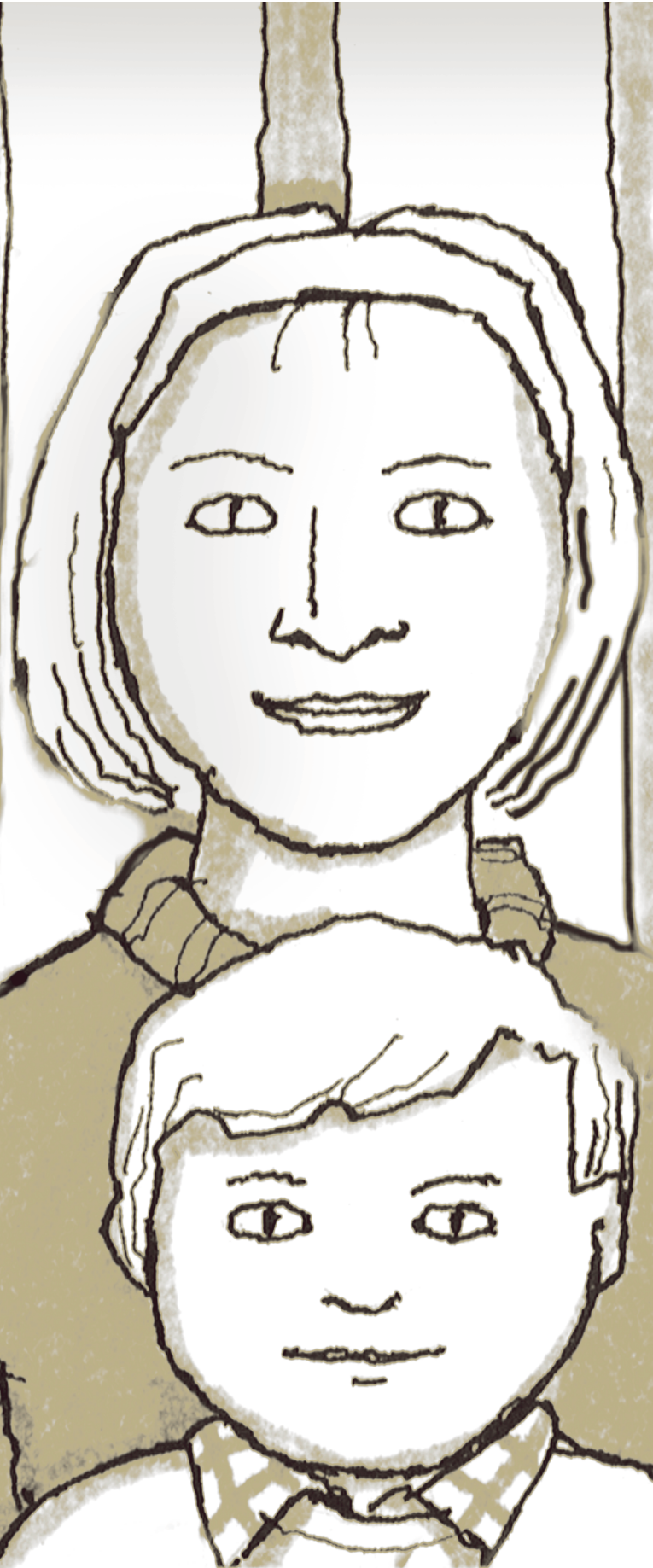




Royal College  
of Nursing



**Specialist  
nursing services  
for children and  
young people  
with diabetes**



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Contributions to the guidance were made by:

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### Note

This guidance replaces *The role and qualifications of the nurse specialising in paediatric diabetes* that was produced by the RCN Paediatric Diabetes Special Interest Group in 1998.

# Specialist nursing services for children and young people with diabetes

An RCN guidance

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# Introduction

## The disease and its incidence

Diabetes is the most common metabolic disease in children and young people, and its incidence is increasing. In Scotland, for example, there are around 2,000 children under 16 years old with diabetes, with an annual incidence of 25 per 100,000 population – and a tripling of cases in the last 30 years (SIGN, 2001). The National Collaborating Centre for Women's and Children's Health (NCC-WCH) reported in 2004 that around 16,000 children and young people aged 0-16 years had attended paediatric diabetes centres in England. Ninety-five percent of these children had Type 1 diabetes (NCC-WCH, 2004).

