach to carrying out a healthcare needs assessment for a whole local diabetes population, providing a comprehensive picture of the level of demand for diabetes services in a locality.

Commissioners and providers should involve other stakeholders in assessing needs. Public health and information specialists can contribute to identifying data sources, whilst other staff such as youth workers may be able to collect service user (including non-attendees), staff and other stakeholder views.

There are many components to the assessment, and commissioners and others involved in services for children and young people with diabetes should consider the following:

- Population profiling (magnitude and burden of diabetes)
 - prevalence and incidence data (including local, regional and national trends);
 - type of diabetes;
 - age profile, age at diagnosis;
 - local health burden: hospitalisations, length of stay, complication rates;
 - health inequalities: ethnicity and deprivation;
 - children with particular needs such as learning difficulties and poor basic skills; and difficult-to-reach groups such as travellers, asylum seekers and refugees and children in care;
 - risk factors: those not yet diagnosed with diabetes but at risk – this is necessary to inform forward planning, particularly with relatively small numbers as new cases may represent a significantly increased demand for services; child health data relating to deprivation, ethnicity and obesity may inform local planning;
 - cost – expenditure with consideration of wider costs, for example social services; and
 - comparative level of risk and need.

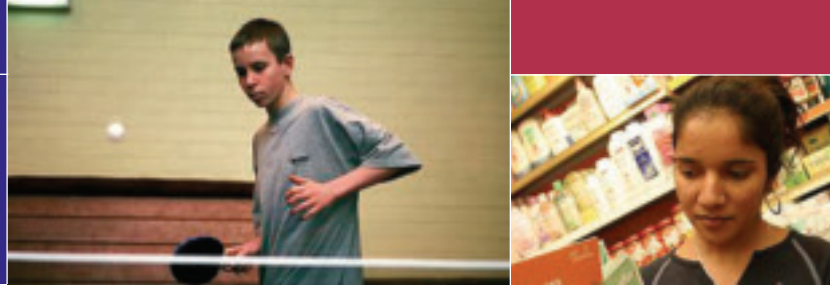


- Effectiveness and cost-effectiveness of current diabetes services
 - current provision, workforce, demand and use;
 - projected trends;
 - cost-effectiveness – local implementation of known effective measures;
 - user satisfaction and perceptions of needs – this should include current service users, parents and other carers as well as those not currently using services;
 - staff and other stakeholders' views, such as early years and school providers;
 - processes: attendance at clinics, opportunities to educate service users and their families about diabetes and supporting children's education, access to specialist staff, screening uptake, access to stop smoking and sexual health services, transition arrangements;
 - outcomes for children and young people: diabetic ketoacidosis (DKA), glycaemic control, hospital admissions, complication rates, quality of life;
 - appropriate policies exist and are adhered to, including child protection, transition, glycaemic control; and
 - benchmark against international and national standards and other similar services through the national paediatric audit.

Generic specification for diabetes care for children and young people: best practice model

Specifying a service is part of the 'designing services' stage of the commissioning cycle. The aim of this generic specification is to help commissioners match national quality guidance to local population needs and arrive at locally appropriate service specifications, with a range of providers, for various elements of a comprehensive service.

Commissioners have to balance many things in finally determining the range and depth of service provision to their local community. This specification aims to support commissioners in their judgements about diabetes services for children and young



people. Using this specification will provide assurance to themselves, to staff, and to children and young people with diabetes and their families, that key success factors for services have been taken into account.

Generic issues

Services should:

- develop in a co-ordinated way as part of Children and Young People's Plans (CYPPs), and work with local authorities and other partners in children's trust arrangements to provide comprehensive care;
- recognise and act to fulfil the duty to co-operate in order to promote the well-being of children and young people, and make arrangements to safeguard and promote the welfare of children and young people;
- be designed in response to the local needs assessment, to meet the specific needs of the local population, including very young children, adolescents, young adults and those with more complex needs such as other medical conditions;
- have an inclusive design process that involves children and young people with diabetes and clinicians with both specialist and generalist expertise;
- meet the *You're Welcome* quality criteria¹ designed to help health services to be young people friendly and covering a number of areas, including confidentiality and consent, and staff training;
- make sure that there is a range of options available to children and young people supporting self-management, informed choice and individual preferences;
- promote full access, timeliness and equity: where possible be close to home and based in the community;
- be available to those people who are not able to access the complete range of services in line with the locally agreed standard model of care, for example children in care, children in the secure estate, refugees and asylum seekers;
- have specific local agreements that enable 24-hour access to emergency advice from competent staff;



- consider provision outside 9 to 5, Monday to Friday, for care (not only emergency advice) to encourage full participation in school, and to support working parents;
- ensure the transition from children's to adults' services is negotiated and explicitly planned around the assessed needs of each individual young person;
- ensure and demonstrate that staff have the competences needed to deliver the functions;
- be covered by written protocols and guidance that are adhered to and monitored;
- have agreed local standards for key outcomes such as timeliness, continuity of care, early years and school settings, monitoring for complications and structured education provision;
- contribute to national data collections or audits;
- be quality assured and have arrangements in place for local audit, benchmarking against national standards (including patient experience); and
- actively monitor take-up, respond to non-attendees, monitor complaints and manage outcomes across the population of service users by seeking out areas and individuals where further input would create improvements.

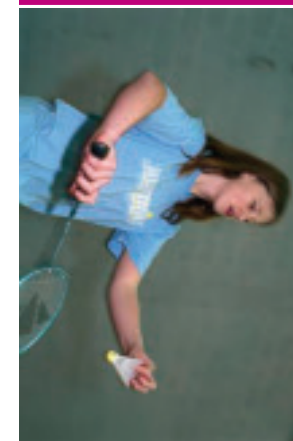
Primary prevention of Type 2 diabetes in children and young people

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>The prevalence of Type 2 diabetes can be reduced by preventing and reducing the prevalence of obesity in the general population, particularly in sub-groups of the population at increased risk of developing diabetes, such as people from minority ethnic communities.</p> <p>Individuals at risk of developing Type 2 diabetes can reduce their risk if supported to eat a balanced diet, lose weight and increase physical activity levels. Interventions to address this, such as Local Exercise Action Pilots, Healthy Schools, the School Sport Strategy and statutory requirements to improve the nutritional standard of food in schools, involve joint action across several agencies.</p> <p>Other initiatives promoting good nutrition prior to and during pregnancy, breastfeeding and appropriate weaning practices may also contribute to preventing obesity and diabetes. These should be commissioned locally.</p>	<p>Children's National Service Framework (NSF) standards 1, 3 and 4²³</p> <p>Diabetes NSF standards 1 and 2²²</p> <p>National Institute for Health and Clinical Excellence (NICE) guidance, <i>Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children</i>³⁵</p> <p>Primary care trusts (PCTs) were asked to put systems in place to measure childhood obesity by the school summer term of 2006, so that interventions could be targeted at schools with higher than average rates of obesity and to help manage performance of PCTs. The guidance for PCTs recently published by the Department of Health (DH)³⁶ advises on how to measure the height and weight of children in maintained schools in reception year (age 4 and 5) and Year 6 (age 10 and 11).</p>	<p>Health and lifestyle surveys illustrate physical activity and food choices at a local level. Consideration of survey sample, particularly of participant numbers and ages, is important.</p> <p>Links to local obesity strategies and initiatives are essential. Commissioners need to ensure that initiatives are co-ordinated, reach those most at risk and are effective, resulting in sustained changes.</p> <p>Services should raise awareness about diabetes – this includes within primary care, school and other settings. Diabetes networks and staff involved in diabetes care should raise awareness of the risk factors (such as obesity) amongst those with Type 2 diabetes and their families, and encourage whole family adoption of healthier lifestyles.</p> <p>Professionals, including midwives, health visitors, child health and Sure Start Children's Centre staff should be involved. Schools are an important setting so teachers, caterers and school nurses will contribute to interventions. In order to reach those excluded from schools, other professional groups such as those working in community and youth settings should contribute to programme development.</p>	<p>Local data on diet and physical activity</p> <p>Child health data</p> <p>Local obesity strategies that refer to children and young people</p> <p>Public awareness of messages</p> <p>Staff training</p> <p>Diagnosis and initial management</p>



