

# COMPLEX NEEDS

**The Nursing Response to Children and Young People  
with Complex Physical Healthcare Needs**

**June 2007**

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### \*Copies of the Appendices are available from:

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Or they can be downloaded from: [www.dhsspsni.gov.uk/latestpublications](http://www.dhsspsni.gov.uk/latestpublications)

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## Executive Summary

The aim of this project, as set by DHSSPS, was to undertake a review of nursing services in order to ensure that they are facilitated to fully support and respond to children with complex needs and their families, and for them to work in partnership with other professions and agencies. However this review needed to take into account the wider service context and commissioning frameworks.

The project commenced in November 2006. In addition to reviewing the international literature, information was gathered from 30 parents, nearly 200 frontline professionals and 30 service managers. Throughout the project, participants repeatedly demonstrated an interest and enthusiasm to produce more efficient and effective service responses to an estimated 500 children and families in Northern Ireland which to date has been ad hoc and often uncoordinated. Many inequities exist in provision across Northern Ireland. Yet individual packages can be a high expense to HPSS.

A series of recommendations have been developed which command a consensus among informants. Chief among them are:

- The need for a specific service framework to guide the commissioning and delivery of services to this client group.
- The development of an assessment instrument for common use throughout Northern Ireland to assist in determining service needs.
- A focus on individualised, family-centred planning and delivery of support services, and improved co-ordination arrangements among them.
- The need for assured funding for community children's nursing services and the provision of flexible 'out-of-hours' responses by nurses in the community.
- Greater interchange between children's nursing in acute and community settings; and an audit of community nursing services.
- Joint planning of provision with the Department of Education; notably on the development of joint funding arrangements and having common healthcare assistant posts.
- Regional training initiatives for nurses and healthcare assistants in the care of the children and their families.
- Improved transition planning, notably from acute hospitals to community; school entry, school transfer and school leaving.
- Review by DHSSPS of the provision of equipment.
- Review by DHSSPS and the Health & Social Care Authority of respite arrangements for these children and families and an increase in the availability of appropriate respite options.

The importance is stressed of continuing the momentum generated by the Project. An action plan for taking forward the work is proposed. For too long this issue has drifted to the detriment of parental and practitioner morale. A common consensus and will for action exists.

Further work is required around palliative care services for children and 'end-of-life' issues along with appropriate service provision to these families when the children become adults.

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## Section 1: Introduction to the Project

At the outset, we would like to pay tribute to the parents and professionals involved with this group of children. They truly have gone the extra mile in providing the children with loving homes, exemplary care and a dedication that has overcome many obstacles and disappointments in what is an evolving area of community health services.

Much of what is written in this report is critical – hopefully constructively so - of our current systems and the way support services have been provided to these children. This has forced people to act in ways that are not always productive or efficient. New wine has been poured into old bottles. Our hope is that we can learn from all these experiences so that more suitable service responses are shaped for the new wine that we as a caring society need to nurture and mature.

### Terms of reference

The aim of this project as set by DHSSPS was to ensure that nursing services are facilitated to fully support and respond to children with complex needs and their families in partnership with other professions and agencies. This includes Community Children's Nurses (CCNs), Community Learning Disability Nurses (CLDNs) and School Nurses as well as those working with children in acute hospitals. These nursing services should significantly contribute to quality of life ensuring that children, young people and their families are enabled to experience a life that is as full and as normal as possible.

In particular the project should identify:

- Model(s) of service delivery for Northern Ireland
- Systems which are required to support the delivery of recommended models of service.
- Elements of systems in which nursing has a particular responsibility to take the lead in securing effective development, delivery and review of services.
- Workforce requirements, training and development needs; funding arrangements and outcome/performance measures.

Although the aims were specific to nursing, these had to be set within a broader service context. This included community health and social services, acute hospital services as well as educational and voluntary sector provision. Indeed the complexity of service responses is another reflection of the challenges these children and families propose to our existing provision.

### Policy and Legislative Context

The policy and legislative context for service provision has been well summarised in a variety reports and policy documents. Moreover legislation is in place that covers this group of children. As will become apparent throughout this report, there is a consensus on what needs to be done. It is the implementation of the necessary actions is often lacking.

#### For *all* children

Government has moral and legal obligations and responsibilities to identify and address the needs of these children and their parents. These are contained in:

- The principles set out in the UN Convention on the Rights of the Child 1989 ([www.unhcr.ch/html/menu3/b/k2crc.htm](http://www.unhcr.ch/html/menu3/b/k2crc.htm)) provide the broad principles that underpin the way in which services develop and progress.

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- The aim of the 10 year Strategy for Children and Young People in Northern Ireland ([www.allchildrenni.gov.uk](http://www.allchildrenni.gov.uk)) is to ensure all children and young people in Northern Ireland are fulfilling their potential and indeed emphasises that actions must be taken to improve the lives of those children, young people and their families who need help most. It recognises that the link to the respect for rights is central to the successful delivery of the outcomes framework described in the Strategy.
  - The emphasis on rights is reiterated in the Green Paper, *Every Child Matters*, 2003 ([www.everychildmatters.gov.uk/publications](http://www.everychildmatters.gov.uk/publications)) which also recognises the deficits within service systems and the need to protect children through early intervention, sharing of information, effective co-ordination of services and appropriate training of staff.

Nationally and internationally a series of governmental and professional reports have delineated the role and nature of service provision that is required. For over 40 years now, it has been well recognised that children are best cared for at home (Platt Report, 1959) and with the increasing numbers of children surviving due to advances in medical technology, there is an ever increasing emphasis on Community Children's Nursing teams with the skills and competencies to provide specialist care within the home setting (House of Commons Select Committee (1997); Health Services for Children and Young People in the Community: Home and School, Third Report, available from [www.publications.parliament.uk](http://www.publications.parliament.uk)).

Multi-disciplinary working is seen as instrumental in the smooth transition of a child with complex needs from hospital to their home environment and the need for a seamless approach is emphasised in Department of Health (1996) *Child Health in the Community: A Guide to good practice* [www.dh.gov.uk/assetRoot/04/01/24/50/04012450.pdf](http://www.dh.gov.uk/assetRoot/04/01/24/50/04012450.pdf). This was further emphasised by the Audit Commission's Review (2003) of *Services for disabled children*.

The National Service Framework for Children and Young People and Maternity Services 2004 [www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices) emphasises the need to provide appropriate support to children and young people and their families at a local level. It also addresses the provision of care for children with complex needs as well as setting standards regarding the delivery of care.

Likewise the DHSSPS (2004) *A Healthier Future, a 20 year Strategy*; DHSSPS (2005) *Primary Care Strategy Framework for Caring for People beyond Tomorrow* and DHSSPS (2000) *Partnerships in Caring* all contain recommendations to develop a model of service which supports the child and family in the home while ensuring links are developed into secondary and tertiary care when required.

### **For children with complex needs**

There is an ever increasing commitment to service development for children with complex needs; for example, as reflected in the publications available from the RCN (2003) *Community Children's Nursing Effective Team Working*: [www.rcn.org.uk](http://www.rcn.org.uk).

Within Northern Ireland, a series of pertinent reports have been produced by DHSSPS including *Nursing Services for the acutely ill child in Northern Ireland* (1999): [www.dhsspsni.gov.uk/726\\_nursing\\_services.pdf](http://www.dhsspsni.gov.uk/726_nursing_services.pdf).

The need for discharge planning was also a key aspect of *Care at its Best: the Regional Multidisciplinary Inspection of the Services for Disabled Children in Hospital* (2005) [www.dhsspsni.gov.uk/care-main-report.pdf](http://www.dhsspsni.gov.uk/care-main-report.pdf) as was the lack of provision of respite for children, young people and their families which is a key element when supporting families.

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The DHSSPS consultative document: *Strategy for Children in Need* (2003) explored the impact of multi-agency and multidisciplinary working on children with complex needs and their families and urged a coherent approach to service provision. Emphasis was placed on the need to work in partnership, have a shared vision and the need for a key worker.

The *Equal Lives Report* (2005) of the Bamford Review on Mental Health and Learning Disability recommended an extension in the volume and range of emotional and practical help that is available to support families and urged the establishment of multi-agency centres to provide a clear pathway to services for parents and carers.

### **In support of parents**

In January 2007, the Family Policy Unit of DHSSPS produced for consultation, proposals for a Regional Family and Parenting Strategy ([www.dhsspsni.gov.uk/families-matter-consultation-document.pdf](http://www.dhsspsni.gov.uk/families-matter-consultation-document.pdf)) under the title 'Families Matter'. Although the focus is primarily on prevention and early intervention, the Strategy recognises "the importance of valuing parents and not diminishing their role and responsibility. Seeking help does not mean that parents simply want to hand over control of their children to others" (p.7).

## **Legislation**

A range of legislation places duties and responsibilities on health, social service and education in relation to the children and young people but also to family carers. This includes:

### **Education (NI) Order (1996).**

Education and Library Boards have a duty to identify and assess children in their area who have special education needs and children who they think have, or will have, special education needs. If the assessment finds that a child has special education needs, the Education and Library Board must issue a statement explaining these needs which must also detail the special arrangements being made by the Education and Library Board to meet those needs. Although the statement may specify particular health services, these remain the responsibility of HSS Trusts to provide.