Type 1 diabetes is a continuing hormonal deficiency disorder that has significant short-term impact on health and lifestyle and is associated with major long-term complications and reduced life expectancy. People with Type 1 diabetes require insulin-replacement therapy from diagnosis.

A very small percentage of children have other forms of diabetes such as Type 2 (linked with rising levels of obesity in children), MODY (maturity onset diabetes in the young), or neonatal, infantile and diabetes secondary to other conditions like cystic fibrosis or chemotherapy. Whichever form of diabetes is diagnosed, children and young people and their families have particular needs which differ from those of adults with diabetes.

## Managing diabetes

The overall goal of managing diabetes in children and young people is to enable the child or young person to lead a life as free as possible from the clinical and psychosocial complications of the disease. This requires that blood glucose is well controlled (an HbA1c level of less than 7.5 per cent without frequent disabling hypoglycaemia (NCC-WCH, 2004) and that adverse lifestyle factors are modified to prevent long term complications. Most importantly, children and young people must be involved in making decisions about their management (NCC-WCH, 2004) and supported to

manage their diabetes as part of their daily lives. A combination of specialist paediatric and diabetes care is required for children and young people with diabetes to be well-adjusted and lead long and healthy lives in families which have come to terms with the condition.

## Paediatric diabetes nurse specialists

Children and young people with diabetes should be offered an ongoing integrated package of care by a multidisciplinary paediatric diabetes care team with the required competencies (NCC-WCH, 2004). Paediatric diabetes specialist nurses are at the core of such teams, providing expert care to children and young people with diabetes. The specific needs of these children and young people can only be met by a nurse who has extended skills in paediatric diabetes care, is an educator, counsellor, manager, researcher, communicator and innovator, and who is a qualified children's nurse and therefore accountable for their own actions. The peripatetic nature of paediatric diabetes nurses enables them to develop close relationships with families which are not always possible in a clinical setting.

## This document

Specialist training in both children's nursing and in paediatric diabetes care is available, and should be mandatory for nurses working with children who have diabetes. This document sets out the role and qualifications of nurses who specialise in paediatric diabetes care and makes recommendations about educational preparation. It also reinforces the necessity for these nurses to be at the forefront of providing services for children with diabetes, especially in the context of the increasing incidence of the condition and the changing nature of health care provision.

## 1

# Background, purpose and sources

The RCN Paediatric and Adolescent Diabetes Special Interest Group was established in 1990 to offer support and development to nurses with a major role in caring for children and young people with diabetes. In 1993, the group published guidance on the role and qualifications necessary for nurses who care for children and young people with diabetes and their families. The document was updated in 1998 and continued to provide employing authorities with a basis on which to develop their services. The document set standards that many NHS trusts aimed to achieve when employing paediatric diabetes nurses, enabling more families of children with diabetes to have access to appropriately qualified nurses for advice and guidance.

This third edition updates the 1998 guidance to take into account developments in the management of diabetes in children and young people, as well as developments in nursing and in health care generally, particularly the development of national service frameworks (DH, 2004, 2005a, 2005b; NHS Scotland 2004, 2005; DHSSPSNI, 2005; NHS Wales 2003, 2005) and national occupational standards (Skills for Health, 2005).

The purposes of this revised guidance document are to:

- ◆ guide specialist nurses in providing safe, effective and accountable care to children and young people with diabetes and their families
- ◆ inform planning and commissioning of comprehensive diabetes services for children and young people (and their families)
- ◆ underpin the development and review of services
- ◆ support managers in workforce planning and preparing role requirements/job descriptions for specific posts.

As well as summarising these nurses' roles and necessary qualifications, we have provided guidance on caseloads and nurse/patient ratios, as well as standards for service development and review.

## Sources

The primary source for this document is the second edition of *The role and qualifications of the nurse specialising in paediatric diabetes* (RCN Paediatric Diabetes Special Interest Group, 1998). RCN competencies for specialist paediatric diabetes nurses were published in 2004 as part of the competency framework in *Services for children and young people: preparing nurses for future roles* (RCN, 2004a). The RCN publication *Paediatric diabetes: RCN guidance for newly appointed nurse specialists* complements this guidance (RCN, 2004b). Role descriptions in section 2 are taken from this document. The relationship between Skills for Health competencies (Skills for Health, 2005) and the competencies of nurses specialising in paediatric diabetes care is also demonstrated in the RCN competency document (2004a).