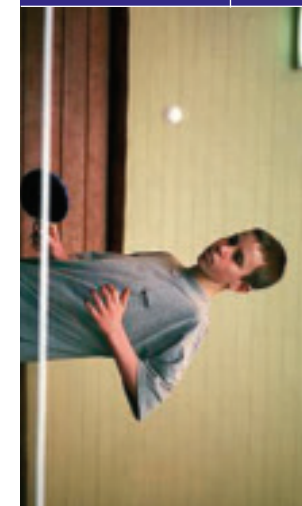
Diagnosis and initial management

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>At diagnosis, children and young people must be able rapidly and readily to access specialist diabetes care services.</p> <p>Children and young people who present with diabetic ketoacidosis (DKA) and are ill, require hospitalisation to stabilise their condition and to initiate insulin therapy. DKA may occur as a result of delayed diagnosis, and a review of cases should be considered to inform service planning.</p> <p>Children and young people without DKA should normally be managed at home or within the community. The location of care may be influenced by local commissioning agreements as well as individual patient and family circumstances.</p> <p>Services should provide for a range of management options – promoting informed choice for children/young people and their families.</p> <p>Substantial education necessary for basic management, often referred to as ‘survival skills’, is provided immediately after the initial diagnosis. The family is likely to be adjusting to the shock and perhaps anger or grief over the diagnosis and may not be able to focus on learning new material.</p> <p>Early identification of children with maturity onset diabetes of the young (MODY) is vital. These children may not need insulin, considerably affecting the care they need, their quality of life and, in the long term, the economic cost.</p>	<p>Children and young people with DKA should be treated according to the clinical guidelines published by the British Society for Paediatric Endocrinology and Diabetes (BSPED).³⁷</p> <p>Children’s NSF standards 6, 7, 8 and 10²³</p> <p>Diabetes NSF standards 3, 5, 7 and 8²²</p> <p>NICE, <i>Diagnosis and management of Type 1 diabetes in children, young people and adults</i>, clinical guidance (CG) 15: 3.1–3.4²⁴</p> <p>Skills for Health competences: Diab CYP01–03 and CYP05–07³⁸</p>	<p>Children and young people should be diagnosed in a timely and accurate way. This applies to all health settings.</p> <p>Intensive and/or high dependency care may be required for some.</p> <p>Children, young people and their primary care team must have access to the children and young people’s specialist multidisciplinary diabetes care (CYPSPD) team on the day of diagnosis.</p> <p>There is a need to commission specialist diagnostic services for those with MODY, neonatal diabetes, cystic fibrosis and other conditions.</p> <p>Except for those with DKA requiring admission, initial management should normally be at home or within the community.</p> <p>Clear and effective communication between the child/young person, family and professional carers is crucial.</p> <p>The child/young person and their family should be provided with clear information about what to expect during the post-diagnosis period.</p> <p>Stabilise and treat any illness.</p> <p>Initiate treatment.</p> <p>Begin education leading to self-care.</p> <p>Support child/young person and family.</p> <p>Promote informed choice about management options.</p>	<p>Incidence and prevalence of Type 1, Type 2 and other forms in children and young people</p> <p>MODY prevalence in population</p> <p>DKA at diagnosis rates</p> <p>Review of diagnosis via approaches such as critical incident analysis</p> <p>Access to intensive care unit/high dependency unit (ICU/HCU) when required</p> <p>Time between referral to CYPSPD team and first access</p> <p>Access to full CYPSPD team (including paediatric dietitian and psychologist) with appropriate skills and competences</p> <p>Service user satisfaction</p> <p>24-hour access</p>



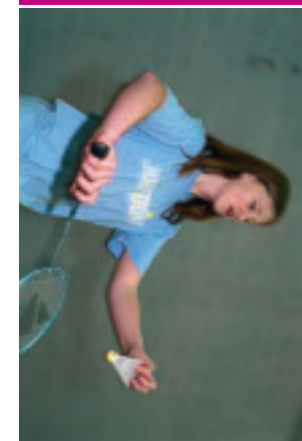
Continuing care

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Continuing care should include on-going proactive clinical assessment, education about self-care, support and access to advice. Care must respond to ongoing needs over time, taking account of individuals' development and maturity. Provision should be as close to home as possible, with the use of appropriate community settings.</p> <p>Services should support families in making informed choices about treatment and, if they cannot provide it themselves, advise where treatment can be obtained.</p> <p>Glycaemic control is a key goal of diabetes care to prevent long-term complications. The target is an HbA1c of less than 7.5%, without frequent disabling hypoglycaemia. This needs to be undertaken in the context of promotion of physical health as well as psychological and emotional well-being.</p> <p>Services should be flexible and have capacity to meet users' needs. This provision should include 24-hour access to diabetes specialist support.</p>	<p>Children's NSF standards 3, 5, 6, 7, 8 and 10²³</p> <p>Diabetes NSF standards 3, 5, 7 and 8²²</p> <p>NICE CG15: 4.1–5.4, 7.1–7.2²⁴</p> <p>NICE, <i>Diabetes (type 1) insulin pump therapy</i>, Health Technology Appraisal (TA) 57³⁹</p> <p>NICE, <i>Diabetes (types 1 and 2) – patient education models</i>, TA60⁴⁰</p> <p>DH, <i>Structured patient education in diabetes</i>⁴¹</p> <p>DH, <i>Insulin pump services</i>⁴²</p> <p>Skills for Health competences: Diab CYP09, CYP11, CYP12, CYP14 and CYP16³⁸</p>	<p>Individual care planning with negotiated personal targets that promote self-care, glycaemic control and physical health with social/psychological support to deliver continuous self-improvement. Adequate timely access to advice about crisis management for sickness, hypoglycaemia and insulin and carbohydrate adjustment.</p> <p>Informed choice of treatment regimen including multiple injection therapy (MIT), insulin pumps (CS II) and carbohydrate management as well as other medication, tailored to developmental stage with promotion of healthier food and lifestyle choices, weight management, physical fitness and avoiding smoking.</p> <p>Holistic care promoting psychological and emotional well-being and physical health centred on the needs and wishes of children and families with user involvement in all aspects of service planning.</p> <p>Clear lines of communication and access should be provided for help and support. Preferred mode of contact (written, telephone, email, text) should be established.</p> <p>Services should promote self-care and empowerment via measures such as education and access to patient-held records. A clear plan with instructions on care should be agreed.</p> <p>Families should be made aware of what care to expect. This should include discussions about different providers' roles within the CYPsD team.</p>	<p>Frequency of investigations</p> <p>Mean HbA1c and range</p> <p>Proportion of HbA1c above target (7.5%)</p> <p>Actions to address glycaemic control</p> <p>Recurrent severe DKA rates</p> <p>DKA complications rates</p> <p>Hypoglycaemia rates</p> <p>Hospital admissions</p> <p>Policies in place for glycaemic and other targets</p> <p>Service user satisfaction</p> <p>School attendance and attainment</p> <p>Access to whole CYPsD team</p> <p>24-hour access</p> <p>Patient-held records</p> <p>Appointment attendance, action to address non-attendance</p> <p>Travel times for appointments</p>



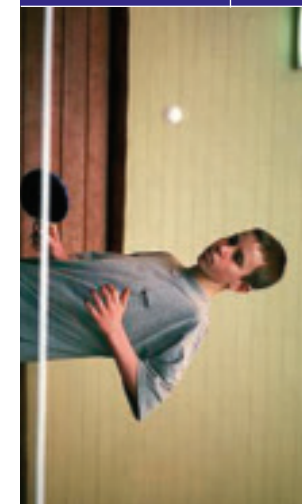
Continuing care (continued)