### **The Children Order (N.I.) (1995)**

This Order brings together most public and private law relating to children and established a new approach to services provided by Health and Social Services Trusts for children and their families. It provides a legal framework for the provision of social care services for disabled children and their families and seeks to ensure the integration of these services. They are to be recognised as children first with the right to have their particular needs met by the provision of services. Young people with disabilities, up to the age of 18 (or 21 in some circumstances), are included in the Order's definition of "children in need" (Article 17).

Disabled children, as children in need, are entitled to services necessary to safeguard and promote their welfare. Trusts are required to take reasonable steps to identify children in need in their area and to assess the needs of such children.

### **Disability Discrimination Act (1996) and SENDO (2006)**

This Act aims to ensure that disabled people have equal opportunities in terms of access to employment, buildings, and goods and services. The Special Educational Needs and Disability Order (SENDO) requires schools, colleges and universities to provide information for people with disabilities and make suitable accommodation for their needs.

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## Legislation relating to carers

In the UK, there have been four Acts of Parliament specifically for carers:

- *The Carers (Recognition and Services) Act 1995*. This gave carers the right to an assessment of their own needs in Great Britain and was recommended as good practice by Health and Social Service Trusts in Northern Ireland.
- *The Carers and Disabled Children Act 2000*. This extended the right to assessment for adults and the provision of services to carers. It also extended the rights to 16 and 17 year old young people who are carers as well as to parents of disabled children.
- *The Carers and Direct Payments (Northern Ireland) Act 2002* places a duty also on HSS Trusts to inform carers of their right to an assessment and to undertake these.
- *The Carers (Equal Opportunities) Act 2004*. This new Act places a duty on local authorities to tell carers about their rights and places a duty on them to consider whether the carer works or wishes to work, wishes to study or have some leisure activities, when they are carrying out a carer's assessment gives local authorities strong powers to enlist the help of health, housing and education authorities in providing support for carers. However this Act has yet to be implemented in Northern Ireland.

In conclusion, no new legislation or policy statements are required. Rather the project had to identify the action steps that need to be taken in order to fulfil the intentions contained in legislation and the numerous policies initiatives of recent years as detailed above.

## Values underpinning service provision

Recent legislation and policy statements reflect a new set of child and family-centred values and principles. These derive from increases in knowledge as well as changes in societal attitudes and aspirations. Thus at the outset, it was important to specify the values and principles that should guide the service provision for children with complex physical healthcare needs and for their families. This is all the more necessary as these children form a new service group that has emerged due to the medical and nursing advances that have sustained and prolonged their lives.

**Table 1: Six key values to underpin services**

- Children are best cared for at home and within families;
- The ordinary needs of children and families have to be met as well as their special needs;
- Parents know their child better than anyone else and must be treated respectfully by professionals as equal partners given the expertise they have in the care of their child;
- Professional supports must be co-ordinated and responsive to the needs of individual children and families.
- Risks to the child's life need to be managed in ways that provide safety and a good quality of life to the child and family;
- Partnership working across disciplines and agencies is essential.

Throughout the project a number of key values were re-iterated by parents and professionals. They are explicitly stated in Table 1 so that common ownership is established across commissioners and providers; by parents and professionals. They also echo the Standard set in the National Service Framework for disabled children and young people with complex health needs (Department of Health, 2004); see Appendix 2a.

## Summary of the process

Figure 1 summarises the process followed in the Project. The aim was to have a process that was inclusive and participative.

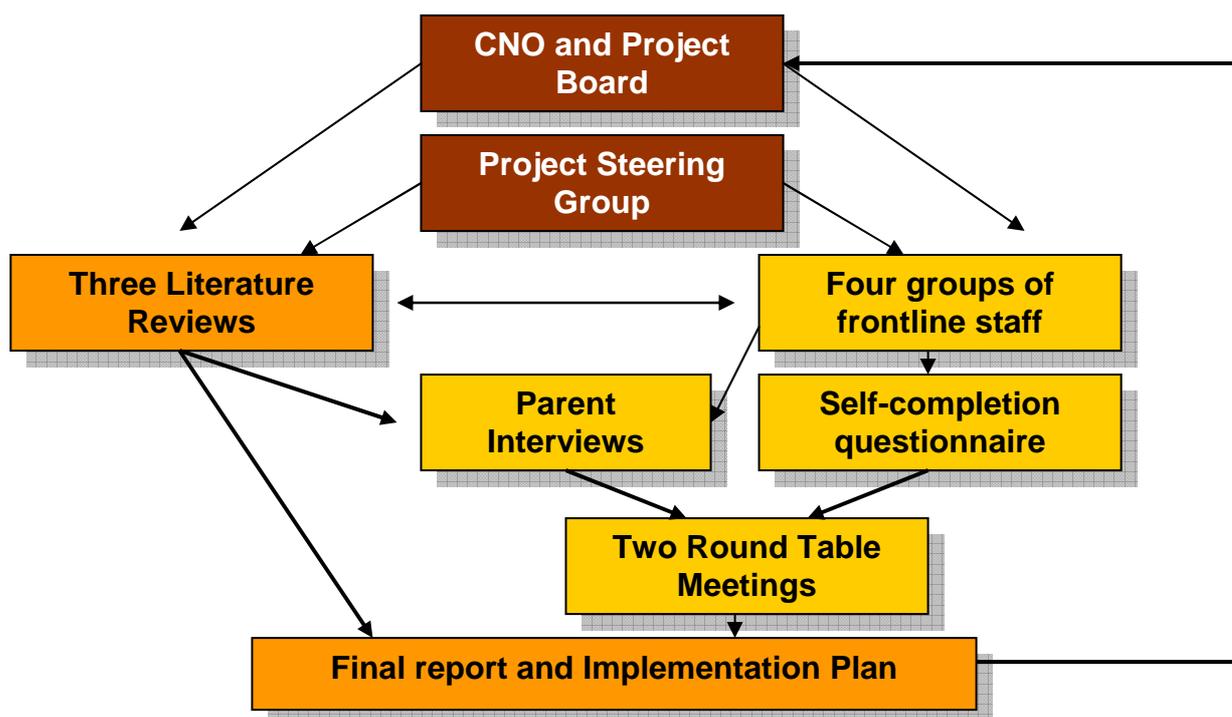


Figure 1: An overview of the process followed.

- It was **inclusive** of parents, front-line support staff, service managers and commissioners as well as those working in community health, social services, acute hospitals, education and the voluntary sector. However time and resources did not allow us to consult as fully with the children as we would have liked.
- **Participation** was achieved for parents through interviews and for professionals by group meetings and self-completion questionnaires. An iterative process was used of feeding back findings as they were obtained.

It was an **efficient** process. A time line was set and maintained over the four-month period. The University team had dedicated time to facilitate the process and the necessary skills and experience to synthesise and analyse the information gained.

The process also aimed to bring together in an **integrated** way, the experiences and insights of all the major service systems involved with this issue: Departments and HSS Boards; HSS Trusts; Education and Library Boards and the voluntary sector. Previously issues relating to this group of children had been debated mostly within single systems.

Throughout the expertise and experience of parents and the workforce was used as the primary knowledge base for system failings and improvements. We trusted people's

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assessments and judgements. However we were able to cross-check and validate their views by collecting information from different groups and using different methods for gathering the information. We were impressed by the willingness of informants to engage with us. Often the numbers contributing were double what we expected or hoped to achieve. This is perhaps an indication of the concern which participants had of the need for action.

Other options for information gathering were considered but were not included in our tender, such as service activity analyses or file searching. We gauged that the effort spent on these 'fact-finding' methods would not yield the information required in the time available.

## **Project Board and Project Steering Group**

Two groups were established to oversee and guide the work of the Project. Their terms of reference and membership are given in the Appendix. The Board focussed more on policy and strategic issues with particular reference to inter-agency working while the Steering Group dealt more with operational and practice issues. Educational personnel as well as parents were represented on both groups and made a valuable contribution.

Each group met on five occasions in the period November 2006 - March 2007. The groups were crucial in assisting with access to service personnel and then to families. They contributed greatly to identifying core issues and helped in framing the final report and implementation plan.

## **Audit of service provision**

The information gathered by the Project was considered as an audit of provision rather than as research. This was confirmed by the Office for Research Ethics in Northern Ireland (OREC-NI). Hence formal ethical approval was not sought for the information gathering.

Nonetheless informed consent was obtained from all individual participants in the project. This stressed the confidentiality of the information provided and the option not to answer any questions and to discontinue participation without giving a reason.

Consent forms were signed by participants in interviews and focus groups. The completion of the postal questionnaire was seen as implicit consent.

The remainder of the report is framed around each element of the process in Figure 1. The Appendices to the Report give fuller details of each aspect of the Project's work.

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## Section 2: Lessons from the Literature

The Project Team undertook reviews of the literature around three themes that were pertinent to the Project.

1. The needs of children and families
2. Multi-agency and multi-disciplinary working
3. Community nursing services to children

The literature consisted mainly of articles in international journal, supplemented by book chapters or reports. The priority was to identify the implications for services within Northern Ireland from experiences elsewhere. The reviews were written with a service readership in mind. The reviews are given in Appendix 2 with the key messages from each summarised below.