## 2

## Qualifications and role

### Qualification as a children's nurse

The RCN (2003) states that children and young people's nursing practice is underpinned by beliefs that are based on the nature of the child or young person and their status and rights within both the family and society. As well as the functions identified in the RCN's (2004a) definition of nursing, children's nurses focus on assisting children and young people and their families in preventing or managing the physiological, physical, social, psychological and spiritual effects of a health problem or condition and its treatment (RCN, 2003).

The health care needs of children and young people are different from those of adults. Children and young people should always be looked after by health care professionals who hold a recognised qualification in caring for children, as well as relevant specialist qualifications and expertise (Bristol Royal Infirmary Final Report, 2001; RCN, 2004a). According to the Audit Commission (1993) there are two main areas of difference between nursing children and nursing adults:

1. the skills required to nurse the child, such as observation techniques and psychological support
2. involving parents in care requires special skills in teaching and support.

A child or young person with diabetes has specific nursing needs that can only be met by an experienced children's nurse who has additional diabetes-related theoretical and practical knowledge. Anyone undertaking a specialist nursing role caring for children and young people must be competent in general children's nursing (RCN, 2004a) at a minimum. This includes competence in:

- ◆ legal, ethical and rights-based care of children and young people
- ◆ protection of children and young people
- ◆ health promotion and growth and development needs that include children/young people with disabilities/learning disabilities

- ◆ communicating with children of different ages/cognitive abilities and their families
- ◆ physiological, physical, social and emotional responses of children and young people to health conditions and their treatment
- ◆ child and adolescent mental health (Tier 2 of CAMHS model, RCN, 2003)
- ◆ family responses/adaptation to long term conditions/disabilities.

### Qualifications for nurses specialising in paediatric diabetes care

There are three levels to support role development, staffing and remuneration decisions for these nurses:

- ◆ specialist nurse
- ◆ clinical nurse specialist
- ◆ consultant nurse.

The nurse will continue to develop expertise in general children's nursing and may incorporate advanced practice skills such as prescribing to supplement the specialist nursing role.

Skill components are drawn from *Services for children and young people: preparing nurses for future roles* (RCN, 2004a). Higher levels build on the qualifications specified for the first level, specialist nurse.

### Qualifications: Paediatric diabetes specialist nurse

*Agenda for Change* level 6.

Level of functioning: starts at advanced beginner (in the specialty) and becomes proficient

	Essential	Desirable
<b>Professional qualifications</b>	<ul style="list-style-type: none"> <li>Registered children's nurse</li> <li>Teaching/assessing qualification</li> <li>First degree or working towards one</li> <li>Specialist diabetes qualification or working towards one, e.g. 'Management of Childhood Diabetes' course or similar</li> </ul>	<ul style="list-style-type: none"> <li>Community nursing qualification (e.g. NMC specialist community practitioner – community children's nursing qualification)</li> </ul>
<b>Experience</b>	<ul style="list-style-type: none"> <li>Minimum of two years' post-registration experience caring for children and young people with diabetes</li> <li>Proven management experience (ward level or equivalent)</li> <li>Proven interest in teaching and counselling</li> </ul>	<ul style="list-style-type: none"> <li>Experience as a paediatric diabetes link nurse</li> <li>Experience of working in a community setting</li> </ul>
<b>Skills</b>	<ul style="list-style-type: none"> <li>Excellent communication skills</li> <li>Teaching and presentation skills</li> <li>Ability to work in collaboration with other professionals/teams</li> <li>Knowledge of standards setting, audit and research</li> <li>Good IT skills</li> </ul>	
<b>Other</b>	<ul style="list-style-type: none"> <li>Car driver/owner</li> </ul>	

### Qualifications: Paediatric diabetes clinical nurse specialist

*Agenda for Change* level 7.

Level of functioning: starts proficient and becomes expert.

	Essential	Desirable
<b>Professional qualifications</b>	<ul style="list-style-type: none"> <li>Has or working towards a masters degree encompassing a specialist diabetes component</li> </ul>	
<b>Experience</b>	<ul style="list-style-type: none"> <li>Minimum of 5 years' experience in paediatric diabetes nursing, including at least three years as a paediatric diabetes specialist nurse</li> </ul>	
<b>Skills</b>	<ul style="list-style-type: none"> <li>Involvement in research and audit</li> <li>Clinical leadership and knowledge</li> <li>Time management</li> </ul>	

## Qualifications: Paediatric diabetes nurse consultant

*Agenda for Change* 8B minimum.

