Diabetes Care for Children and Young People

What Needs To Be Done

Dear Colleagues

The Diabetes NSF lays out specific standards that diabetes services for children and young people should attain by 2013 as well as ensuring they are included in the standards that also cover adults. The Children’s NSF highlights the importance of holistic care for those with Long-Term Conditions. However there is evidence that the needs of children and young people with diabetes are not being given a high enough priority by healthcare providers.

The recent Diabetes UK report, Your Local Care 2005 – a Survey of Diabetes Services provided by Primary Care Trusts in England, highlighted significant pressure on services for children and young people. It reported that only a quarter of PCTs had made improving paediatric diabetes care a priority in their local delivery plan at a time when 85% of children are not meeting their recommended blood glucose levels. The full report can be seen at: http://www.diabetes.org.uk/yourlocal_care2005/index.html

Provision of services for children and young people was also stretched with an average case load of more than 100 children for every paediatric diabetes specialist nurse. Only 54% of PCTs provided psychological support and half of PCTs do not have adequate systems for transferring young people to adult care.

This gap in provision has been recognised by the Department of Health and, with the support of the National Diabetes Support Team and Diabetes UK, a Children’s and Young People’s Diabetes Services Working Group has been established and its terms of reference are to identify:

“What needs to be done to enable the NHS and local care services to meet the needs of children and young adults with diabetes as framed in national guidance including the Diabetes and Children, Young People and Maternity Services National Service Framework’s and NICE guidelines and appraisals”
The group is considering type 1 and type 2 diabetes involving children and young people up to the age of 25. It will publish a report which will act as an implementation support tool and use any resources available to enable people to commission and deliver the services necessary to meet the commitments as framed in national guidance including the Diabetes and Children, Young People and Maternity Services National Service Framework’s and NICE guidelines and appraisals.

The final report will include a number of service models detailing how services for children and young people with diabetes should be structured in different clinical settings and the standards of care that should be provided.

This group has recently held its inaugural meeting where a number of challenges to improving diabetes care for children and young people were identified. Separate work programmes involving group members have been set up and these cover:

- Psychological and educational support
- IT and the worldwide web including audit
- Models of care
- Developmental / transition
- Interdepartmental DfES (schools), DWP (benefits)

For more information about the group including minutes of the first meeting, presentations and details of the above work programmes and their membership visit [http://www.diabetes.nhs.uk/Work_areas/Children_and_Young_People.asp](http://www.diabetes.nhs.uk/Work_areas/Children_and_Young_People.asp)

To further support the work of the group the National Diabetes Support Team have also established a Discussion Forum covering issues surrounding care for Children and Young People. This can be accessed at [http://www.diabetes.nhs.uk/forum/forum.asp?ForumID=7](http://www.diabetes.nhs.uk/forum/forum.asp?ForumID=7)

We welcome contributions from anyone involved in the care of children and young people with diabetes whether healthcare professionals, parents or carers as well as children and young people with diabetes. These can be emailed to cyp@diabetes.nhs.uk.

Although it is very early days I am confident that with the wholehearted commitment of group members and the rest of the diabetes community we will enable a thorough analysis of the needs of children and young people with diabetes and produce positive proposals for improving that care.

**Professor Peter Hindmarsh**
Chair
Diabetes NSF Standards  For Children and Young People To Be Reached by 2013

**Standard 3**
All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.

**Standard 5**
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 the control of their blood glucose and their physical, psychological, intellectual, educational and social development.

**Standard 6**
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.

**Standard 8**
All children, young people and adults with diabetes admitted to hospital, for whatever reason, will receive effective care of their diabetes. Wherever possible, they will continue to be involved in decisions concerning the management of their diabetes.

**Standard 10**
All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.

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**The National Service Framework for Children, Young People and Maternity Services**

**Standard 1**
The health and well-being of all children and young people is promoted and delivered through a co-ordinated programme of action, including prevention and early intervention wherever possible, to ensure long term gain, led by the NHS in partnership with local authorities.

**Standard 2**
Parents or carers are enabled to receive the information, services and support which will help them to care for their children and equip them with the skills they need to ensure that their children have optimum life chances and are healthy and safe.
Standard 3
Children and young people and families receive high quality services which are coordinated around their individual and family needs and take account of their views.

Standard 4
All young people have access to age-appropriate services which are responsive to their specific needs as they grow into adulthood.

Standard 6
All children and young people who are ill, or thought to be ill, or injured will have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness.

Standard 7
Children and young people receive high quality, evidence-based hospital care, developed through clinical governance and delivered in appropriate settings.

Standard 8
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, which enable them and their families to live ordinary lives.

Standard 10
Children, young people, their parents or carers, and health care professionals in all settings make decisions about medicines based on sound information about risk and benefit. They have access to safe and effective medicines that are prescribed on the basis of the best available evidence.

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National Diabetes Support Team
working in partnership with

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