### 1. The needs of children and families.

**The key message is that the needs of children must be seen within an empowered family context.**

The impact of having a child with complex physical health needs in the family is a combination of positive and negative consequences: a combination of joy (at achievements however limited) and sorrow (from missed opportunities and distress experienced). Many parents and siblings demonstrate tremendous resilience and develop a range of effective coping strategies which helps them to respond to the challenges they encounter.

The impact on the family spans physical, psychological and social domains, and therefore to be effective, interventions by professionals must do the same. However their interventions must empower parents so that they remain in control of their life and that of their child. In seeking to support families it is important to respond to the key areas of parental need that have been identified within the literature review, namely:

- The need for increased certainty;
- The need for information;
- The need to acquire knowledge and develop skills in caring for their child;
- The need for co-ordinated services;
- The need for respite care.

In developing future services whose hallmarks are engagement and partnership, it is also necessary to bear in mind the characteristics that distinguish successful services for children with disabilities.

- Listening to disabled children and young people; listening to parents and other relevant family members;
- Providing information and advice and assisting parents to make use of it;
- Inculcating positive attitudes and a co-ordinated approach;
- Providing flexible support services which are tailored to individual children's and families needs

- 
- Having more money so that financial pressures on children and parents are eased;
  - Measuring the actions of all statutory and voluntary agencies against the human rights of disabled children

It is necessary to take time to obtain a clear understanding of how the child and all family members perceive their situation, and the coping strategies employed by individuals and the family as a functional unit. In doing so, a more accurate picture of family interactions and priorities is gained and consequently flexible support can be successfully targeted to facilitate family adaptation (Todd & Jones 2003, Hilbert et al 2000). Recognition of parental expertise is fostered by their participation in service planning, reviews and staff training.

## 2. Multi-agency and multi-disciplinary working

**The key message is that effective co-ordination and information sharing is needed to make multi-agency working successful.**

A dominant issue within health and social services at the start of the 21<sup>st</sup> century is the need for joint working with other departments and agencies in order to achieve better outcomes for service-users. The achievement of effective multi-agency working is a complex and intricate process which needs to be replicated at all levels within service systems – policy, operations and service-user. It is the latter aspect that currently holds most promise, namely making multi-agency working happen for individuals.

From the extensive literature that is now available on this theme, the following implications were drawn in determining a nursing response to families who have children with physical healthcare needs:

- Holistic support is required by families including their emotional and social needs. This is frequently neglected by professionals.
- Defined roles and structures need to be agreed for the team as a whole as well as for individual members of the team. This applies to different nurses who may be involved with the family. The leadership function must be clearly defined.
- A team development strategy is devised and the work of the team is regularly reviewed to assure a positive impact on children and families.
- A named person (key-worker/coordinator) should be appointed for each family.
- Trans-disciplinary practice should be encouraged across team members.
- Joint training opportunities should be provided across professions and parents.
- Nurse training should incorporate family-centred care and multi-disciplinary working.

Services need to focus on key themes such as ‘family support’ as they embody both the reasons for multi-disciplinary working and to ensure its delivery in a co-ordinated manner. Team members have an important advocacy role for families with their colleagues, managers and service commissioners.

A person-centred approach that is unique to each child and family is likely to provide the most efficient use of resources.

There are an increasing number of examples of delivering person-centred services; for example the Wraparound approach in the SHSSB ([www.shssb.org/partnerships/wraparound/](http://www.shssb.org/partnerships/wraparound/)).

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### 3. Review of community nursing services to children.

**The key message is that community nursing services must continue to expand and develop in a creative, flexible and innovative way that characterises a proactive service**

Nine different models of nursing provision to children were identified and combinations of these can be seen around Northern Ireland. There is variation in current provision across HSS Boards and HSS Trusts than is not explained by different needs and demands for services.

Critical aspects in developing a community nursing service include:

- The physical and intellectual resources required to deliver innovative services to a high-risk group of children in potentially high-risk environments.
- Creating and developing a therapeutic culture that strives to meet the needs of children and families.
- Attention must be given to matters such as education and training, documentation, policy, funding, and professional development planning for lay and professional carers.
- Good practice, where it is identified must be exploited to effect better care for other families elsewhere in the region.
- Paying existing family carers, and the expansion of a variety of options of respite care in the home or another facility must be flexible and available, to lift the burden of caring and to attempt to normalize family life.
- Evaluation of services is an essential component especially in terms of securing future resources.
- Regional oversight of the development of children's nursing needs to be improved so that better workforce planning occurs to overcome the present shortage of paediatric trained nurses.

The outcome of initiatives to improve the quality of life and services to children with complex physical health needs will have implications for the development of all future services. It is therefore all the more important to design a nursing service that other areas might wish to follow. In addition nursing children with complex physical health needs in the community might offer lessons for other nursing disciplines facing parallel challenges, such as district nursing.

## Conclusion

Internationally services are grappling with the many challenges that children with complex physical healthcare needs present to existing provision. There is no one answer or any speedy response. However the pool of expertise represented in the literature does identify the core issues that must be addressed and offers pointers in developing a strategy for service evolution. Nonetheless these have to be interpreted in the context of local circumstances. Hence a key aspect of the Project's work was an examination of the local situation in Northern Ireland.

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## Section 3: Definitions of complex physical healthcare needs

The project was focussed on children who had *physical* healthcare needs. It was recognised that complex health needs could include children and young people with behavioural difficulties, emotional problems or mental illnesses. Such children would also fall within this grouping provided they had a significant physical healthcare need as well. Otherwise children with behavioural and emotional problems were not included in this Project although it is likely that many of the recommendations contained in this report would be applicable to them.

Even so, the population of children and young people with physical healthcare needs are a heterogeneous group that are not easily defined in simple terms. They form a sub-set of children with disabilities and/or long-term illness but their defining characteristics are not easily identified. One approach is to base the definition around the child's characteristics, such as their medical condition. Hence the project began with this working definition:

*“they are children primarily with physical care needs, such as those who are technologically dependent, have a life limited or life threatening condition, acquired brain injury resulting in significant impairment and /or children with multiple impairments from birth”.*

An alternative approach was then considered. In the USA, the Federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs (DSCSHCN) established a working group to develop a definition of children with 'special healthcare needs' (McPherson et al., 1998). Their recommended definition was:

*“Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (p.138).*

The distinctive feature of this type of definition is that it defines a need for service which may not be determined solely by a child's condition. For example, two children may have an acquired brain injury but one may require additional services and another will not.

In Northern Ireland, The Children (NI) Order, 1995 placed a requirement on each HSS Trust to open and maintain within their geographical boundary a register of 'children with a disability'. The definition that was proposed by the Project Team who developed the business case for the Register (Association of Directors of Social Services, 2003) also reflected this focus on support:

*“A child/young person has a disability if he/she has a significant impairment and, without the provision of additional assistance, resources or information, would be disadvantaged /restricted in, or prevented from, participating in the life of the community both in the manner which might reasonably be expected, and in comparison to other children of similar age, respecting individual culture and circumstances” (p.3)*

Following discussion with the Project Board and Steering group, we propose that a definition that focuses on support needs rather than children's conditions should be used.

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*Children (and young people) with complex physical healthcare needs are those who require a range of additional support services beyond the type and amount required by children generally and those usually provided to children with impairments and long-term illnesses.*

The rationale is as follows:

- This approach is in keeping with the International Classification of Functioning promoted by the World Health Organisation ([www3.who.int/icf/icftemplate.cfm](http://www3.who.int/icf/icftemplate.cfm)).
- It is in line with social models of disability and illness that are widely accepted internationally.
- It links directly to person-centred (care) planning that attempts to address the individual needs of people rather than the provision of 'block treatments'.
- It is implicit within the development and operations of Service Frameworks and of individualised payments (Direct Payments).

However this type of definition is not easy to operationalise. It requires a framework on which decision can be made about the child's and family's needs for services. To date two scales have been used in Northern Ireland; namely the 'National needs assessment tool for long term ventilated children in the community' - Bradford continuing care (used by Royal Belfast Hospital for Sick Children) – and Leeds Nursing Dependency Score (used in Homefirst HSS Trust and elsewhere). Table 2 gives an example of the different criteria that can be used to determine eligibility for additional support and examples of the form this may take are also provided. Appendix 3 gives details of other criteria that might be included.

However members of the Project Board and Steering group along with practitioners we consulted, felt that none of the existing scales were adequate. Nonetheless they recognised the need for a common instrument to be used throughout Northern Ireland so that the inequities that exist in access to services might be addressed.

#### **Recommendation**

Services should work to develop an assessment instrument that can be used to determine a child's physical healthcare needs and their family's need for additional support services (including respite breaks) and to assist with reviews of their needs. This would be used by all HSS Trusts, Education and voluntary organisations in Northern Ireland.

This would form a discrete piece of work that could be commissioned by the Department in conjunction with the Health and Social Care Authority.

A number of further points were noted in arriving at a definition and assessment framework.

- The definition has to embrace the impact of family circumstances on children and young people and parental needs for support.
- The assessment would embrace a range of settings, including school.
- An absolute definition is not achievable but rather it is best termed as probabilities, based as it is on professional judgements.