Level of functioning: expert

	Essential	Desirable
<b>Professional qualifications</b>	<ul style="list-style-type: none"> <li>• Masters degree encompassing specialist diabetes component</li> <li>• May be working towards or considering PhD</li> </ul>	
<b>Experience</b>	<ul style="list-style-type: none"> <li>• Minimum of five years' experience as paediatric diabetes clinical nurse specialist</li> <li>• Able to demonstrate extensive experience of caring for children and young people of different age groups with Type 1 diabetes</li> <li>• Able to demonstrate knowledge of more uncommon types of diabetes in children and young people e.g. Type 2, secondary diabetes, infantile, neonatal, MODY</li> <li>• Demonstrable teaching experience at diploma level and above</li> <li>• Demonstrate different teaching methods for educating children and young people about their diabetes</li> <li>• Demonstrable participation in research and audit</li> <li>• Experience of working in a community and secondary care setting</li> </ul>	<ul style="list-style-type: none"> <li>• Experience as a paediatric diabetes specialist nurse at a highly specialised level</li> <li>• Examples of innovative ways of working</li> <li>• Experience of some of the less common types of diabetes in children and young people such as Type 2, secondary to cystic fibrosis or steroids, neonatal, MODY, DIDMOAD (Wolfram syndrome).</li> </ul>
<b>Skills</b>	<ul style="list-style-type: none"> <li>• Proven teaching and presentation skills at diploma level and above</li> <li>• Proven research skills and knowledge</li> <li>• Extensive clinical leadership and knowledge</li> </ul>	

## Role descriptions

### Paediatric diabetes specialist nurse

These nurses establish a holistic and developmental approach to diabetes care in patients from infancy to adolescence. They achieve this by setting realistic objectives according to the age and level of understanding of the child, and the needs of the family. In conjunction with other members of the paediatric diabetes team, the nurse co-ordinates care for children and young people with diabetes and their families, assessing, developing, implementing and evaluating programmes of holistic care and providing specialist clinical advice to health carers and others.

The nurse uses clinical judgement and autonomous decision-making about the specialist nursing care and management of patients and, after assessing a patient's needs and preferences, undertakes a range of specialist clinical actions within a specific setting.

The responsibilities of a paediatric diabetes specialist nurse based in hospital or community and working as a member of the team specialising in the management of childhood diabetes are listed here:

#### Specialist diabetes care management:

- ◆ assess, plan, implement and evaluate holistic specialist diabetes nursing care in the hospital or home setting
- ◆ act as a source of specialist advice for children, young people and families on the nursing care and management of diabetes, including the provision of basic dietary advice and the management of acute complications
- ◆ provide individual specialist teaching for children, young people and families, facilitating the development of self care skills and knowledge, at time of diagnosis and in planned, ongoing, age-appropriate education, both individually and in groups.

#### Specialist psychological/psychosocial/physical and clinical interventions:

- ◆ provide ongoing counselling and support to children, young people and families
- ◆ provide information about diabetes, sick day rules, lifestyle changes and long-term implications for children, young people and families

- ◆ undertake nurse-led clinics and baseline assessments, formulating clinical management plans
- ◆ instigate treatment and adjust insulin according to protocols
- ◆ undertake specialist investigations, interpret results and initiate appropriate action.

#### Practice and service development:

- ◆ contribute to policy, standards and development of specialist diabetes care delivery strategies
- ◆ implement and evaluate specialist diabetes care innovations across the catchment area of their organisation.

#### Teaching and education:

- ◆ provide specialist education/training for nurses and other professionals.

#### Professional, ethical and legal practice:

- ◆ act in accordance with NMC *Code of Professional Conduct* (2004)
- ◆ act as a source of specialist advice for staff on the specialist nursing care and management of diabetes.

#### Development of self and others:

- ◆ maintain own professional development, including regular training in paediatric resuscitation and child protection
- ◆ support the development of skills and knowledge amongst students and junior members of the team.

#### Leadership:

- ◆ act as a role model for junior members of staff and non-specialists.

#### Research and evidence-based practice:

- ◆ identify opportunities for clinical audit and research, promoting a culture of research awareness within the specialist area.

