Making every young person with diabetes matter

Introduction

The management of diabetes in children and young people is significantly different and more complex than it is for adults. With the increase in diabetes among this group, it is essential that effective targeted services are provided.

This Factsheet summarises the key points of *Making Every Young Person with Diabetes Matter: Report of the Children and Young People with Diabetes Working Group* (Department of Health (DH), 2007): http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=SS_GET_PAGE&siteId=en&ssTargetNodeId=566&ssDocName=DH_073674

Prevalence

The prevalence of Type 1, Type 2 and other forms of diabetes among children and young people is increasing.

Type 1 diabetes is rising in all age groups but particularly in under-five-year-olds[1]. The current estimate of prevalence in the UK is one per 700-1,000 children, that's about 25,000 people with diabetes under the age of 25.

Type 2 diabetes is also on the increase[2], 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[3]. This increase is not evenly spread across the population and predominantly reflects the positive correlation between deprivation and diabetes[4], as well as black and minority ethnic communities who are at increased risk of developing the condition.

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.

Current provision

Service provision has improved in the UK, but some say it still lags behind the provision available in much of Europe[5], and includes wide variation in care delivery and outcomes.

The provision of services in England by PCTs for children and young people is stretched, with an average case load of more than 100 children for every paediatric diabetes specialist nurse[6] – the Royal College of Nursing recommends a maximum of 70.

There is still a long way to go in terms of access to dietitians, psychologists, retinal screening and transition to adult services.

Current policy

Current policy for the treatment and welfare of children and young people is wide-ranging and thorough.

[1] Gardner SG, Bingley PJ, Sawtell PA, Weeks A, 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

[2] Fagot-Campagna A, Venkat Narayan KM, Imperatore G (2001) *Type 2 diabetes in children*. BMJ (Feb), 322: 377-8

[3] Ehtisham S, Hattersley AT, Dunger DB, Barrett TG, for the British Society of 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

[4] Marmot M (2004) *Status Syndrome*. London: Bloomsbury, pp. 115-18

[5] Danne T, Mortensen HB, Hougaard P et al. (2001) *Persistent differences among centers over 3 years in glycemic control and hypoglycaemia in a study of 3,805 children and adolescents with Type 1 diabetes from the Hvidore Study Group.* Diabetes Care, 24(8): 1342-7

[6] Diabetes UK (2005) *Your Local Care 2005 – a survey of diabetes services*, Research by Dr Foster and Diabetes UK

Key DH documents include:

Every Child Matters (2003) and *Every Child Matters: next steps (2004)*:
http://www.everychildmatters.gov.uk/health/

Our health, our care, our say: a new direction for community services (2006):
http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Modernisation/Ourhealthourcareoursay/index.htm

National Service Framework for Children, Young People and Maternity Services (2004):
http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/ChildrenServices/Childrenservicesinformation/index.htm

Health Reform in England – update and commissioning framework (2006):
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4137226

Joint planning and commissioning framework for children, young people and maternity services (2006):
http://www.everychildmatters.gov.uk/_files/312A353A9CB391262BAF14CC7C1592F8.pdf

Diabetes Commissioning Toolkit (2006):
http://www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=SS_GET_PAGE&siteId=en&ssTargetNodeId=566&ssDocName=DH_4140284

You're Welcome quality criteria (2005):
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4121562

Transition: getting it right for young people (2006):
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4132944

Commissioning

Commissioners and providers of diabetes services will need to have a good understanding of the needs of children and young people.

The *Joint planning and commissioning framework for children, young people and maternity services* includes a nine-step cycle for joint planning and commissioning, and there is another approach outlined in *Health Reform in England – update and commissioning framework.*

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.
- Children and Young People's Plan and children's trusts
- Pooled budgets and resources
- Improvement and performance management cycle
- Children's services inspection

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

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Designed and produced by: NHS National Diabetes Support Team website: www.diabetes.nhs.uk

Provision of services and organisation of care

However the model of care is designed, clear and easy access to specialist care will be required, as children with diabetes often have complex needs.

According to *Making Every Young Person with Diabetes Matter,* Children's services will now be provided according to the *Guide to Promote a Shared Understanding of the Benefits of Managed Local Networks* (DH, 2005): http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4114364

The preferred option to provide consistent high quality support for children with diabetes is a combination of local provision of care through local diabetes services and regional networks providing oversight, direction, support and combined use of resources.

Developing these regional networks involves collaboration between those commissioning children's diabetes services. It will 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, the PCT and/or children's trust commissioners, local diabetes networks, the voluntary sector and representatives from the strategic health authority (SHA).

More details on what local and regional diabetes services will need to provide can be found in *Making Every Young Person with Diabetes Matter*.

Workforce planning and development

Children and young people with diabetes and their families and 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). Along with skills specific to diabetes care, there are those more generic relating to working with children, young people and families are essential to develop.

The more generic skills are featured 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
- 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.

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Workforce planning is now moving away from the traditional idea of identifying the number of professional staff required to deliver a service, however, the new emphasis is on commissioning the workforce in the context of a model of care. Increasingly, National Workforce Competences are being used as a common currency for undertaking workforce planning.

A resource that can help with this is *Levels of Care: A New Language for Service Planning and Design* published by the NDST in 2006: http://www.diabetes.nhs.uk/downloads/levels_of_care1d.pdf

More information can also be found on the Skills for Health website: http://www.skillsforhealth.org.uk/

Service design

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*[7] criteria, 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.
- Be quality assured and have arrangements in place for local audit, benchmarking against national standards including the patient experience.

[7] DH (2005) *You're Welcome quality criteria: Making health services young people friendly*

Further information included in working group report annexe

- Lifestyle – activity, weight loss and nutrition
- Complications monitoring and management
- Structured education
- Sexual health
- Smoking, alcohol and drugs
- Management of diabetes at school
- Psychological input
- Support of child and family

Further information

For more information visit the NDST website at: www.diabetes.nhs.uk

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