**Table 2: Examples of items common to Bradford and Leeds Scales**

<b>Criteria</b>	<b><i>High probability of additional support needs required</i></b>	<b><i>Examples of support options that would help</i></b>
Breathing/Airways	Total ventilator dependence/ Oxygen dependent/episodes of apnoea	Trained staff needed to assess and monitor Carer training completed and monitored
Feeding	Total parental nutrition - Tube-fed (Gastronomy/Naso-gastrically) Complex feeding regimes including TPN or overnight nasogastric feeds	Trained staff needed to assess and monitor Carer training completed and monitored
Epilepsy	Major seizures – daily/ Seizures require acute medical interventions	Medication reviewed regularly – blood tests; EEGs
Mobility	Immobile over 5 stone/requires two people	Necessary equipment /adaptations installed at home
Carer	Main carer has physical illness; mental health issues; learning disabilities	Counselling for carer; domiciliary support and shared care arrangements
Siblings	Another sibling has chronic illness/disability	Domiciliary support; sitting services Daytime breaks: family placements; overnight stays
Child Protection issues	Grounds for concern	Shared care arrangements
Child has mental health difficulties	≥ 20 risk factors identified and / or ≤ 4 resilience factors present..	Specialist mental health services
Child has sensory impairments	Moderate/profound sensory impairment / which affects ability to function relative to age	Provision of aids

- The decision to classify a child or young person as having complex needs that require additional support should be taken by a minimum of two or a team of professionals in conjunction with the parents.
- Moreover the designation of having ‘complex needs’ is not fixed but is variable and needs to be regularly reviewed; i.e. children can have complex needs for a period of time.

### **Understanding the Needs of Children in Northern Ireland (UNOCINI)**

Preliminary studies are underway to develop and implement a standardised approach to carrying out an assessment of a child's and their family's additional needs and deciding how those needs should be met. It is intended that “the UNOCINI will assist with a more effective, earlier identification of additional needs, particularly in *universal services*” (emphasis added). “It should provide a simple process for a holistic assessment of a child's needs and strengths, taking account of the role of parents, carers and the impact of environmental factors on their development” (DHSSPS, 2007’ p.29).

It is likely that UNOCINI will not capture the specific needs of children with complex physical healthcare needs hence the assessment instrument proposed for these children and families could form an additional module of the UNOCINI. Certainly the ethos underlying both approaches appears very similar.

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## Agreement on ages

At present variations exist throughout Northern Ireland as to the upper age at which young people can access children's services. For example children may transfer to adult wards in acute hospitals at 14; they may transfer from community children's nursing between 16 and 18 years; they may no longer qualify for children's respite services at 16 years of age and they may leave school at 16 years.

A standard age cut-off is recommended for all health and social services and it is proposed that the Children Order definition is followed, i.e. children up to 18 years of age. However a child may remain in a special school for the whole of the school year in which they become 19 years. In this instance some tolerance should be permitted for the continuation of children's services.

The age extension to 18 years will have implications for certain community services but more especially for acute hospital provision. Discussions will be required with consultants and nursing staff about the best location for the care of teenagers aged 16 to 18 years of age.

As a marker for the future, more of these children will survive into adulthood and plans need to be made now for suitable provision for their needs, especially within community nursing services serving adult persons. This was beyond the scope of the present project although certain of our recommendations around nurse training do take this into account.

However a planned transition from children's services is an issue that must be addressed. Best practice suggests that this planning should commence at 14 years of age so that new service arrangements can be developed as required.

## Estimated Numbers

At present we do not have an accurate count of the number of children in Northern Ireland who meet the proposed definition of physical healthcare needs and as explained above it may not be possible to arrive at an accurate count although estimates could become more precise if a common instrument was used.

However an attempt was made to gain some insight into the numbers of children in Northern Ireland. Using data obtained in surveys conducted by Homefirst HSS Trust and in SHSSB area and information gathered in Merseyside (Merseyside and Cheshire Cancer Network, 2004), we estimate around 250 children in Northern Ireland would require active support at any one time with around 250 liable to make demands on services and require some form of ongoing support. This gives an estimated incidence of one per thousand children although anecdotal reports suggest that this rate can vary markedly across different geographical areas.

However certain children with complex physical healthcare needs are liable to require high cost packages. The total amount spent by HPSS in recent years is not easily determined from existing information sources as they can be drawn from various programmes of care.

Existing information systems in HPSS and Education do not identify these children and families. Possible improvements could include:

- Resourcing Module V of the Child Health System so that they can be recorded by community paediatricians and reports on numbers made available to Trusts;
- Ensuring the proposed disability register under the Children Order identifies these children. However some families may prefer not to register their child as 'disabled'.

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- Assessment and statementing information obtained by Education and Library Boards could also be used to identify these children. However a change would be required to present recording systems for this to be done.

More broadly, issues around the sharing of personal information across agencies will also need to be addressed as will the duplication inherent in maintaining these different information systems.

### **‘End of life’ needs**

Finally, the proposed definition may not identify the particular needs of children at the ‘end of life’. For these children it is proposed that the Care Pathway produced by ACT (The Association for Children’s Palliative Care: 2004) be adopted in Northern Ireland. It is proposed that community children’s nursing service should take responsibility for co-ordinating its implementation on a multi-disciplinary basis within their Trust area.

## Section 4: Existing services

As the Project progressed it quickly became apparent that sizeable numbers of professionals are involved with this client group. Figure 2 lists those named by the Project Board, Steering Group and professional focus groups (see below). These are divided into four main service systems but they are arranged in terms of parents' experiences in the interviews undertaken with them as part of the project (see later).

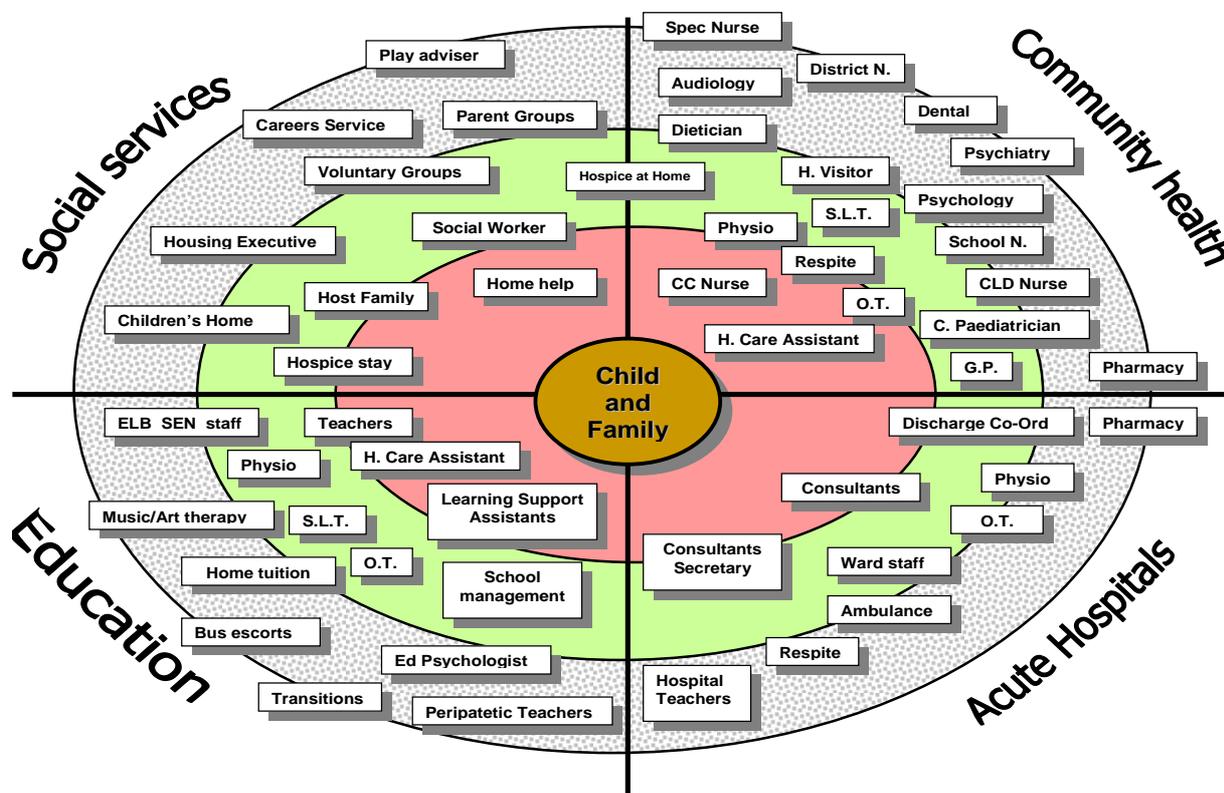


Figure 2: Professional involvement with children and families

Some points of note:

- Those named within the inner circle are those with whom parents report closest links and contact.
- Those named in the middle circle are people with whom they have ongoing contact to varying degrees or with whom they had significant contact in the past (and may again in the future). Those staff who overlap into the inner circle, tended to have significant contact for some parents.
- The outer circle is for those persons who were identified by professionals as having an involvement with these families, but they were not mentioned by any of the parents interviewed. This is indicated by being placed on the outer part of the circle. Those overlapping with the middle circle were mentioned by a few families as having had contact in the past due to particular circumstances.
- Some professionals may be employed by one system but work predominantly in another (e.g. healthcare assistants, therapists working in schools but employed by HPSS). Also staff from the same discipline can be employed by different systems to work with the same family at different stages of the child's life.
- This map does not show other groups that could be of significance, such as community associations and the politicians at local council, NI Assembly or Westminster.