#### Communication:

- ◆ maintain effective communication with children, young people and families to give information about paediatric diabetes to enable informed choices
- ◆ establish and maintain effective communication with members of the multidisciplinary team.

**Working with other professionals/agencies:**

- ◆ liaise with members of the primary care team and other organisations i.e. schools to provide co-ordinated packages of care.

**Knowledge and information management:**

- ◆ interpret and analyse information from a variety of sources to underpin decision-making
- ◆ maintain accurate and legible clinical and legal documents.

**Health, safety and security:**

- ◆ promote best practice in health, safety and security in self and others in area of specialist practice.

**Equality, diversity and rights:**

- ◆ enable others to exercise their rights and promote equality and diversity.

**Paediatric diabetes clinical nurse specialist**

In conjunction with other members of the multidisciplinary diabetes team, clinical nurse specialists enable the development of district-wide services for children with diabetes, families and professionals by identifying needs and facilitating the implementation of services, whilst setting standards for care. They use clinical judgement and autonomous decision-making about the specialist nursing care and management of patients, undertaking a range of specialist clinical actions across a variety of settings following assessment of patients' needs and preferences.

As well as the responsibilities of a paediatric diabetes nurse (see above), a clinical nurse specialist supports the development of district-wide services for families and professionals with additional responsibilities listed here.

**Specialist diabetes care management:**

- ◆ lead and develop specific specialist education and training programmes for children, young people, families and lay carers, facilitating the development of self-care skills and knowledge.

**Specialist psychological/psycho-social/physical and clinical interventions:**

- ◆ develop and evaluate counselling strategies and provide support to children, young people and families

- ◆ undertake nurse-led clinics, baseline assessments and annual reviews.

**Practice and service development (including quality):**

- ◆ formulate policy, standards and specialist diabetes care delivery strategies and protocols
- ◆ lead the implementation and evaluation of specialist diabetes care innovations across the catchment area of the organisation to meet national and international standards
- ◆ identify needs and facilitate implementation of services
- ◆ work closely across the primary and secondary care providers to establish and maintain best practice for transition into adult diabetes services.

**Teaching and education:**

- ◆ lead and develop specific specialist education programmes for nursing and other professionals across all care sectors including education, as well as patients, their families, carers and the general public.

**Professional, ethical and legal practice:**

- ◆ act as a prime source of authority for specialist advice for staff on the specialist nursing care and management of children and young people with diabetes.

**Development of self and others:**

- ◆ enhance the development of skills and knowledge of team members, providing clinical supervision for junior team members.

**Leadership:**

- ◆ lead and manage personnel, services and resources, facilitating teamwork through the identification of a shared vision.

**Research and evidence-based practice:**

- ◆ initiate nursing research, clinical audit and development programmes
- ◆ write for publication on issues within professional practice and encourage junior team members to share best practice examples.

**Communication:**

- ◆ develop and initiate strategies to effectively communicate key messages and information about paediatric diabetes to enable informed choices.

**Equality, diversity and rights:**

- ◆ lead and implement practices, policies and strategies which enable others to exercise their rights, promotion of equality and diversity.

**Paediatric diabetes nurse consultant**

Nurse consultants provide the highest level of expert nursing practice for paediatric diabetes, acting autonomously and with authority, using advanced knowledge and skills, to shape and develop high quality paediatric diabetes services across their organisation and beyond.

With the same responsibilities as paediatric diabetes nurses and paediatric diabetes clinical nurse specialists, paediatric diabetes nurse consultants also provide additional expertise across special groups and with national or international responsibilities as listed here.

**Specialist diabetes care management:**

- ◆ provide expert clinical care for a caseload of children and young people with rare/unusual forms of diabetes and those with persistently poorly-controlled diabetes.

**Practice and service development (including quality):**

- ◆ act as a catalyst for change, challenging professional and organisational boundaries, generating new solutions which will best meet the needs of the children or young people and their families and which are sensitive to local challenges and resources
- ◆ lead the implementation and evaluation of specialist diabetes care innovations across the catchment area of the strategic health authority (or part of) to meet national and international standards
- ◆ be actively involved in professional and other networks for the improvement of paediatric and adolescent diabetes services.

