

## Service Provision for Children and Young People with Complex Needs in a Community Setting from The Perspectives of Nursing and Allied Health Professionals

**SERVICE PROVISION FOR CHILDREN AND YOUNG  
PEOPLE WITH COMPLEX NEEDS IN A  
COMMUNITY SETTING FROM THE PERSPECTIVES  
OF NURSING AND ALLIED HEALTH  
PROFESSIONALS**

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## **GLOSSARY**

ADL – Activities of Daily Living  
AHP – Allied Health Professional  
ASD – Autistic Spectrum Disorders  
ASL Act – Additional Support for Learning Act  
CAMHS – Child and Adolescent Mental Health Services  
CCN – Community Children’s Nurse  
CDC – Child Development Centre  
CDT – Child Development Team  
CHIP – Child Health Improvement Partnership  
CHN – Community Health Nurse  
CHNR – Community Health Nursing Review  
CHP – Community Health Partnership  
CHSP – Community Health and Social Partnership  
CLT – Child Locality Team  
CPD – Continued Professional Development  
CYP – Children and Young People  
DN – District Nurse  
GIRFEC – Getting it Right for Every Child  
GP – General Practitioner  
HCA – Health Care Assistant  
HALL 4 – Health for All Children  
HV – Health Visitor  
LA – Local Authority  
LAAC – Looked After and Accommodated Children  
NAHP – Nursing and Allied Health Professional  
NHS – National Health Service  
OT - Occupational Therapist  
PDP – Personal Development Plan  
TAC – Team around the Child  
SLA – Service Level Agreement  
SLT – Speech and Language Therapist  
SNIP – Special Needs Information Point  
SSA – Single Shared Assessment  
TI – Technical Instructor



# EXECUTIVE SUMMARY

## Introduction

Researchers at Queen Margaret University, Edinburgh were commissioned by the Health Department in the Scottish Government to scope the nature and provision of care provided by Nurses and Allied Health Professionals in the provision of services for children and young people with complex needs across Scotland. Drawing on data from four health boards, the report links together information from workforce development plans, a survey of practitioners and a series of detailed interviews with practitioners and managers.

## Background

Health services for children and young people (CYP) with complex needs are changing in terms of both service delivery and service provision. There is an increased focus on person centred care, prevention and locally based community services. The organisation and delivery of Community Nursing is also changing which will impact on children's services.

The role of Nursing and Allied Health Professionals<sup>1</sup> (NAHPs) is seen as crucial in providing services for CYP with complex needs in a variety of settings. It is important, therefore, to understand whether they have the necessary capacity, knowledge and skills to meet the increasing demands placed on them.

The objectives of the research were to:

- Review the UK and international literature on the models of care for CYP with complex needs in the community.
- Present a picture of where CYP currently receive care (multi-agency); knowledge and skills involved in providing that care; and the issues facing the service.

## Who has complex needs?

The term complex needs encompasses children with a range of conditions and medical needs. A definition agreed by the Complex Needs Group, Scotland (ISD 2006a) is:

*“A child with multiple and complex disabilities has at least two different types of severe or profound impairment such that no one professional, agency or discipline has a monopoly in the assessment and management.”*

*Delivering a Healthy Future* (Scottish Executive 2007) states that there are approximately 7000 CYP with a range of complex needs at any one time in Scotland, but this figure needs to be kept under review as criteria change and services develop. For example, it will decrease if only the most stringent criteria are applied but is likely to increase with increasing survival rates of pre-term infants; those born with congenital impairments and cancer; and the improved prognosis for children with chronic diseases, over 85% of whom survive into adulthood.

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<sup>1</sup> The Allied Health Professionals in Scotland are:- Art Therapists, Dieticians, Drama Therapists, Music Therapists, Occupational Therapists (OTs), Orthoptists, Orthotists, Physiotherapists, Prosthetists, Podiatrists, Diagnostic Radiographers, Therapeutic Radiographers, Speech and Language Therapists (SLTs).

## **Who works with children and young people with complex needs in the community?**

CYP with complex needs may come into contact, at any one point, with as many as ten different professionals and several agencies (Abbott et al, 2005). The agencies concerned include health, social care services and education, together with extensive input from the voluntary and non-statutory sector. NAHPs play a considerable role in service delivery both in hospital and in the community.

Many of these children will have daily care needs which are provided through social services (care assistants to social workers) and educational needs provided through special needs and school nurses, classroom teachers and teaching assistants.

Carers and family members play a central role in caring for children with complex needs. The presence of a child with complex needs may have a dramatic effect on the family dynamics. NAHPs play an important role in educating and supporting families to care for their child alongside other family members.

## **Methodology**

This project was conducted in 2 phases:

*Phase 1* of the project involved a literature review and analysis of health board workforce data. Four overarching themes of direct relevance to the aims of the study were identified: integration within and between services; service capacity and capability; equity; and communication and information sharing. These themes were then incorporated into the research tools used in Phase 2.

*Phase 2* involved an exploration of the nature, role and models of NAHP services for CYP with complex needs in the community in 4 contrasting health board areas in Scotland. This work involved:

- Telephone interviews with senior managers (n=7).
- A questionnaire survey of lead managers and grass roots practitioners including representatives from school nursing, looked after children, community children's nursing, physiotherapy, occupational therapy and speech and language therapy. 33 out of 107 questionnaires were returned, a response rate of 31%.
- 4 focus groups with NAHPs exploring issues raised in the survey, supplemented by 4 interviews where focus groups were not possible.