Of course, the detail of this map will vary from family-to-family depending on their needs and the availability of services in their locality. This generalised service map illustrates how existing services have tried to respond to the needs of a new client group that has emerged over the past two decades. In many ways their responses were ad hoc and piece-meal with no strategic planning nor dedicated financial resources provided. The result is a delivery system that is inefficient even if it does manage to be effective – at times.

- It is inefficient economically, e.g. there is duplication of resources.
- More crucially it is inefficient of human effort and emotions. Energies are diverted into managing conflict, responding to crises, patching together fragile responses.

Another approach would be to develop an individualised, family-centred service plan within an overall service framework. This is recommended for all children with special needs but if it even more imperative when sizeable numbers of professionals and services are involved.

### Recommendation

A service map as per Figure 2, should be created for each individual child and family and shared with all services and persons who have an involvement with them. Names and contact details should be provided of all those included in the map.

An individualised plan would identify:

- Those people who have greatest involvement with the child and family at present. The accompanying plan would describe how they co-ordinated their support.
- Those personnel who may have more peripheral but significant contact with the family. The accompanying plan would identify how they are kept informed.
- Those professionals and services that are absent for the child and family. This would raise questions about equity and need.

It is likely that nursing would be an integral feature of every plan although this process would help to identify those nurses who are (or need to be) involved and the co-ordination of their inputs.

## Service systems

Figure 3 illustrates the various systems in which staff are employed. The five new

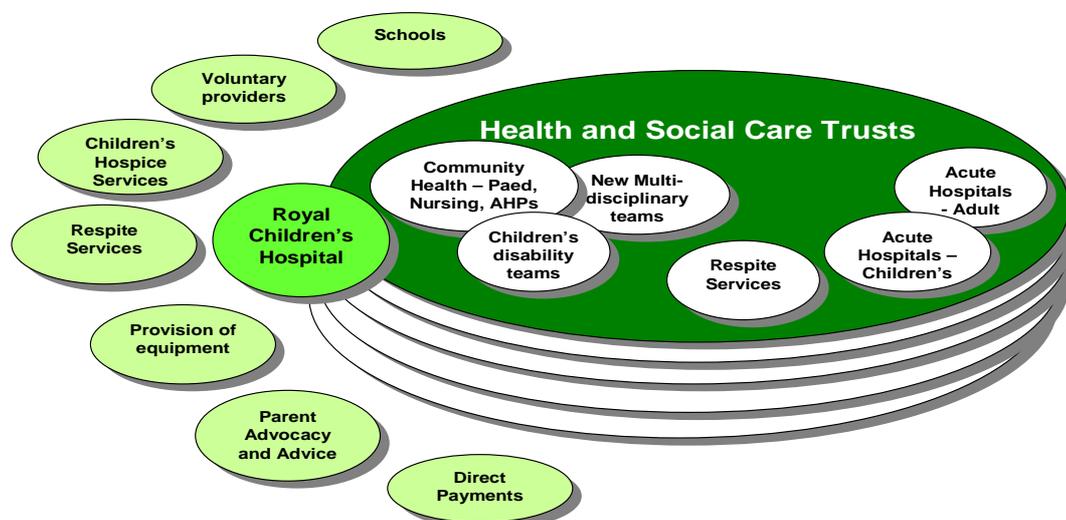


Figure 3: The different systems involved in service delivery

Health and Social Care Trusts have the major role in service provision although it is not altogether clear how the six different facets of their provision will be managed under the new arrangements. There is the possibility that nursing services across community services and acute hospitals can work in a more co-ordinated manner.

The Royal Belfast Hospital for Sick Children is identified separately because of its regional remit.

There are a number of other significant service systems that often operate in isolation from one another. As the Figure shows these include voluntary providers although the services provided by the Children’s Hospice has been identified separately as it serves all of Northern Ireland whereas other providers may have a more local remit. (NB These include care at home and an additional residential facility as well as the Hospice in Newtownabbey.)

Nurses may be employed in a number of these services such as the Children’s Hospice and respite provision. They can also be employed on a part-time basis by families using Direct Payments.

In Section 6 of the Report recommendations are made for better co-ordination among service systems.

## Nursing responses

Figure 4 illustrates the range of nurses who have an involvement with the children and their families.

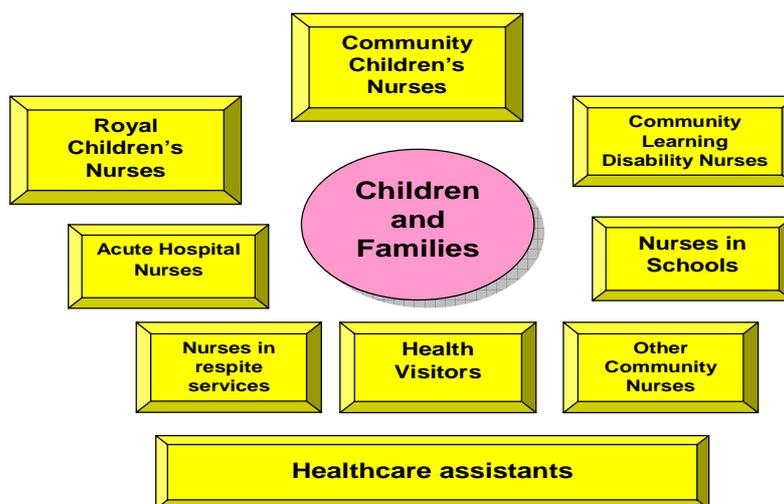


Figure 4: Nurse involvement with children who have complex physical healthcare needs

### Community services

The main involvement in the community tends to be with community children’s nursing (CCNs). An accurate count of those currently in employment is not available but it is estimated that there are around 30 in post at present, although the size of the teams does vary across HSS Trusts.

In addition other community nurses may have an involvement, notably community learning disability nurses (Regional Forum, 2007). This is especially so for children with associated severe learning difficulties and who may co-work the nursing care with the CNN or receive re-referrals from the CCN when acute episodes of care have stabilised. Other community nurses also include district nurses who may provide weekend cover or

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specialist nurses for diabetes or epilepsy. Palliative care nurses may also have an involvement with some families.

In some special schools, a nurse is based full-time although this happens in only certain HSS Trusts.

Health visitors provide little hands-on care for the child and their involvement with the family is reported to be more of a support for the mother. Along with other nurses they may also fulfil child protection responsibilities.

### **Acute services**

Many children and families have an ongoing contact with nurses in the acute hospitals, both the Royal Children's and the Area Hospitals. Many children have frequent admissions to hospital and arrangements are often in place for them to by-pass A&E and to go straight to the children's ward. Parents may also telephone the ward to get advice about possible admission. A nurse may also act the discharge coordinator for the child and family.

Similar arrangements are required for adult wards but these are likely to be in place.

Nurses are also employed in the Children's Hospice which provides respite breaks for children and families and also in respite facilities provided by statutory and voluntary organisations. Indeed these children cannot be safely placed in respite homes without adequate nurse cover and this reduces the availability of respite breaks for these parents.

Parents also reported that nurses from the acute sector also worked as bank staff to cover shifts in community services.

Finally concerns were expressed about a shortage of paediatrically trained nurses within Northern Ireland and that insufficient numbers were in training.

### **Healthcare assistants**

Increasing numbers of healthcare assistants are now employed in both sectors although the total number is not recorded. They work under the supervision of a nurse and are deployed in family homes and classrooms. However there are disparities around Northern Ireland in their terms and conditions and issues around legal liability need to be clarified.

Recommendations around improvement in nursing services are presented in Section 6.

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## Section 5: Views of Parents and Practitioners

Two major studies were undertaken as part of the Project. One documented the experiences and views of parents in Northern Ireland obtained through personal interviews. The second gathered the opinions of practitioners to present provision and their suggestions for improvement.

### The views of parents

Service personnel passed on to prospective parents an invitation letter on behalf of the Project team. In all 34 parents volunteered to participate. Face-to-face interviews were conducted with 15 families and with a further 15 families were interviewed by telephone; a completion rate of 88%.

Parents came from all over Northern Ireland and the full age range of children was covered with upwards of 20 different conditions reported and 16 invasive procedures being conducted by family carers.

The children had a range of technological supports and other requirements that required the parents to undertake a variety of invasive procedures. These were:

Peg Tube feeding	Illiostomy bag	Catheter
NG tubes	Portacav	Bi-Pap
Duodenal Tube	Rectal Valium	Insulin injections
Tracheotomy	Buccal Midazolam (epilepsy)	Insulin pump
Suction	Nebuliser	Blood tests
Oxygen	Mini-button	
Shunt		

Information was gathered about the care tasks that parents undertook with their child; the support they received from professionals and services; their experiences of education and respite breaks, the services they had found most helpful and the reasons for this; the negative experiences they had encountered and their advice to other families. A full report of the findings is given in Appendix 4.