**Teaching and education:**

- ◆ proactively identify educational needs across the strategic health authority area, leading and developing multidisciplinary training and development, lobbying for resources as necessary

- ◆ work in partnership with education providers to ensure that continuing professional development provision meets local needs, participating in the development of new courses as required.

**Leadership:**

- ◆ contribute to policy-making at local, strategic health authority, national and international levels.

**Research and evidence-based practice:**

- ◆ undertake research projects in conjunction with education providers, participating in the formation of research bids and national centre research and clinical audit activities
- ◆ facilitate multidisciplinary and cross-sector clinical audit activities.

**Communication:**

- ◆ facilitate communication with teams, other centres and networks by attending suitable local, national and international diabetes and paediatric events, organising events when appropriate, disseminating information gained and writing for publication.

**Support and development**

Establishing a support network and appropriate supervision are essential prerequisites for developing and maintaining expertise and delivering best practice. Maintaining links with the local community children's nursing team will be part of this process, as will links with the adult diabetes nursing team, particularly when planning and organising transition services. Nurses must ensure they receive mandatory and other regular paediatric updates, especially in child protection (see *Safeguarding children and young people*, page 11).

Although they are responsible for their own professional development, nurses can expect support with time and funding from their employing authority. This is particularly important for those who work within a predominantly adult-based service and may not have access to paediatric diabetes networks.

Support can also be obtained through local and UK networks such as the RCN special interest group. Other opportunities for support and development include spending a day observing another paediatric diabetes nurse to observe a role model, attending study days and conferences and undertaking courses. Section 6 gives details of organisations and websites that provide information and support.

## 3

## Specialist nursing services

### Team working

The first objective of paediatric and adolescent diabetes specialist nurses is to empower those affected by diabetes by providing information, support and advice about the condition from the time of diagnosis. By enabling a good understanding of the condition, and through a holistic, collaborative and co-ordinated approach to care, nurses help children and young people as well as their families to reach their goals of self-management.

The intricate management of childhood diabetes care lends itself to a specialist team approach. The successful team has clear goals and distinct, complementary roles for its members, as well as a common philosophy of care. A team approach to paediatric diabetes care has been shown to enhance parental satisfaction and is therefore likely to have beneficial effects on motivation and on outcome, as is the case when children are managed at home on diagnosis. The active involvement of the child and carers as members of the paediatric team is essential to promote self motivation and empowerment.

A clinical nurse specialist in paediatric diabetes is central to the effective functioning of the team and must aim to co-ordinate and implement the overall strategy for diabetes care in their area. The role includes acting as a consultant and educational resource for other professionals striving towards improved, evidence-based management of diabetes in health, social care and educational settings.

Ways of working within the team and scope of nursing practice will vary according to local requirements, and to the knowledge and experience of the individual nurse. However, there are common service principles that can be used to guide development of new services and review existing ones:

- ◆ specification of the service
- ◆ ways of working
- ◆ the nursing role (as defined above).

### Specification of the service

When specifying how a service will operate, it is important to define its scope and standards. Here are elements which should be included in a specification:

#### ◆ Mission statement

A mission statement or service outline is a way of communicating to children, young people, families and other professionals about the paediatric and adolescent nursing service. It should be developed with other members of the paediatric team and include:

- ◆ what the service is, and who it is for
- ◆ aims and objectives of the service
- ◆ specific information about how the service is provided and how to access it.

#### ◆ Caseload

A caseload is a population for which a nurse has designated responsibility. In a paediatric diabetes service, the specialist nurses' caseloads will usually include children and young people with diabetes from birth until managed transition to adult services. The caseload needs to be clearly defined and regularly reviewed. It should include:

- ◆ referral sources and criteria for accepting/redirecting referrals
- ◆ type of service to be offered such as home visits, school visits, nurse-led clinics, joint transition clinic
- ◆ location and extent of integration across tertiary, secondary or primary care
- ◆ population served, including geographical area, numbers of children with diabetes, age limits
- ◆ social and environmental factors affecting the client group in the area.

Defining the caseload and making this information public (as part of the mission statement or service outline) is essential for managing the expectations of the families and other professionals. Regular audit of referral criteria and outcomes informs workload management and provides evidence for requesting additional resources.

#### ◆ Nurse-to-patient ratio

In 1993, a review undertaken through the RCN paediatric diabetes special interest group showed an average of 137

children per nurse (whole time equivalent or WTE), where the area covered was up to 30 square miles. In 1998 the RCN recommended a maximum case load of 100 children per paediatric diabetes liaison nurse (WTE) with considerably less for a clinical nurse specialist.