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Local provision should include access to CYPSPD team with appropriate paediatric training and competences; likely to include doctors, nurses, dietitians, mental health professionals as well as school and social support, consistent with other local children's services. This team will link with its partners in children's trust arrangements (including education), primary care and adult diabetes services to promote effective care. They will be responsible for providing routine care including diagnosis, initial management, continuing care and annual assessment as agreed with other providers, including regional network arrangements (see Section 5).</p> <p>Integrated work, supported by adequate IT allowing access to service users' records, is necessary.</p>		<p>The role of primary care should be explicitly agreed, for example in dealing with childhood illnesses. Regular access to whole CYPSPD team, including 24-hour access to emergency support. Care provided outside regular work/school hours. The team should include staff able to provide psychological and emotional support, education as well as physical care, and work across settings including schools.</p> <p>Those who are poorly controlled and/or experiencing problems require more frequent contact.</p> <p>Primary care should have access to full diabetes records and care plans. They also require 24-hour access to the CYPSPD team for advice.</p> <p>Services should try to maintain contact with non-attendees. Primary care may have a key role in supporting these children and young people, and in encouraging them to seek appropriate specialist diabetes care.</p> <p>Good records and information systems with local protocols and guidelines should be available to all and delivered in a means that is tailored to learning needs, for example language and presentation.</p> <p>A continuous quality assurance and improvement process is in place.</p> <p>Links to local interventions that encourage healthier lifestyles through dietary change and/or physical activity, as described in tables relating to health promotion and prevention. Other aspects of continuing care such as monitoring and effective integrated work with schools and early years settings are outlined in other tables in this report.</p>	



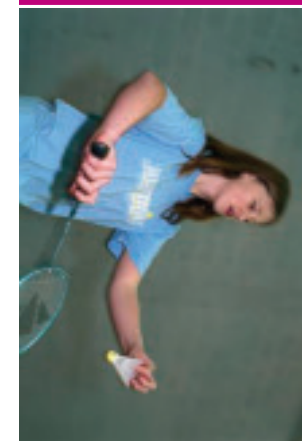
Other forms of childhood diabetes, including Type 2

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>The correct diagnosis of the type of diabetes has important implications for therapy. Early identification of children with specific varieties of MODY is vital. These children (including a majority of neonates) may not need insulin, considerably improving their quality of life and reducing economic costs.</p> <p>Children and young people with Type 2 diabetes may respond to lifestyle change and weight loss.</p> <p>Continuing vigilance for these different forms of diabetes is essential in order to determine the likely impact on future diabetes care, and such surveillance should be carried out through established regional and national registers.</p> <p>Children with Type 2 diabetes should receive care in conjunction or consultation with a CYPsD team. Whilst there is a lack of data about the successful management of Type 2 diabetes in children, adult management principles should be adapted for this population, including consideration of the sociocultural environment associated with obesity. In addition, psychoeducational issues, such as depression, self-destructive behaviour patterns and stopping smoking, may need to be addressed, and interventions offered as required.</p>	<p>With increased prevalence and more research into effective interventions, guidance will emerge in the near future.</p> <p>Children's NSF standards 1, 3, 4, 5, 6, 7, 8 and 10²³</p> <p>Diabetes NSF standards 3, 5, 10, 11 and 12²²</p> <p><i>You're Welcome</i> quality criteria¹</p> <p>Skills for Health competences: Diab CYP04 and CYP15–21³⁸</p>	<p>Generally, the care of these children can be carried out by the local children's diabetes service where they benefit from the same multidisciplinary approach that is applied to Type 1 diabetes. In the case of secondary forms of diabetes, close liaison with other services such as the oncologist and the respiratory physician is needed.</p> <p>Care will usually involve an intensive behavioural approach to lifestyle management and family therapy. This approach may require new competences within CYPsD teams.</p> <p>Particular issues need to be resolved such as frequency of screening for complications, as these may occur earlier in those with Type 2.</p> <p>Intensive lifestyle intervention in obese young people with Type 2 diabetes, with family support, should be the first line of therapy. Medication with metformin should be considered as part of a management strategy.</p> <p>There needs to be access to genetic testing for known genes causing MODY, neonatal and other forms of diabetes.</p>	<p>Incidence and prevalence of Type 2 diabetes in children and young people</p> <p>Incidence and prevalence of other forms, including MODY</p> <p>Comparison with expected prevalence</p> <p>Access to specialist diagnostic services</p> <p>Joint working arrangements for children and young people with diabetes secondary to other conditions</p> <p>Service user satisfaction</p> <p>Attendance</p> <p>Uptake of screening</p> <p>Outcomes – HbA1c and complications</p>



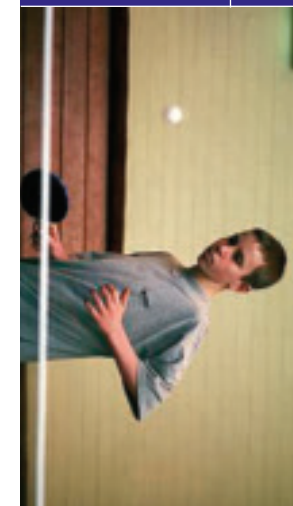
Annual assessment of the continuing care plan and monitoring for complications

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>The annual assessment should centre around the patient's health and care planning, and should include the following:</p> <ul style="list-style-type: none"> • a contact point to assess skills and expertise in aspects of diabetes care and to review current practices; • a time to explore issues surrounding normal development and impact of chronic disease; • consideration of transition from children's to adults' services; and • an environment in which to undertake surveillance for complications of diabetes. <p>Despite the evidence of complications in early adulthood, the effectiveness of monitoring, costs incurred in managing complications and NICE guidance, there is still widespread disparity in practice and overall poor coverage of monitoring for complications.</p>	<p>Children's NSF standards 1, 3 and 5²³ Diabetes NSF standards 3, 5 and 10²² NICE CG15: 5.5²⁴ <i>You're Welcome</i> quality criteria¹ Skills for Health competences – Diab CYP10³⁸</p>	<p>Annual assessment should be offered to all children and young people with diabetes.</p> <p>All children and young people with diabetes should be screened in accordance with NICE guidance.</p> <p>Components of monitoring (some are age-dependent):</p> <ul style="list-style-type: none"> • ophthalmology with retinal photography; • blood pressure measurement; • early morning or overnight urine collection for albumin; • fasting blood sample for lipids, thyroid function, HbA1c, coeliac antibodies and creatinine; • standard anthropometric data and pubertal staging; • feet checks with measurement of peripheral nervous system and use of Doppler blood flow in lower limbs assessment as necessary; • psychological assessment; • dietary and lifestyle assessment; and • sexual health and preconceptual care. <p>Additionally, dental health assessment may be commissioned according to local needs.</p>	<p>Annual assessment provision and uptake</p> <p>Screening provision frequency</p> <p>Uptake</p> <p>Action to address deficits</p> <p>Complication rates</p> <p>Service user satisfaction</p> <p>Child-appropriate environment, considering child protection issues – cluster appointments, joint clinics</p> <p>Staff undertaking monitoring are competent to work with children and young people</p>



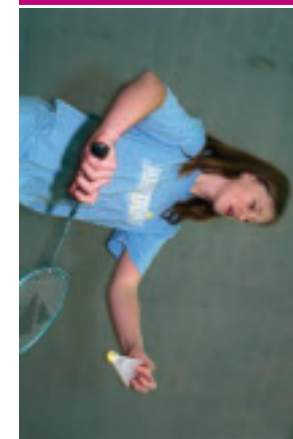
Management of complications

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Complications affect young adults with diabetes so clear management arrangements should be in place. These should include consideration of the needs of children and young people as well as their families, with provision of appropriate and competent staff and care environment.</p> <p>Management of complications should be explicitly planned – a key worker needs to be identified for each young person. This team member is responsible for co-ordinating care and ensuring effective communication.</p>	<p>Children’s NSF standards 3, 5, 6, 7, 8 and 10²³</p> <p>Diabetes NSF standards 11 and 12²²</p> <p>Skills for Health competences: Diab CYP15³⁸</p>	<p>Specialist care for children and young people with complications must be explicitly commissioned.</p> <p>Mechanisms should be in place to feed-back surveillance results to the child/young person and family, as well as primary care team.</p> <p>National protocols for action (modified for the local setting) should be followed for abnormal monitoring results with instigation of therapy or an agreed continuing care plan in place within a specified time of a problem being identified.</p> <p>These should include arrangements for rapid access to specialist care, which may be based at the regional level once complications are identified. These should include referral by primary care, and for those children and young people not in contact with specialist diabetes services.</p> <p>Ongoing therapy for complications may involve liaison/shared care with other specialist teams or specialist centres.</p> <p>Handling of complications will be subject to a rigorous quality assurance scheme.</p>	<p>Complication rates</p> <p>Time to instigate corrective measures</p> <p>Quality contract scoring system</p> <p>Key worker audit</p> <p>Service user satisfaction</p> <p>Child-appropriate environment, considering child protection issues – cluster appointments, joint clinics</p> <p>Care protocols with written individual care plans</p> <p>Referral arrangements allowing for rapid access</p>