Talking with the parents was a humbling experience. They came from all walks of life: ordinary people called to become exceptional parents. Their challenge was to provide the specialist assistance that kept their child alive while being a mummy and daddy to their much loved child. In essence, they wanted and needed support to maintain this balance. Among the key messages that families felt needed to be heard by service planners and providers were:

- They wanted their child to be part of the family; stays in hospital should be minimal.
- Caring for the child had had a major impact on their lives: moving house; marital separation; giving up careers; financial difficulties; illness and stress.
- A recurring theme in talking with parents about services was the fight they had in order to get the help and support they needed. Parents talked about “battles” and “being in the trenches”.
- Building up a trusted relationship with service personnel was seen as the best form of support.
- Community children’s nurses were mentioned as being the most helpful.

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- Families spoke of the very limited amount of time they were given for respite breaks and they could do with more. They wanted residential facilities to be available locally for their children to stay.
  - Getting appropriate equipment was the thing that made the biggest difference for them even though the costs were small. Delivery times were protracted.
  - Their advice to other parents was to remain in control; decide who comes to their home and stand by what you believe is best for you and your child.

An interim report on the findings from parental interviews was shared with the Project Board and Steering Group and a copy was given to all participants in the Round Tables. They felt that the main messages were similar to those they had encountered in their services which suggests that the sample validly represented the broader parent population.

## The views of practitioners

The views of practitioners were sought in three ways. First, a total of 52 professionals drawn from a range of services across Northern Ireland attended one of four focus groups. Two groups were exclusively for a range of nurses in community and acute settings; and two were for personnel from a range of disciplines including nursing. They were facilitated by two members of the project team.

The groups were asked to focus on four issues.

- Confirm the professionals and services involved in supporting children with complex physical health needs and their families.
- Confirm the list of issues facing nursing services at present when seeking to support children with complex physical health needs.
- Give examples of developments within local services which could be built upon
- Propose creative solutions to overcome challenges in service provision at present and priorities for service development

A report detailing the information gathered was prepared and circulated (see Appendix 5).

## Self-completion questionnaire

The information gained in the focus groups was used to frame a self-completion questionnaire that the Project Steering Group scrutinised and revised. The questionnaire consisted of 51 recommendations for service improvements; grouped into six sections that reflected the core themes to emerge from the focus groups and parent interviews. The themes and sample items are given in Table 3. The questionnaire was widely circulated throughout HSS Trusts, acute hospitals, children's disability teams, education and library boards, special schools and major voluntary providers.

The aim was to identify those recommendations on which a broad consensus existed and those that deserved to have priority. Respondents were asked to indicate the extent of their agreement with each recommendation by choosing one of five options from strongly agree to strongly disagree. Secondly, respondents were asked to prioritise the recommendations by selecting for each theme, one or at the most two recommendations that they felt should have priority. These would be ones that they feel will make a real difference and which should be implemented immediately.

Responses were received from 159 respondents from a range of disciplines and services. In all 81 identified themselves as nurses or healthcare assistants with 54 non-nursing

Table 3: The recommendations receiving highest agreements and priority rating.

<b>Recommendation</b>	<b>SA</b>	<b>A</b>	<b>N</b>	<b>D</b>	<b>SD<sup>1</sup></b>	<b>Priority (N=135)</b>
<b>Theme 1: Co-ordination of services locally</b>						
An accessible information booklet should be developed for parents and professionals that signposts where information can be found about hospital and community services for children with complex physical health needs.	86%	13%	1%	-	-	19
Each child with complex physical health needs should have one key worker who is the main point of contact across all health and social services supporting that child.	66%	28%	4%	2%	-	56
<b>Theme 2: Co-ordination of services regionally</b>						
An overall service framework should be put in place for children with complex physical healthcare needs across Northern Ireland that outlines minimum standards and regional procedures.	58%	39%	3%	-	-	39
Regional procedures should be put in place to plan for the transfer from 14 years of children with complex physical health needs to adult services in the community.	61%	31%	2%	3%	2%	29
<b>Theme 3: The need for equity in service provision</b>						
Any assessment of the dependency of a child should also include an assessment of the capacity of parents and families to cope with care required.	64%	32%	2%	1%	1%	45
An out-of-hours service by community nurses for children with complex physical health needs should be provided throughout Northern Ireland.	49%	38%	10%	3%	-	41
<b>Theme 4: Developments in respite (short break) provision</b>						
Locality-based, nursing-led, respite care facilities should be developed to support children with complex physical health needs* ( <i>Nurses more strongly agree 77%</i> ).	66%	28%	5%	1%	-	39
4.8 Staff working in existing or planned respite facilities should receive training in the care for children with complex physical healthcare needs.	71%	26%	2%	1%	-	32

<sup>1</sup> *Strongly agree (SA)* – would mean that you have no reservations at all and consider this to be essential; *Agree (A)* – you may have a few reservations but on the whole you feel this is worthy of support.; *Neutral (N)* – means you have no strong feelings one way or the other or that you do not sufficient information on which to make a decision.; *Disagree (D)* – means you have reservations about the recommendations or feel it is unlikely to lead to any benefits; *Strongly disagree (SD)* – you have major reservations and feel it will not lead to any benefits.

Table 3: The recommendations receiving highest agreements and priority rating (contd).

Recommendation	SA	A	N	D	SD	Priority (N=155)
<b>Theme 5: The provision of education for professionals and family members</b>						
Health Care Assistants in community settings should be appropriately trained (e.g. to NVQ Level 3) with access to regular top-up training	66%	28%	6%	-	-	35
A budget for education and training of staff in relation to caring for children with complex physical health needs should be identified and ring fenced.	57%	36%	7%	-	-	34
A training needs analysis should be undertaken across Northern Ireland to identify the major areas of deficit in knowledge and skills among professionals who work with children with complex physical health needs and their families.	49%	43%	6%	1%	1%	34
<b>Theme 6: The views of children and their families</b>						
Parents need to given a clear and realistic indication of the supports that will be available to them on discharge from hospital and the demands likely to be placed on them.	79%	20%	1%	-	-	73
Active steps should be taken to increase the involvement in service planning of family carers of children and young people with complex physical health needs.	49%	47%	4%	-	-	41

personnel such as doctors and therapists (N=16); social service staff (N=9) and educational personnel (N=30).

Table 3 summarises the recommendations that had the highest level of agreements and those which most respondents identified as a priority out of the 159 respondents. Appendix 6 details all the recommendations and the ratings given to each.

There was a marked degree of unanimity around the majority of recommendations. This suggests that respondents irrespective of their discipline or location had come to common conclusions as to what would help the children and their parents. Indeed respondents noted that some of them were already implemented in their area. It was not clear why this had not happened in other areas or indeed why other recommendations had not been acted on that did not seem unduly difficult to implement. These and other issues were explored in the third phase of consultations with practitioners.

### Round Table Meetings

Invitations were extended to service managers and commissioners across a range of agencies to attend one of two meetings held in Omagh and Antrim. Nearly 40 people participated from different HSS Trusts and Boards but also from education and voluntary agencies. The aims of the Round Table were:

- To feedback on the work of the project in terms of information obtained from parents, front-line service staff and the literature reviews;

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- To elicit comment on the proposed models and systems emerging from the above.
  - To explore the implementation issues that arise from the above with personnel who likely will have responsibility for these.

A briefing sheet was distributed prior to the meetings along with the two reports outlining the views of parents and practitioners. Diagrams similar to Figures 2 and 3 were used to summarise the systems and issues that had been identified by the Project up to that point along with a listing of pertinent issues for nursing services in particular.

The task set for the participants was simply stated: we knew **WHAT** needed to be done but we were less clear about **HOW** these developments could come about and **WHO** could make them happen.

At the round tables, discussion took place in smaller groups with participants drawn from pertinent backgrounds. Different groups focused on one of three broad themes:

- Commissioning arrangements and guidance;
- Co-ordination of service delivery at provider level.
- Nursing services for children.

A recurring theme was the uncertainties that presently exist because of RPA. This made it difficult to identify with certainty the agencies and people who had an involvement in service improvement.

Also it was felt that the needs of this client group could have low priority in these times of change. The counter-argument was that the anticipated changes provided a much better context for dealing with issues and a prepared plan assisted the new agencies by defining a role for them.

Appendix 7 details the recommendations that emerged in the discussions. Once again there was a high degree of unanimity about what needed to happen and how the recommendations might be achieved.

The views of participants in the Round Tables have shaped the recommendations described in the next section of the Report.

# Section 6: Recommendations

The recommendations have been grouped into three main themes.

1. Commissioning of services
2. Service delivery improvements
3. Nursing responses

However they are inter-related in that progress in one area will help to drive change in another. Nonetheless it is possible that certain improvements can be made within one area despite lack of progress in another.

A number of key proposals have been identified, although many others were suggested by informants during the course of the Project. It is our judgement that the proposals we have nominated will subsume others and if implemented will create the conditions for tackling others.

## 1. Commissioning Recommendations

**Recommendation**  
 A specific service framework should be produced for families and children with complex physical healthcare needs that is multi-agency and multi-disciplinary.