Since then the role of the paediatric diabetes nurse has changed, with recommendations for home stabilisation (NCC-WCH, 2004), emphasis on patient empowerment through education, changes in insulin regimes (NCC-WCH, 2004), and the effects on the nurse's time of the need for life-long learning. As a result, the RCN is recommending a maximum of 70 patients per paediatric diabetes nurse (WTE). This will need to be reduced in caseloads where there is:

- ◆ a wide spread very rural area, involving much travel for the nurse
- ◆ areas of high deprivation and poverty
- ◆ areas where there are large social problems e.g. areas with many refugees
- ◆ areas where there is frequently a language barrier and interpreters are needed
- ◆ many complicated or less common types of diabetes e.g. a semi-regional centre for cystic fibrosis and diabetes.

Appropriate reductions in caseload will be required where the nurse has additional responsibilities, for example, for service development, staff and service management, representation for service users and staff locally regionally or nationally.

Where there is only one nurse specialising in paediatric diabetes, that nurse will require cover and professional support from paediatric community colleagues and/or adult diabetes specialist nurses.

#### ◆ Practice standards

Organisational protocols and guidelines that are used to underpin paediatric diabetes practice must follow National Institute for Health and Clinical Excellence (NICE) guidelines, as well as standards for children's services such as the National Service Frameworks for children and for long-term conditions (DH, 2005a and 2005b). Protocols and guidelines that are used or developed should cover all aspects of the diabetes specialist nurse role. They should also be agreed by local management and reviewed regularly. As far as possible they should be evidence-based.

Networking will identify whether the RCN group or other specialist teams have already developed a similar policy or guideline that would meet local service needs.

Practice standards also provide a mechanism for developing benchmarks and reviewing, or for comparing practice as part of the nurse's clinical governance responsibilities.

#### ◆ Safeguarding children and young people

Local child protection policies form the basis of action when there is cause for concern. However, a diabetes nurse may cover a wide geographical area and have to work to different policies and child protection leads and contacts. Nurses should have access to annual child protection updates covering health, social services, education and police.

#### ◆ Information management

Communicating and providing information is central to the role of nurses specialising in diabetes care. Good information systems need to be in place to ensure that up-to-date information resources can be provided in a form that children, young people and families can understand and use for themselves. Patients and carers should be offered information about local or national support groups and the potential benefits of membership (NCC-WCH, 2004). A library of pre-prepared information, booklets and web addresses, for example, will ensure such resources are at hand when needed.

All patient contacts must be documented in keeping with NMC record keeping guidelines (NMC, 2005). Diaries, message books and so on that contain data about patients are legal documents. They must be stored like records and are subject to confidentiality policies. The format and location of records is a matter for local policy. However, we recommend that care plans are 'held by the person and regularly evaluated and reviewed with them by the clinical team,' (DH, 2005a). This is especially important for a child or young person who is expected to perform their own blood glucose monitoring and insulin injections. Moves towards electronic records that are shared between health and social services teams (with appropriate confidentiality safeguards) should improve communication and co-ordination of services.

#### ◆ Infrastructure

The paediatric diabetes specialist role sometimes requires the nurse to be a car driver and issues such as insurance, travel limitations and allowances and lone worker safety need to be considered. Insurance may be affected if the nurse is using their own car for business use. Other factors to consider are:

- ◆ membership of a car recovery scheme
- ◆ carrying documents, equipment and resources safely out of sight
- ◆ protocols for reporting planned work locations.

The NHS Counter Fraud and Security Management Service (2005) guidance *'Not Alone': a guide for the better protection of lone workers in the NHS* sets the standard for local policies to support staff who may work alone. In particular, nurses are advised to carry out a risk assessment prior to any home visit. If a risk is identified the family should be seen in a clinic or some safe establishment such as a school.

To support nurses in delivering a quality service, employers should consider the following when a post is established or reviewed:

- ◆ administrative support
- ◆ office space
- ◆ funding for mandatory updating and ongoing education
- ◆ cover
- ◆ supervision
- ◆ management arrangements.

Guidance developed by the RCN Paediatric Oncology Nurses Forum (RCN, 2000) includes a set of questions supporting the development of specialist services and nursing roles.