Structured diabetes education

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Children and young people have different educational needs from adults. Effective structured education for children, young people and their parents is therefore different from that provided for adults.</p> <p>Evidence suggests that the most effective interventions are those that include active problem solving and practical skills, with approaches that engage and empower behaviour change.</p> <p>There are no evidence-based programmes for children and young people with diabetes, although several centres have produced some that meet relevant criteria and a trial is planned. Evaluation of effectiveness should be based on assessing learning outcomes as well as changes in knowledge, attitude and/or behaviour.</p> <p>Current provision is variable and often inadequate. The importance of structured education programmes should be recognised and they need to be prioritised alongside clinical care.</p>	<p>Children's NSF standards 2, 4 and 6²³</p> <p>Diabetes NSF standards 3 and 5²²</p> <p>NICE TA60⁴⁰</p> <p>NICE CG15²⁴</p> <p>DH, <i>Structured patient education in diabetes</i>⁴¹ outlines criteria to enable commissioners to judge if NICE criteria are being met.</p> <p>International Society for Pediatric and Adolescent Diabetes (ISPAD) patient education consensus guidelines (due to be published in 2007)</p> <p><i>You're Welcome</i> quality criteria¹</p> <p>Skills for Health competences: Diab TPA01³⁸</p> <p>Patient Educator competences</p>	<p>Regular, documented assessment of need, agreed and reviewed with young people and their families.</p> <p>Young people's, families' and carers' levels of education and learning needs should be addressed.</p> <p>A range of methods and delivery styles should be provided. Models need to be flexible to suit age, culture and developmental stage of each patient, with regard to the educational approach, pace and content of the material delivered.</p> <p>The training and teaching skills of educators should be addressed so that they have designated time for training and for critical reflection on their teaching. Approaches to quality assurance should be in place.</p> <p>Local services may consider involving other disciplines, such as youth workers and teachers, in delivering education.</p> <p>Approaches which are more age appropriate, such as play and art sessions for younger children, the use of newer technologies such as texts, emails and DVDs, activity weekends and residential holidays for young people all may help to promote self-care skills and provide valuable learning opportunities.</p> <p>Local services should meet the needs of those with learning difficulties, poor basic skills and difficult-to-reach groups, such as travellers, asylum seekers, refugees and children in care.</p>	<p>Range of learning opportunities available to children/ young people, family and other carers</p> <p>Learning outcomes: knowledge, attitude and behaviour assessments</p> <p>Peer review</p> <p>User and family satisfaction</p> <p>Quality of life measures, confidence, self-care competences</p> <p>Glycaemic control, admission rates and hospital stay</p> <p>Staff competences</p>



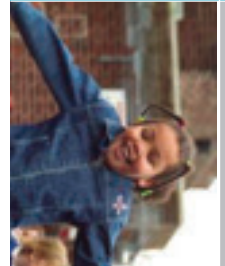
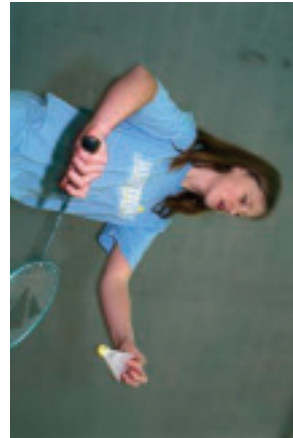
Mental health and emotional well-being: psychological input

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Diabetes may result in additional psychosocial vulnerabilities such as eating problems, social isolation, fear of stigma, depression and psychiatric difficulties, depending upon factors such as coping skills, support and resilience. The long-term implications and life-threatening nature of this condition make the psychological and social challenges particularly complex.</p> <p>For diabetes services to respond to these emotional needs and the varying levels of complexity, psychological provision must be a central component. The challenge is to integrate psychological developmental principles into routine provision for children and young people.</p> <p>Inadequate access to psychology and psychiatry services has been recognised as a significant concern to children/young people with diabetes, their families and staff.</p>	<p>Children's NSF standards 6 and 9²³</p> <p>Diabetes NSF standard 5²²</p> <p>NICE CG15: 6.1–6.8²⁴</p> <p><i>You're Welcome</i> quality criteria¹</p> <p>Skills for Health competences: Diab PE01 and PE04³⁸</p>	<p>Local needs assessment (including service user, family and staff views) should inform planning of psychological services.</p> <p>In planning psychological services, a range of service models that can achieve integrated psychology provision should be considered. This may involve working with child and adolescent mental health services (CAMHS), paediatric psychology services and clinical health psychology services in identifying competences to be met. These services may need support in working with children and young people who have diabetes so there should be effective links between the CYPSPD team and other such specialist services.</p> <p>Routine psychological support should be part of normal service provision, rather than restricted to crisis management.</p> <p>Recurrent DKA is most likely due to insulin omission, therefore input from social services and psychology is essential.</p> <p>Services should include psychology provision specifically for young adults aged 16 to 25, and throughout transition to adulthood.</p> <p>Specialist service arrangements need to be established for specific specialist psychological support, for example for eating disorders, self-harm, substance use and other issues.</p>	<p>Waiting times for referral to psychology</p> <p>Service user satisfaction</p> <p>Quality of life assessments</p> <p>Prevalence of eating disorders, self-harm, depression</p> <p>Integrated team working and training, includes input from trained mental health professional(s), for example psychologist, therapist and/or counsellor</p>



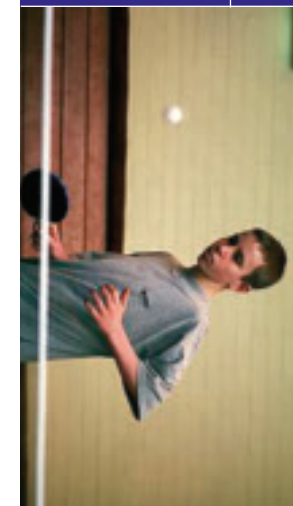
Support of child and family

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Initial diagnosis and ongoing demands of living with diabetes can have a significant impact on family life. This includes day-to-day activities including mealtimes, injections and testing, dealing with hypos as well as health-care attendance and negotiating care provision in early years and schools.</p> <p>Parents and children/young people often struggle with moving from a dependent state (completely reliant for all diabetes care), to a co-dependent state where parents are supporting children/young people to take on more self-care with their support, to an independent state where the young person is fully prepared with the necessary knowledge and skills for self-care.</p> <p>Both children/young people and their parents need support and guidance to enable them to move between these states and bring about a positive outcome in which they know what to expect from each other.</p>	<p>Children's NSF standards 2 and 3²³</p> <p><i>You're Welcome</i> quality criteria¹</p> <p><i>Every Child Matters</i>, Common Core of Skills and Knowledge²⁵</p>	<p>Services should consider the impact on families of diagnosis and adapting to life with diabetes. Children and young people with diabetes may at times refuse parental help with self-care, such as blood testing, injections and/or hospital attendance. Parents may need to acquire the skills to motivate and support their children.</p> <p>Professionals should support families seeking to develop further parenting skills. Staff should have access to appropriate training to do this. Primary care professionals have a key role in supporting families dealing with behavioural issues, and/or helping parents accept the diagnosis, and therefore should be able to directly refer children and young people to the specialist psychology and social care professionals that form part of the CYPSP team.</p> <p>Mental health specialist professionals, such as psychologists and social workers, working in or with the CYPSP team, have a key contribution to this work. The involvement of other roles such as youth workers and early years workers should also be considered.</p> <p>Services and families should be aware of the potential impact events such as bereavement or separation may have on a child/young person's diabetes. Families in need of crisis support should be able to access such support in a timely manner so services should be aware of helpful agencies and how to refer or signpost families to these.</p>	<p>Service user and family satisfaction</p> <p>Audit family-centred policies, such as access outside school and work hours</p> <p>Record of significant life events</p> <p>Timely access to crisis support</p> <p>Availability of staff with specific skills</p>