There was unanimity on the advantages of having a common framework for services within Northern Ireland. This would set the standards expected from services; ensure greater equity in access to services and more consistency in the supports that would be available to children and their families. It would enable deficits in current provision to be planned and costed. The framework would have the potential in to promote cross-sector working (e.g. between acute and community services) as well as encouraging multi-agency approaches.

It was felt that a specific service framework needed to be within the context of an overarching framework for children and families. The National Service Framework for Children, Young People and Maternity Services produced by the Department of Health (2004) for England provides a possible example of this, This could be readily adapted for Northern Ireland with perhaps more cognisance given to our joint Health and Social Services Structures and greater involvement of Education.

Table 4: Issues to be covered by the proposed service framework

Definition	Hospital-community liaison
Assessment of need	Healthcare assistants
Family supports	Managing transitions
Core groups of professionals	Workforce planning
Co-ordination of services	Joint planning and funding

The English framework contains Standard 8 that focuses on disabled children and those with complex health needs; Standard 6 that deals with children and young people who are ill and Standard 7 that looks at children and young people in Hospital.

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What is proposed for Northern Ireland is one framework document that is focussed on all the differing support needs for children and young people with physical healthcare needs from birth up to 18 years of age. Hence it would integrate the recommendations that in the English framework are tackled thematically and tailor them to the needs of this specific group. The primary rationale is that these children above all others require coherent and co-ordinated responses that can be of high cost to HPSS and Education.

Table 4 summarises some of the issues that a service framework might cover. As noted in Section 3, further work is required to develop an assessment instrument that would closely link with the service framework.

**Recommendation**

Services should work to develop an assessment instrument that can be used to determine a child's physical healthcare needs and their family's need for additional support services (including respite breaks) and to assist with reviews of their needs. This would be used by all HSS Trusts, Education and voluntary organisations in Northern Ireland.

Also it would be important to develop procedures and protocols relating to staffing and coordination of services with particular attention being given to the management of transitions between services as well as at different stages of the child's life.

Many of the recommendations developed in the Project (see Appendix 6 and 7) would likely be included within the proposed Framework. Hence a great deal of the preparatory work has been accomplished. Given the centrality of nursing within service provision in this group, it seems appropriate for the Chief Nursing Officer to progress this work.

Although the production of such a framework had wide support, it was less clear how the framework would be achieved. Discussion revealed some of the complexity of the issues that require consideration. These were:

- Joint planning must be undertaken by DHSSPS and the Department of Education. The existing interdepartmental committee on special education needs might consider establishing a subgroup to specifically address this issue. The review of special educational needs by DE is also nearing completion and may provide another context for joint working. Moreover there are local experiences of joint working between Boards and ELBs, notably in the Southern Board area to guide this work (SHSSB/SELB, 2005).
- The new Health and Social Care Authority will have a major role to play in the future commissioning of services. Likewise the proposed Education and Skills Authority will likely attempt to bring greater equity to educational provision across the existing Education and Library Board areas. Both bodies are likely to be involved with the commissioning arrangements inherent in the Service Framework. The two departments will need to ensure that the two authorities apply the framework in their commissioning.
- The nursing response to families and children with complex physical healthcare needs should be defined with the service framework. There appears to be a degree of unanimity on the form this should take. To date though, there has not been a co-ordinated response to children's health within DHSSPS and no recent review of children's nursing services.

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- The preparation of these frameworks and reviews should be inclusive and participative (e.g. with voluntary sector involvement) but equally they should be done within a short time frame. A 'bottom-up' as well as 'top-down' approach is required to gain ownership.
  - A care pathway approach may work well in caring for children at 'end of life'. However there was less support for care pathways in general being applied to this group of children given the variety of conditions that come under the rubric of 'complex physical healthcare needs'.
  - The frameworks will provide the standards against which services will be assessed by the RQIA. It is not clear what function, if any, they need to have in the development of the Frameworks.
  - Given the high cost of certain packages and the low incidence of their occurrence in any one year, there may need to have regional commissioning of health and social services for children with PHC but they should be delivered locally. Alternatively a contingency fund could be held centrally which Trusts can draw down according to need. The framework could address the issue.
  - Local Commissioning Groups have a key role on identifying inequities across Northern Ireland so that commissioning can be adapted to local needs. However it is not clear how this will be achieved nor whether Children's Services Planning by HSS Boards will continue.

Two further commissioning recommendations were strongly endorsed by our informants.

### Review of equipment

DHSSPS needs to instigate urgent reviews of the commissioning and delivery of equipment (e.g. hoists, frames) to children and families. This review must involve education.

The recently commenced review of wheelchairs that is lead by the SHSSB, should give specific attention to the needs of children.

The provision of aids and wheelchairs is one of the pressing concerns and frustrations experienced by families and professionals. Yet the provision of appropriate equipment (often at relatively low cost) in a timely way, was the thing that made most difference to family life. Various accounts told of inefficiencies and waste in present arrangements. Equipment is an integral part of the nursing response yet it is often beyond the control of nurses to effect the necessary improvements as they do not have access to a dedicated equipment budget.

### Review of respite provision

DHSSPS and the HSC Authority need to urgently review respite provision for children with special needs; particularly with respect to nurse involvement as this is deemed necessary for children with complex physical healthcare needs. This review should involve education.

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The overall dearth of respite options in Northern Ireland has been widely reported in research papers (e.g. McConkey and Adams, 2000) and policy reviews (e.g. Equal Lives, 2005).

Moreover there are particular issues around the registration of residential respite homes as 'children's homes'. We were given various examples of families being turned away from facilities on the grounds that they were unable to manage the risks these children presented. Arguably these parents are the very ones who are most in need of respite breaks. Hence the review needs to look at issues around registration and inspection of respite services as well as age range of children covered (i.e. up to 18 years); the transition options available in adult services and assess the need for increases in the number of places.

The outcomes of this review would also have major implications for nursing and yet it is an issue that nursing per se cannot take forward.

## Service Delivery recommendations

The service framework will provide the overarching context for service delivery. This will continue to take place across a range of agencies. The five new Health and Social Care Trusts will continue to provide the bulk of services and their advent may provide an opportunity to achieve greater service cohesion than has been the case thus far among the various service domains they cover (see Figure 3). However voluntary providers will continue to have an important role to play as will educational services. A priority is to ensure better co-ordination among these services.

### **Recommendation**

Each family should be allocated a member of staff who will act as the main point of contact for the family and the co-ordinator of service inputs.

The co-ordinator will be the professional who has most ongoing contact with families and will sign-post them to services and well as acting as a conduit of information for other services. In many instances community children's nurses will continue to fulfil this role although this may need to be made more explicit than at present. It is possible that this person could come from voluntary as well as statutory provision.

A core feature of their role is to assist with the planning of transitions in the life of the child, for example from hospital to home; from home to school entry and transfer to adult services. It is likely that the co-ordinator will be part of the proposed core group of professionals who have most contact with the child, such as teacher, therapist, social worker or nurse. It is suggested that this core group would meet regularly with parents to review service plans. These two proposals should ensure that no child with complex with physical healthcare needs should ever be on a waiting list for services, as their needs will have been identified and planned for well in advance.

However there a number of considerations in relation to the proposed co-ordinator role.

- Under the Children Order, a child who spends more than 90 days away from the family home is deemed to be a 'Looked After Child'. Usually a nominated social worker has responsibility for convening regular LAC reviews which involves co-ordinating the inputs of various professionals to this process. It is anticipated that they would continue to exercise this discrete function. This arrangement would provide families with access to a health contact as well as a social services contact.

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- There may be scope to combine the role of co-ordinator with some of the functions of care manager if this model is used within children's services. For example, there would be advantages in co-ordinators having access to budgets that can be used to provide emergency respite or augmented home supports on a short-term basis. This could be channelled through nursing budgets as bank/relief staffing.

Two further significant recommendations are urgently required to improve services.

## Healthcare Assistants

### **Recommendation**

A common policy should be developed by HSS Trusts and Education and Library Boards (Education & Skills Authority) regarding the employment of healthcare assistants.

A primary source of support for families is from personnel who can provide competent 'hands-on' care to the child in home, school and respite setting. In recent years, healthcare assistants have been trained and deployed in various settings although issues still remain about these posts; such as level of pay, roles, accountabilities, contracts and training.

HSS Trusts and ELBs need to come to an agreement about joint funding of posts within school settings. Moreover the roles of healthcare assistant and learning support assistant should be combined for certain children; the so-called 'hybrid worker'. Already there are effective arrangements in place within Trusts that could be emulated throughout Northern Ireland although more work needs to be done with respect to governance issues.

Mechanisms also need to be found so that healthcare assistants employed by one agency can easily transfer to another, for example between HSS Trusts, between ELBs and Trusts, or between voluntary sector and Trusts. At present, the lack of these mechanisms can mean long delays in filling posts and providing continuity of employment to well-trained assistants.

Nursing has a key role to play in the training and supervision of these staff. They can be considered within the revised skill mix in the nursing workforce.

## Greater choice of respite options

### **Recommendation**

An increase is needed in local respite options for these children and families.

In addition to the commissioning review of respite provision, there is an urgent need to address the particular dearth of facilities that can offer either emergency care of the child on a short-term basis or planned breaks so that parents can have a respite during the day or overnight. Failure to do so can mean unnecessary hospital admissions with the attendant risks to the child and family well-being.