## Ways of working

Points to consider when establishing ways of working:

### ◆ Communication

An office-based answer phone is essential so that messages can be left and information given about how to obtain emergency help, providing 24 hour support. A system should be set up to ensure that messages are checked frequently and appropriate responses made. Ensuring that all those involved in diabetes care know how to make contact maintains the nurse's role of co-ordinator and single point of contact.

Most importantly, children, young people and families need to know when and how to make contact. The use of pager, mobile phone, business cards, letters, information in writing to introduce new team members

and so on are all strategies to ensure access to support and advice. However, staff should never give out home or personal numbers to clients.

### ◆ Team communications

Regular team meetings are important to keep other team members up to date. Frequency of meetings will vary depending on the caseload and the amount of information to discuss. Service developments, clinical governance, research and educational issues should also be on the agenda.

### ◆ Uniform

Clinical nurse specialists do not generally wear a uniform when visiting children and families in their homes. There should be an organisational policy related to dress and appearance that includes allowances for wearing nurses who do not wear a uniform. Nurses should present a clean, tidy, professional appearance to inspire confidence and trust and avoid unusual clothes, shoes, hair styles or jewellery.

### ◆ Workload planning

Advice for nurses new in post includes:

- ◆ write out a plan with objectives to achieve within a specific period of time
- ◆ schedule any regular meetings and clinics in a diary
- ◆ lunch and other breaks are legal as well as practical necessities, so plan them into daily schedules
- ◆ don't overbook appointments (especially for home or school visits), and allow for adequate time for travelling
- ◆ anticipate that plans may need to change at short notice for emergencies or newly diagnosed clients.

### ◆ Home visits

A nurse visiting a child or young person and family at home is a guest and must respect their home and privacy. Permission needs to be sought from the child or young person and parent before taking a student or colleague to a meeting. Arriving on time and establishing beforehand how long the visit is likely to take allows the family to make their own plans, as does telephoning to let them know of late arrival; they may wish to rearrange the date.

## 4

## Summary and recommendations

This guidance recognises the dynamic nature of services in the fields of children and young people's health care and diabetes. It incorporates recommendations and guidelines published since 1998 related to child health and diabetes care management and provides a framework to ensure that nursing services for children with diabetes continue to develop as part of the overall care provision for this group. Key recommendations:

1. **Qualifications:** nurses caring for children with diabetes must be qualified children's nurses.
2. **Caseload:** There should be a maximum caseload of 70 children (WTE) per nurse, reduced in areas with a large geographical spread, cultural variations and language barriers, much social deprivation, and caseloads specialising in less common forms of diabetes
3. **Paediatric diabetes team:** The nurse should work within a multidisciplinary paediatric diabetes team (NCC-WCH, 2004)
4. **Professional support:** In areas where there is only one nurse specialising in paediatric diabetes they will require cover and support from colleagues
5. **Infrastructure:** access to secretarial and IT support is essential for the nurse to fulfil their administrative commitments
6. **Professional development:** A nurse specialising in paediatric diabetes is responsible for their own professional development but it is the responsibility of their employer to support and assist in funding this. Regular child protection and diabetes related updates should be a high priority in professional development.

## 5

## Next steps

The RCN Paediatric and Adolescent Diabetes Group would appreciate your feedback on this guidance and role framework so that we can update and amend the document in future. If you would like to comment on the framework, please write to:

RCN Adviser in Children's and Young People's Nursing  
Royal College of Nursing  
20 Cavendish Square  
London  
W1G 0RN.

The RCN fully supports its members in raising concerns about the care of children and young people. If you feel you are not getting the help you need in your workplace, contact RCN Direct on 0845 772 1066 or ring your local RCN office. You will find the appropriate contact numbers in your RCN *Members' handbook*.

## 6

## References and resources

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## Resources and contacts

### **RCN Paediatric and Adolescent Diabetes Group**

For information visit the forum pages of the RCN's Children and Young People's Zone. This site also has information about the **RCN Diabetes Nursing Forum** and the **RCN Community Children's Nursing Forum**  
[www.rcn.org.uk/cyp](http://www.rcn.org.uk/cyp)

### **Diabetes UK**

[www.diabetes.org.uk](http://www.diabetes.org.uk)

### **Juvenile Diabetes Research Foundation**

[www.jdrf.org.uk](http://www.jdrf.org.uk)







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