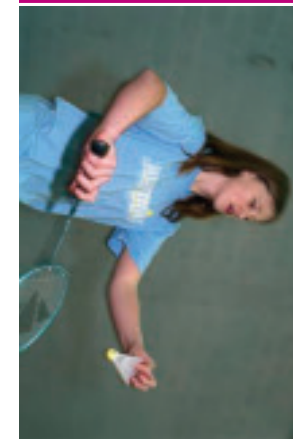
Early years and school settings

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Education is a very valuable part of children's and young people's lives. Appropriate diabetes care in the school and day-care setting is necessary for the child's immediate safety, long-term well-being, and optimal academic performance.</p> <p>Low and/or fluctuating blood glucose concentrations will impact adversely on academic performance as well as resulting in reduced school attendance. Children with diabetes may need to take more time off school to attend clinics; they can develop emotional problems or mental disorders such as depression; and they may have problems learning. Schools should see benefits in supporting the full range of options for managing diabetes.</p> <p>There are examples of early years and school settings offering good levels of support for pupils and parents, but substantial variation in practice exists, not only between areas, but between individual providers. As a result, care in early years and school settings can be a significant concern for children and their families. All settings should be encouraged to offer good levels of support, so that parents can work rather than having to attend school to administer medicines; and they should also offer appropriate environments (such as an empty classroom at break times) for monitoring or insulin injections; facilities for sharps disposal; and inclusion in school activities and visits.</p>	<p>Children's NSF standards 6, 8 and 10²³ NICE CG15: 7.1²⁴ <i>You're Welcome</i> quality criteria¹ DfES, <i>Implementing the Disability Discrimination Act in schools and early years settings</i>⁴⁴ DfES/DH, <i>Managing Medicines in Schools and Early Years Settings</i>⁴⁵ DfES and Council for Disabled Children, <i>Including Me: Managing complex health needs in schools and early years settings</i>⁴⁶ National Children's Bureau, <i>Meeting medical needs in mainstream education</i>⁴⁷</p>	<p>Joint working arrangements across health, social care and education need to be agreed, sensitive to the needs of children and young people with diabetes and their parents and to the constraints on individual schools and early years settings; care in school should not fall automatically to parents.</p> <p>Diabetes services should work closely with local children's services to ensure that all children are able to access safe and appropriate care in the school and early years settings. Local protocols regarding staff training, support and supervision, access to appropriate facilities and equipment, including sharps disposal, should be drawn up by each PCT and local authority.</p> <p>Schools should allow children and young people with diabetes to manage their diabetes according to their chosen management form and to take part in the full range of school activities.</p> <p>Education about diabetes must be provided by the CYPSPD team to day-care providers, teachers and other school personnel, including school receptionists, PE teachers and school nurses, on a regular basis.</p> <p>Current recommendations and up-to-date resources regarding appropriate care for children with diabetes in the school must be universally available.</p>	<p>Service user satisfaction</p> <p>Early years/ school satisfaction</p> <p>Audit of management plans</p> <p>Audit of local protocols</p> <p>Training arrangements, uptake and satisfaction</p> <p>Appropriate environment, including medicine storage and sharps disposal arrangements</p> <p>School attendance and attainment</p> <p>Involvement in full range of early years/ school activities</p> <p>Audit of blood glucose concentrations during early years care/school</p> <p>Audit of critical incidents in early years or school setting related to diabetes</p>



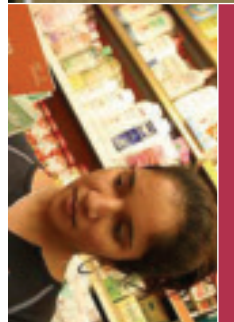
Early years and school settings (continued)

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p><i>Implementing the Disability Discrimination Act in schools and early years settings</i>⁴⁴ is a training resource for schools and local authorities to help them implement the duties they have under the Disability Discrimination Act to make reasonable adjustments to improve the accessibility of schools and promote disability equality.</p> <p>The Disability Discrimination Act defines a disabled person as someone who has “a physical or mental impairment which has a substantial and long term adverse effect on his or her ability to carry out normal day-to-day activities”. The definition is broad and the wide range of impairments covered includes diabetes. As well as increasing schools’ understanding of the duties they owe to their disabled pupils, the resource also gives health professionals a useful insight into the support schools will need from them to include pupils with diabetes in all aspects of school life. This will include an understanding of diabetes, training in the day-to-day management of the needs of individual pupils with diabetes and what to do in emergencies. Key success factors include an inclusive ethos, a ‘can do’ attitude from all staff, anticipating pupils’ needs and strong collaborative relationships, as well as use of expertise from outside the school.</p>		<p>An individualised diabetes medical management plan should be agreed by the parent/guardian, the early years setting or school, and the student’s CYPSP team. This describes all parties’ responsibilities, addresses the child’s specific needs and provides clear instructions for ongoing and emergency care, including the administration of insulin and carrying out blood glucose testing as necessary. This should be regularly updated and made available to all professionals, involved including the primary care team.</p> <p>There is a need for:</p> <ol style="list-style-type: none"> children with diabetes at school and in early years settings to receive appropriate healthcare and support; schools and education services in local authorities to know how to appropriately engage with parents and to commission help and support to make reasonable adjustments; staff in schools and early years settings to access appropriate information from parents, and training and support from health services; and CYPSP teams need to be organised to do (a) and (c) effectively and provide guidance at a local level to schools and early years settings to ensure these settings know what they need to do about (b). 	



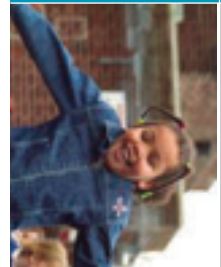
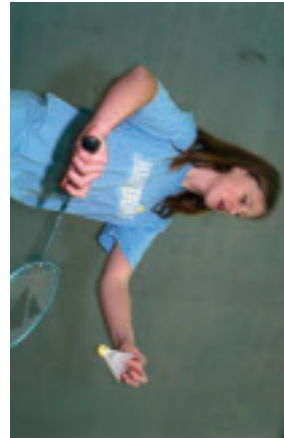
Early years and school settings (continued)

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Healthcare professionals should consider that a school may lack prior experience of helping pupils with diabetes and that school staff may not be aware of the kinds of support pupils with diabetes need. Schools will be better placed to provide help and support for pupils with diabetes if head teachers and governing bodies can access information, awareness-raising sessions, training on specific points and examples of practical ways in which schools can get help from competent healthcare professionals</p>			



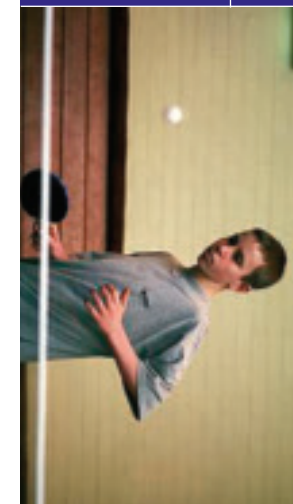
Promoting good health and healthier choices