A range of options are required in order to meet family preferences and there are examples of good practice available from around Northern Ireland, such as 'Hospice at Home', relatives acting as paid replacement carers, and the Children's Hospice. These options need to be available in all areas and not be dependent on short-term funding as is the case at present.

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Although families may use Direct Payments to fund their respite services, this option depends on suitable personnel (i.e. nurses and healthcare assistants) and services being available for them to avail of.

Given the needs of the children, it is likely that trained children's nurses will be required in the staffing of respite services, especially those where the child stays overnight. Hence workforce planning for nursing children must take account of this service need.

## Nursing Recommendations

It will be possible to define more definitively the nursing response to these children and their families when there is greater clarity around the commissioning of services and improvements to service delivery systems. Nonetheless it is apparent that two recommendations should be implemented immediately.

### **Recommendation**

Each new HSS Trust should undertake an audit of nursing services for children with particular respect to future roles and functioning of children's community nursing; the interface it has with the acute sector and with other community nurses, notably learning disability nursing. Voluntary services also need to be included.

Children's community nurses began to be appointed in the latter part of the 1990s. The numbers in post are still small and resources were not available for out-of-hours cover at evenings and weekends. Moreover little consideration appears to have been given to the impact these appointments would have on other community nursing services, notably community learning disability nurses but also district nursing and school nurses.

Similarly there appears to have been little explicit acknowledgement of the interface with acute hospitals despite many of the nurses having been recruited from the hospitals. The new Health and Social Care Trust arrangements may make it easier for Nursing and Children's services to span these two domains.

The proposed audit should be done speedily as much of the information should be readily available and indeed the new directorates may be eager to have it. The CNO could negotiate the time-frame in conjunction with the CEO of the Trusts.

The audit should consider related issues such as 24 hour emergency cover, partnerships with the voluntary sector; options for emergency respite provision outwith hospitals; flexible working across acute hospitals and community children's nursing; discharge planning procedures; the transfer to adult wards in acute hospitals; transfer between community nursing services and a review of innovative practices such as telemedicine.

The outcomes of the audits would be essential for workforce planning and the commissioning of increased numbers of children's nurses. The consensus appeared to be that there were insufficient pre-registration training places for paediatric nursing.

## Training for nurses and healthcare assistants

### **Recommendation**

Accredited core training in specific procedures needs to be available regionally for nurses and healthcare assistants (e.g. provided by a peripatetic training team). This core training could then be individualised for specific children according to their needs. Opportunities should be given to parents to avail of this training.

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The life of children with physical healthcare needs is often dependent on a range of sophisticated technical procedures. However the numbers of children requiring each procedure can be small at any one time. As noted in Section 3, parents can become adept in using these procedures but they, along with healthcare assistants and nurses who have no previous experience of certain procedures, require training in their use. The latter are those nurses and other professionals who may come into contact with the child, e.g. in respite or school settings. At present this training can be ad hoc and it would be more cost-effective for this to be provided on a regional basis, perhaps by a small peripatetic training team.

The availability of such training opportunities would increase the number of trained personnel who would be able to meet the needs of children with complex PHC needs, e.g. it would also provide a common training for healthcare assistants and increase their employability across a range of children.

This training could also be made available to parents, respite carers and other personnel who may come into contact with the child, e.g. community activities and clubs. This should also include access to other pertinent courses such as back care and manual handling.

Certain procedures would need to be particularised for individual children but training in these could be given to the personnel involved with that child, e.g. those in acute hospitals.

## **Further issues for consideration**

A number of 'cross-cutting' issues arose during the project that need to be considered in any further work within the three areas detailed above; namely commissioning, service delivery and nursing responses. They are summarised here so that their importance is noted although it was not immediately apparent how they could be taken forward.

### **Voice of parents and children**

The opinion and aspirations of parents, and where possible that of the children and young person, must be reflected in all decision-making. This is easiest to do at the level of the individual family. However it is important that their voice is included in commissioning and service delivery. This might be done through engagement with existing parent groups such as the newly formed Northern Ireland Parent Carer Council (NB This has grown out of the group formed in the SHSSB as part of the Wraparound Project.) At present the Northern Ireland Children's Commissioner has commissioned research on the advocacy of children and young people with complex needs. This may yield further ideas and proposals.

### **Ethical and legal issues**

Children with complex physical healthcare needs pose various ethical and legal dilemmas in service delivery; for example protocols and permissions around non-resuscitation. These sorts of issues have received sparse attention within this Project although they will continue to feature of practice in this area for many years to come. Nursing personnel need to be aware of them and enabled to make informed contribution to these debates.

### **Local coordination of services**

The emphasis in this report has largely been on centrally driven initiatives. Within these is the need to define how local coordination (e.g. at a Trust and sub-Trust level) can be

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achieved across sectors (e.g. with education and HSS), and in particular how existing inequities will be addressed.

### **Drivers of change**

A major concern among informants is that the needs of this client group will be forgotten among the many other pressing demands within health and social care. Comment was made about how children's health issues have not had a priority within the DHSSPS and it is not clear how the new Health and Social Care Authority will handle the commissioning of children's health services. One proposal is the appointment of a regional co-ordinator of health services for children within the DHSSPS and/or the Health and Social Care Authority.

### **Financial resources**

Services to this group of children and their families are currently under-funded although it is not possible to put a figure on the deficit. Equally demand is likely to increase as children survive for longer and more children are born who require complex physical healthcare throughout their life. Part of the recommended actions will enable more accurate costings to be derived but acquiring the necessary resources to implement them will remain a challenge.

### **Individualised payments**

Although direct payments have the potential to give families more choice and control of services, further work is needed in order to make these schemes work better for families. In part it is a matter of educating service practitioners as well as parents about how the schemes can operate in practice. More fundamentally training a suitable workforce whom parents can employ is essential and this must be factored into any workforce planning.

## **Summary of core recommendations and implementation**

Table 5 summarises the core recommendations emerging from this study. More detailed recommendations are noted in the survey of professionals (see Appendix 6) and in the report of the Round Tables (see Appendix 7). These could be subsumed within the recommendations listed or would follow on when those noted above are implemented.

### **Action Plan**

Following acceptance of the Report by the Board of DHSSPS, the following actions were agreed for taking forward the implementation of the recommendations.

1. The Report is considered and endorsed by the Department of Education.
2. A project group is formed from the membership of the existing groups - with augmentation as required - to oversee the implementation phase.
3. A specific service framework for children with complex physical healthcare needs is developed for Northern Ireland.
4. A single assessment tool for identifying and assessing children with complex healthcare needs is developed for use by services in Northern Ireland.
5. An audit of nursing services to children is undertaken in the five new Health and Social Care Trusts.

**Table 5: Summary of key recommendations**

- A specific service framework should be produced for families and children with complex physical healthcare needs that is multi-agency and multi-disciplinary. This must cover transition arrangements from acute hospitals to community; school entry, school transfer and school leaving.
- Services should work to develop an assessment instrument that can be used to determine a child's physical healthcare needs and their family's need for additional support services (including respite breaks) and to assist with reviews of their needs. This would be used by all HSS Trusts, Education and voluntary organisations in Northern Ireland.
- Each family should be allocated a member of staff who will act as the main point of contact for the family and the co-ordinator of service inputs.
- A 'service map' should be created for each individual child and family and shared with all services and persons who have an involvement with them. Names and contact details should be provided of all those included in the map.
- Each new HSS Trust should undertake an audit of nursing services for children with particular respect to future roles and functioning of children's community nursing; the interface it has with the acute sector and with other community nurses and their partnerships with the voluntary sector.
- Assured funding is needed for community children's nursing services and the provision of flexible, out-of-hours responses by nurses in the community.
- Joint planning with the Department of Education is required, notably on joint funding arrangements and having common healthcare assistant posts in schools.
- Accredited core training in specific procedures needs to be available regionally for nurses and healthcare assistants (e.g. provided by a peripatetic training team). This core training could then be individualised for specific children according to their needs. Opportunities should be given to parents to avail of this and other training.
- DHSSPS needs to instigate urgent reviews of the commissioning and delivery of equipment (e.g. hoists, frames) to children and families. This review must involve education. The recently commenced review of wheelchairs that is led by the SHSSB, should give specific attention to the needs of children.
- DHSSPS and the HSC Authority need to urgently review respite provision for children with special needs; particularly with respect to nurse involvement as this is deemed necessary for children with complex physical healthcare needs. This review should involve education.
- An increase is needed in local respite options for these children and families.

6. The DHSSPS and the HSC Authority will commission a review of respite provision for children throughout Northern Ireland.
7. A review of provision of equipment to children with complex physical healthcare needs will be undertaken. This will be done with reference to the ongoing review of wheelchair provision.

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8. A regional Forum on nursing children with complex physical healthcare needs will be established to share good practice.
  9. There will be regional commissioning of training for nurses and healthcare assistants.

In conclusion, an ambitious but attainable programme of work has been identified. Resolving some of the issues highlighted in this Report will probably bring benefits to other client groups and it may provide a 'test-bed' for new methods of co-ordinating the planning and delivery of services. The changes resulting from RPA offer a unique opportunity to develop innovative approaches; albeit ones that have proved useful beyond Northern Ireland as well as those that are particular to the local situation.

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