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>A quality service is concerned with individuals' health during childhood and beyond. It should be focused not only on diabetes self-care, but also on broader aspects of health and promoting healthier choices, including healthier eating and physical activity. Activities promoting good health and healthier choices should seek to engage the whole family.</p> <p>Children and young people as well as their parents and carers need to be aware of the effects of smoking, alcohol and other drugs on their diabetes and general health.</p> <p>Young people should be supported in accessing support and advice with regard to smoking, alcohol and other drug use.</p> <p>Young people need to be aware of the legal requirements with regard to driving and diabetes.</p>	<p>Children's NSF standards 1 and 4²³</p> <p>Diabetes NSF standard 3²²</p> <p>NICE CG15: 4.7– 4.11²⁴</p> <p><i>You're Welcome</i> quality criteria¹</p>	<p>Care includes promotion of healthier eating throughout service activity and access to advice and support about dietary choices.</p> <p>Care includes promotion of physical activity throughout service activity.</p> <p>Specialist advice for high-intensity sports is available.</p> <p>Young people should be asked about smoking, alcohol consumption and drug use on a regular basis from age 12 and data recorded.</p> <p>Formal stop smoking support should be provided. Local arrangements for the provision of nicotine replacement therapy for children and young people should be in place.</p> <p>All facilities, including training and educational, should be smoke-free. Staff providing home visits should be supported in avoiding exposure to second-hand smoke.</p> <p>Alcohol and/or substance misuse counselling should be provided, either by the CYPSPD team or via referral to specialist substance use services. There should be effective links between the CYPSPD team and other such specialist services.</p> <p>Advice about driving is provided and clearly documented in a way that can be audited.</p>	<p>Service user satisfaction</p> <p>Access to dietary advice</p> <p>Consistent promotion of healthier choices</p> <p>Access to specialist advice</p> <p>Numbers asked about smoking, alcohol and drug use</p> <p>Prevalence of smoking, alcohol and substance use</p> <p>Referrals to stop smoking, NRT prescriptions</p> <p>Number successfully stopping smoking</p> <p>Referrals to substance misuse services</p> <p>Audit of driving advice</p>



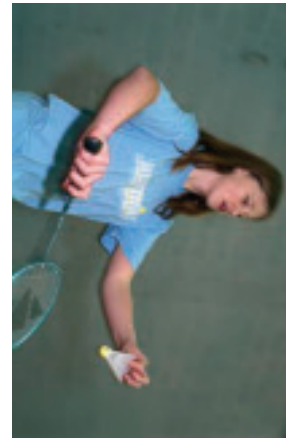
Sexual health and pregnancy

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Young people with diabetes, like other young people, need high-quality advice and support about sexual health. There is evidence that they do not feel they receive this. Advice should be concerned with both preventing unwanted pregnancies and promoting safe sex.</p> <p>The Confidential Enquiry into Maternal and Child Health (CEMACH) 2007 report into diabetes in pregnancy⁴⁸ highlighted the increased risks in pregnancy for women with diabetes, and the poorer pregnancy outcomes experienced.</p> <p>Young people with diabetes who receive regular care from their CYPSP team may be less familiar with accessing primary care services.</p> <p>Care by a multidisciplinary diabetes team prior to conception and during pregnancy has been shown to minimise maternal and fetal risks. The incidence of congenital anomalies decreases as preconception glycaemic control improves.</p> <p>Management before and during pregnancy should be explicitly planned – there is a need to identify a key worker for each woman. This team member is responsible for co-ordinating care and ensuring effective communication.</p>	<p>Children’s NSF standard 11²³</p> <p>Diabetes NSF standards 3 and 9²²</p> <p><i>You’re Welcome</i> quality criteria¹</p> <p>Child protection guidance</p> <p>Skills for Health competences: Diab PD01³⁸</p> <p>CEMACH and the Royal College of General Practitioners have developed information for primary care focusing on practical advice on preconception and antenatal care for all women with diabetes of child-bearing age.</p> <p>NICE has commissioned the National Collaborating Centre for Women’s and Children’s Health to develop a clinical guideline on diabetes in pregnancy for use in the NHS in England and Wales. This is due in November 2007.</p>	<p>Specialist services should consider the active provision of sexual health advice or joint work with young people’s sexual health services and/or primary care.</p> <p>Primary care and sexual health services should be regularly updated about the needs of young people with diabetes.</p> <p>Preconception and safe-sex counselling should be provided for all young people.</p> <p>Information about the risk of fetal malformations and of diabetes in offspring should be provided to all sexually active young people.</p> <p>Unplanned pregnancies should be avoided as pregnancy in women with poorly controlled diabetes has higher risks of maternal and fetal complications.</p> <p>Women with diabetes should optimise glycaemic control before and during pregnancy.</p> <p>Women with diabetes who are planning pregnancy should be referred to the diabetes team, working with obstetric services.</p> <p>A named key worker should be identified for each woman.</p> <p>Women should take higher dose folic acid supplements (5mg) from preconception until 13 weeks’ gestation.</p>	<p>Access to sexual health advice</p> <p>Service user satisfaction</p> <p>Number prescribed contraceptives</p> <p>Number of pregnancies</p> <p>Number of unwanted pregnancies</p> <p>Number of teenage pregnancies</p> <p>Glycaemic control before and during pregnancy</p> <p>Maternal and fetal outcomes</p> <p>Named key worker audit</p> <p>Folic acid uptake</p>



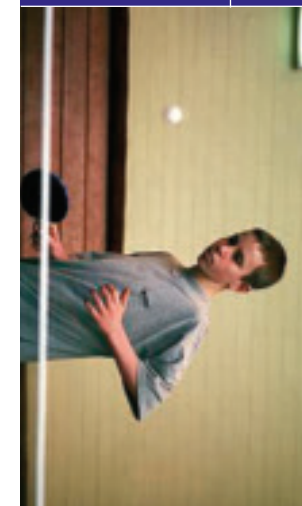
Transition

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Transition from paediatric to adult care is a major milestone for young people with diabetes. Despite this, it is too often poorly organised and fails to meet the needs of the young person.</p> <p>Young people are frequently regarded as adults following transfer from paediatric services, although this occurs at a sensitive time when other life transitions are taking place, making young people a vulnerable group at risk of adverse events such as diabetes emergencies.</p> <p>Ineffective transition leads to young people being 'lost' or 'dropping out' of adult services and therefore effective transition must focus on the partnership with the young person to ensure that a service is provided which takes into account their views and wishes.</p> <p>Management during transition should be explicitly planned – a key worker needs to be identified for each young person. This team member is responsible for co-ordinating care and ensuring effective communication.</p>	<p>Children's NSF standard 4²³</p> <p>Diabetes NSF standard 6²²</p> <p>NICE CG15: 7.2²⁴</p> <p>DH guidance, <i>Transition: getting it right for young people</i>³²</p> <p><i>You're Welcome</i> quality criteria¹</p> <p>RCN, <i>Adolescent transition care; Guidance for nursing staff</i>⁵⁰</p> <p>Datta, <i>Moving up with diabetes: the transition from paediatric to adult care</i>⁵¹</p> <p>Skills for Health competences: Diab TPA01–TPA04³⁸</p>	<p>Transition is an explicit, purposeful, planned, yet flexible movement of a young person from a child-centred to adult-orientated healthcare system. The age of transition will not be the same for every child, and it is important that arrangements are centred around the child rather than the clinic.</p> <p>Each young person must be individually assessed and their services matched and co-ordinated to their needs with one identified person. The process is negotiated with the child/young person and the needs of parents, carers and families addressed.</p> <p>A named key worker, who oversees care and offers support through transition as and when appropriate, should be identified for each young person.</p> <p>Youth workers may be able to help services improve transition arrangements, maintaining a focus on young people's needs.</p> <p>Primary care teams must be kept informed of transition arrangements, with full access to care records.</p> <p>Inpatient provision arrangements need to be considered – if young people are admitted to adult wards, child protection issues must be addressed, including the provision of a suitable environment.</p>	<p>Service user satisfaction</p> <p>Attendance rates pre- and post-transition</p> <p>HbA1c pre- and post-transition</p> <p>Named key worker audit to explicitly identify diabetes care provider between age 16 and 25</p> <p>Transition plans audit</p> <p>Inpatient processes and policy</p>



Benefits

Descriptor	Best practice quality markers	Evidence for improvement	Suggested key outcomes
<p>Disability Living Allowance (DLA) entitlement is a key concern to families of children with diabetes. These concerns generally relate to how entitlement is determined and to the application processes.</p> <p>Additionally, staff, particularly specialist nurses, report spending significant amounts of time completing forms.</p>	<p>Children's NSF standard 2²³</p> <p>Diabetes NSF standard 12²²</p> <p>NICE CG15: 7.1²⁴</p> <p><i>Every Child Matters</i>²⁵</p>	<p>Local deprivation levels should be considered alongside local needs assessment.</p> <p>When considering claims and reviews for DLA, decision makers will request further evidence from the most appropriate source, determined by the individual circumstances of each case, for example hospital consultant, GP or diabetes specialist nurse.</p> <p>The Disability and Carers Service is currently testing a new system called customer case management, which is an IT-supported approach that underpins evidence gathering and decision making in a structured and consistent way. It enables customers, carers and their representatives to provide information that accurately describes their care and mobility needs and provides decision makers with on-line, up-to-date, medical and legislative guidance to help them apply a consistent approach to evidence gathering and decision making.</p>	<p>Provision of information</p> <p>Uptake of benefits</p> <p>Staff time completing applications</p>





Annex 2: The Department of Health's Children and Young People with Diabetes Working Group: Terms of reference

This group is charged with establishing what needs to be done to enable the NHS and local care services to meet the needs of children and young adults aged up to 25 years with Type 1, Type 2 and other forms of diabetes as framed in national guidance, including the Diabetes and Children, Young People and Maternity Services National Service Frameworks (NSFs) and NICE guidelines and appraisals.

Aims and tasks of the group

1. To identify the key service principles and functional requirements of the Children's and Diabetes NSFs that are:
 - safe for service users, their families and health professionals;
 - effective in providing appropriate services, based on scientific knowledge, to all who can benefit;
 - able to promote effective partnership between children/young people and their families and carers, supporting mutual decision making between them and care professionals;
 - efficient in avoiding waste of equipment, supplies, ideas and energy; and
 - equitable.
2. To agree the standards and quality indicators appropriate for commissioners and key components of the service organisation necessary to deliver this, and to consider the necessary commissioning linked to system reform.
3. To identify different models of care.



4. To identify what needs to be done to enable the development of best practice models. In particular, to define within the models of care the components required to attain self-care and management along with structured education and support for the person with diabetes, the family, carer, school personnel and others as appropriate.

Outcomes

To publish a report that will act as an implementation support tool to enable the commissioning and evaluation of service delivery necessary to meet the commitments set out in the Children's and Diabetes NSFs' standards.

The working group gathered a number of examples of diabetes services for children and young people. These can be found on the Diabetes UK website at www.diabetes.org.uk/sharedpractice



Annex 3: Membership of the working group

Chair: **Professor Peter Hindmarsh**, Consultant in Endocrinology, Institute of Child Health, Great Ormond Street Hospital, London

Diabetes UK representative: **Simon O'Neill**, Director of Care and Policy, Diabetes UK

Consultant paediatricians:

Dr Jeremy Allgrove, Consultant Paediatric Endocrinologist, Royal London Hospital

Professor David Dunger, Professor of Paediatrics, University of Cambridge

Dr Julie A Edge, Consultant in Paediatric Diabetes and Endocrinology, Oxford Children's Hospital

Manager/diabetes specialist nurse: **Jackie Stedman**, Diabetes Specialist Nurse/Clinical Service Manager, Salford Primary Care Trust

Paediatric diabetes specialist nurses:

Emma Day, Paediatric Specialist Nurse, Birmingham Children's Hospital

Sue Greenhalgh, Paediatric Diabetes Specialist Nurse, Royal Manchester Children's Hospital/ Salford PCT

Rebecca Thompson, Paediatric Specialist Nurse, University College Hospital, London

General Practitioner: **Dr Mary Pierce**, GP and Epidemiologist, University College London, Confidential Enquiry into Maternal and Child Health (CEMACH)

Parent representatives:

Alison Piper, parent of a child with diabetes and Consultant Clinical Psychologist to the Young Person's Diabetes Clinic, Queen Elizabeth Hospital, King's Lynn

Tracy Slater, parent of a child with diabetes and the Eastern Regional Manager for Diabetes UK

Dietitian: **Sheridan Waldron**, Dietetic Manager and Specialist Dietitian for Children's Diabetes, Leicestershire Nutrition and Dietetic Service



Department for Education and Skills (DfES) representative: **John Hubbard**, Health Strategy Team, Children, Young People and Families Directorate, DfES

Clinical psychologist: **Dr Gail Dovey-Pearce**, Chartered Clinical Psychologist, 11–20 Clinical Health Psychology Service and Northumbria Diabetes Service, Northumbria Healthcare NHS Trust

Commissioner of children’s services: **Eugene Staunton**, City and Hackney PCT

Service user information and communication: **Dr Sandy Oliver**, Reader in Public Policy/Deputy Director, Social Science Research Unit, Institute of Education, University of London

DH Children’s Team representative: **Noel Durkin**, DH

National Clinical Director for Diabetes: **Dr Sue Roberts**, DH

National Clinical Director for Children, Young People and Maternity Services: **Dr Sheila Shribman**, DH

National Diabetes Support Team (NDST): **Bill O’Leary**, Communications Lead

NDST: **Clare Beard**, Programme Manager Children and Young People with Diabetes

Workforce: **Karen Walker**, Programme Manager, Skills for Health

Secretariat: **Gary Tempest**, Policy Lead, and **Dawn Jones**, Policy Manager, Diabetes Policy and Development Team, DH

Other contributors:

Bev Bookless, Sarah Walter and Chris Lambourne, NDST

Amy Nicholas, Kathryn Halford and Judy Stone, Partnership for Children, Families and Maternity team, DH

Julie Henderson, National Diabetes Audit Senior Project Manager, Information Centre for Health and Social Care

Karen Naya, Development Manager Strategy Children, Healthcare Commission



Professor Brian Ferguson and Andy Kingdom, Yorkshire and the Humber Public Health Observatory

Dick Reed, Chris Booth and Debbie Owens, Department for Work and Pensions

Fiona Smith, Adviser in Children and Young People's Nursing, Royal College of Nursing

Catherine Powell and Alison Thompson, DfES



Annex 4: References

- 1 Department of Health (2005) *You're Welcome quality criteria: Making health services young people friendly*
www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_4121562
- 2 Bryden KS, Dunger DB, Mayou RA, Peveler RC, Neil HA (2003) Poor Prognosis of Young Adults With Type 1 Diabetes. *Diabetes Care* (Apr), 26(4)
- 3 Gardner SG, Bingley PJ, Sawtell PA, Weeks S, Gale EAM, EURODIAB and Barts Oxford Study Group (1997) Rising incidence of insulin dependent diabetes in children aged under 5 years in the Oxford region: time trend analysis. *British Medical Journal (BMJ)*, 315: 713–17
- 4 Fagot-Campagna A, Venkat Narayan KM, Imperatore G (2001) Type 2 diabetes in children. *BMJ* (Feb), 322: 377–8
- 5 Ehtisham S, Kirk J, McEvilly A, Shaw N, Jones S, Rose S, Matyka K, Lee T, Bennett Britton S, Barrett T (2001) Prevalence of type 2 diabetes in children in Birmingham. *BMJ* (Jun), 322: 1428
- 6 Ehtisham S, Hattersley AT, Dunger DB, Barrett TG, for the British Society for Paediatric Endocrinology and Diabetes Clinical Trials Group (2004) First UK survey of paediatric type 2 diabetes and MODY. *Archives of Disease in Childhood* (Jun), 89(6): 526–9
- 7 Marmot M (2004) *Status Syndrome*. London: Bloomsbury, pp. 115–18
- 8 Diabetes Control and Complications Trial Research Group (1993) The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine (NEJM)*, 329(14): 977–86
<http://diabetes.niddk.nih.gov/dm/pubs/control/index.htm>
- 9 Lachin JM, Genuth S, Cleary P et al., on behalf of the Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group (2000) Retinopathy and Nephropathy in Patients with Type 1 Diabetes Four Years after a Trial of Intensive Therapy. *NEJM*, 342: 381–9
- 10 Diabetes UK (2005) Resources to support the delivery of care for children and young people with diabetes
www.diabetes.org.uk/Documents/Shared%20practice/cypresourcesdocpdf%20updated%20april%202006.pdf



- 11 Department of Health (2004) *Securing good health for the whole population: Final report* (Wanless Report)
www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_4074426
- 12 Yorkshire and Humber Public Health Observatory (YHPHO) (2006) *Diabetes: Key Facts*
www.diabetes.nhs.uk/downloads/YHPHO_Diabetes_key_facts.pdf
- 13 Diabetes Control and Complications Trial Research Group (1996) Lifetime benefits and costs of intensive therapy as practiced in the diabetes control and complications trial. *Journal of the American Medical Association (JAMA)*, 276(17): 1409–15
- 14 Danne T, Mortensen HB, Hougaard P et al. (2001) Persistent differences among centers over 3 years in glycemic control and hypoglycemia in a study of 3,805 children and adolescents with Type 1 diabetes from the Hvidøre Study Group. *Diabetes Care*, 24(8): 1342–7
- 15 Edge J, Swift P, Anderson W, Turner B (2005) Diabetes Services in the UK: fourth national survey. Are we meeting NSF standards and NICE guidelines? *Archives of Disease in Childhood* (Oct), 90: 1005–9
- 16 Diabetes UK (2005) *Your Local Care 2005 – a survey of diabetes services*, Research by Dr Foster and Diabetes UK
www.drfooster.co.uk/websites/objectlist.aspx?w=17
- 17 Royal College of Nursing (RCN) (2006) *Specialist nursing services for children and young people with diabetes*
www.rcn.org.uk/publications/pdf/specialist_nursing_services_for_children_and_young_people_with_diabetes.pdf
- 18 Innove (2006) *How PCTs are implementing the Diabetes NSF: Findings from DiabetesE, First National Report*
www.innove.co.uk
- 19 National Diabetes Audit (NDA) (2004/05) *Key findings about the quality of care for children and young people with diabetes in England, incorporating registrations from Wales*
www.icservices.nhs.uk/ncasp/pages/audit_topics/diabetes/default-new.asp
- 20 Diabetes UK (2005) *Diabetes: State of the Nations 2005: progress made in delivering the national diabetes frameworks*
www.diabetes.org.uk/Documents/Reports/StateOfNations.pdf
Diabetes Dialogue: Paediatric care
www.diabetesdialogue.org.uk/forum/pediatric_care
- 21 Diabetes UK (2004) *The National Paediatric Diabetes Audit, Results from the audit year 2002*
www.bsped.org.uk/professional/diabetesuk/NationalPaediatricAudit.pdf



- 22 Department of Health (2001) National Service Framework for Diabetes: Standards
www.dh.gov.uk/assetRoot/04/05/89/38/04058938.pdf
- 23 Department of Health and Department for Education and Skills (2004) National Service Framework for Children, Young People and Maternity Services
www.dh.gov.uk/assetRoot/04/09/05/52/04090552.pdf
- 24 National Institute for Health and Clinical Excellence (NICE) (2004) Clinical Guideline CG15: Diagnosis and management of Type 1 diabetes in children, young people and adults
www.nice.org.uk/guidance/CG15
- 25 HM Government (2003) *Every Child Matters: Change for Children*,
www.everychildmatters.gov.uk/_files/F9E3F941DC8D4580539EE4C743E9371D.pdf
- 26 HM Government (2005) *Every Child Matters: Outcomes Framework*
www.everychildmatters.gov.uk/_files/F25F66D29D852A2D443C22771084BDE4.pdf
- 27 Department of Health (2006) *Our health, our care, our say: a new direction for community services*
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453
- 28 Department of Health (2006) *Health reform in England: update and commissioning framework*
www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_4137229
- 29 Department for Education and Skills and Department of Health (2006) *Joint planning and commissioning framework for children, young people and maternity services*
www.everychildmatters.gov.uk/_files/312A353A9CB391262BAF14CC7C1592F8.pdf
- 30 Communities and Local Government (2005) Best Value Performance Indicators 2005/06: Guidance Document
www.communities.gov.uk/index.asp?id=1136118
- 31 Department of Health (2006) Diabetes commissioning toolkit
www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_4140284
- 32 Department of Health (2006) Transition: getting it right for young people: Improving the transition of young people with long term conditions from children's to adult health services
www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145
- 33 Department of Health and Department for Education and Skills (2005) *A Guide to Promote a Shared Understanding of the Benefits of Managed Local Networks*
www.dh.gov.uk/assetRoot/04/11/43/68/04114368.pdf



- 34 Royal College of Paediatrics and Child Health (2006) *A guide to understanding pathways and implementing networks*
www.rcpch.ac.uk/doc.aspx?id_resource=1739
- 35 NICE (2006) Clinical guideline CG43 Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children
www.nice.org.uk/guidance/CG43
- 36 Department of Health (2006) Measuring childhood obesity: Guidance to PCTs on data handling
www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_4134465
- 37 British Society for Paediatric Endocrinology and Diabetes (BSPED) (2004) Recommended DKA Guidelines
www.bsped.org.uk/professional/guidelines/docs/BSPEDDKAApr04.pdf
- 38 www.skillsforhealth.org.uk
- 39 NICE (2003) Health Technology Appraisal TA57: Diabetes (type 1) – insulin pump therapy
www.nice.org.uk/guidance/TA57
- 40 NICE (2003) Health Technology Appraisal TA60: Diabetes (types 1 and 2) – patient education models: The clinical effectiveness and cost effectiveness of patient education models for diabetes
www.nice.org.uk/guidance/TA60
- 41 Department of Health (2005) *Structured patient education in diabetes: Report from the Patient Education Working Group*
www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_4113195
- 42 Department of Health (2007) *Insulin pump services: report of the Insulin Pumps Working Group*
www.dh.gov.uk/en/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/DH_072777
- 43 Kyriacou C (1998) *Essential Teaching Skills*, 2nd edn. Cheltenham, UK: Nelson Thornes
- 44 Department for Education and Skills (2006) Implementing the Disability Discrimination Act in schools and early years settings
<http://publications.teachernet.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductId=DFES+0160+2006&>
- 45 Department for Education and Skills and Department of Health (2005) Managing Medicines in Schools and Early Years Settings
www.standards.dfes.gov.uk/eyfs/resources/downloads/1448-2005dcl-env3final.pdf



- 46 Carlin J (2005) *Including Me: Managing complex health needs in schools and early years settings*. London: Council for Disabled Children and Department for Education and Skills
www.ncb.org.uk/Page.asp?originx2964rs_77640241276965p56v30647296
- 47 Datta J, Ryder N and Madge N (2006) *Meeting medical needs in mainstream education*. London: National Children's Bureau
www.ncb.org.uk/dotpdf/open_access_2/meet.pdf
- 48 Confidential Enquiry into Maternal and Child Health (CEMACH) (2007) *Diabetes in pregnancy: are we providing the best care? Findings of a national enquiry*
www.cemach.org.uk/Final%20CEMACH%20report%20070207.pdf
- 49 Confidential Enquiry into Maternal and Child Health (CEMACH) and the Royal College of General Practitioners (2006) *Diabetes in pregnancy – information leaflet*
www.cemach.org.uk/publications/CEMACH_leaflet_DiabetesPrimaryCare.pdf
- 50 Royal College of Nursing (RCN) (2004) *Adolescent transition care: Guidance for nursing staff*
www.rcn.org.uk/publications/pdf/adolescenttransitioncare.pdf
- 51 Datta J (2003) *Moving up with diabetes: the transition from paediatric to adult care*. London: National Children's Bureau





© Crown copyright 2007

279775 1p 2k Apr 07 (CWP)

Produced by COI for the Department of Health

If you require further copies of this title quote

279775/*Making Every Young Person with Diabetes Matter*

DH Publications Orderline

PO Box 777

London SE1 6XH

Email: dh@prolog.uk.com

Tel: 08701 555 455

Fax: 01623 724 524

Textphone: 08700 102 870 (8am to 6pm Monday to Friday)

www.dh.gov.uk/publications