The issues explored included topics identified in the literature:

- the range of NAHPs involved
- the settings within which they work
- type of interventions, generalist or specialist, predictable or unpredictable requirements e.g. crisis intervention, critical incidents
- expertise, experience, and ongoing educational needs and skill mix requirements
- the nature of unmet healthcare needs
- issues associated with management, staffing and funding arrangements
- existing strategies for joint and integrated working between service providers
- constraints and supportive influences related to service provision and partnership working

- recent or planned changes to existing service provision
- examples of good practice.

### ***Limitations of study***

The low response rate of the survey of lead managers and grass root practitioners means the findings of this report are largely based on a small number of responses and therefore must be treated with caution.

### **Findings**

These are based on the work carried out in stage 2 which explored the themes identified in the literature review. The findings are reported under 4 themes:

#### ***Integration and delivery of services***

Provision for CYP with complex needs was characterised by a multiplicity of practitioners working in a great many settings (residential accommodation, nursery, primary and secondary schools, community centres, health centres and the home). Typically, the majority of respondents worked with a variety of client groups and were not working exclusively with CYP with complex needs.

The majority of respondents were positive about the way the services were developing. Their concerns centred on funding, education and skills, recruitment and staff retention. An assigned key worker was identified within the literature review and by respondents as an example of good practice and as a preferred approach to providing a participatory, continuous and consistent quality of care. A key worker need not be a nurse or allied health professional and could be selected by both the parent/carer and child or young person, based on a set of agreed criteria.

Partnership working was endorsed by all staff, but it was felt there was a need for more leadership in the implementation of joint working practices.

CYP with complex needs are increasingly managed in the community and this has implications for the transfer of resources from acute to community settings to ensure that quality services are delivered to the right person and at the right time.

There was evidence that practitioners were using, or were moving towards, a person centred model of care, with the child and the family at the centre. This increases the need to integrate services, and strengthen partnerships and collaborative working.

#### ***Service capacity and capability***

A lack of suitably qualified staff was a recurring theme in the research. It was felt that there were not enough staff with the appropriate level of expertise to deliver the necessary services. Lack of available qualified staff with appropriate expertise and experience was also felt to inhibit the scope for developing capacity within the workforce. Within occupational therapy, physiotherapy, nursing related to paediatrics and the care of CYP there was also concern that there were both fewer and less experienced staff available to take up vacant posts.

One suggestion put forward to overcome the lack of staff was for a bank of trained staff, coordinated at health board level, which would be able to provide specialist, flexible services and expert input as and when appropriate.

In one area, speech and language therapists were pairing up with less experienced therapists and therapy partners including parents, carers or school auxiliaries as a way of improving skills.

There were reports that staff, such as health and social care support workers, were asked to undertake tasks (such as feeding within a school environment or carrying out physical activity regimes) previously undertaken by professional staff, for example, community children's nurses, health visitors, school nurses, and physiotherapists.

Lack of expertise was also an issue for those in post. For example, respondents identified a lack of experience in paediatrics, child development, and, specifically, children's health care in general. There was an indication that NAHPs required an increased knowledge base of family health, family dynamics and their coping mechanisms and use of support systems.

Although education opportunities were available to increase knowledge and skills, a number of barriers to uptake were identified including finance, funding and "backfill" i.e. covering for staff in training. Concern was also expressed about an increasing trend for individual practitioners to be responsible for their own professional education and updating their skills. It was felt this could contribute to a haphazard model of service delivery.

A well defined competency base was suggested as one route which would develop shared understanding, and increase opportunities for nurses and allied health professionals to be educated/trained together.

It was felt to be critical that health care assistants and support workers, who contribute so much to service provision in this area, have sufficient skills to take on the roles that are delegated to them. This has implications for risk management, clinical governance, quality assurance and staff development.

### ***Equity and gaps in service provision***

While there was a broad acceptance of the need to move towards a model of family centred or child-centred service delivery, practitioners were not confident that the needs of CYP with complex needs in the community were being met, or that the views of this client group were being taken into account, particularly in relation to service planning and implementation. This was particularly true for families in rural and remote areas and those less able to fight for the needs of their child.

In general, issues relating to age-appropriate services were highlighted at particular transition points. The "in-betweenagers" i.e. adolescents and young people, were felt to be particularly disadvantaged. Transition arrangements across sectors and between different services were often felt to be at best inconsistent, and at worst, non-existent. Constraints within children's services, and the inappropriateness of adult services, were perceived to be problematic in responding to the complex needs of this particular group of CYP.

A number of funding gaps were identified, for example within respite and palliative care and discharge planning. Anticipatory care for discharge planning highlighted problems related to equipment availability and educational preparation for the carer or family in order to care for the individual child or young person at home (e.g. ventilatory support, oxygen therapy), all of which are essential to a person-centred model of service delivery. While these applied across all health boards they tended to be more pronounced when there was no specialist children's medical facility (hospital or children's ward) nearby.

### ***Communication and information***

The number of practitioners involved with CYP can lead to duplication of record keeping, frustration on the part of families and young people and considerable potential risk in terms of safe case management. Participants suggested that one way of addressing this issue was the use of joint record keeping within and across services however, there was little evidence of shared assessments in use. There was a view that vertical and horizontal transmission of information within professions, between professional groups, and across multiple service providers, could be improved.

Participants stated clearly that it was critical for them to be able to share information effectively both within and across services, in order to provide a "joined-up" approach to service delivery and development. This study suggested progress in some regions and across some services, but there remained inconsistencies. Geographical challenges were evident, although these should not be insurmountable, with increased usage of information technology and electronic data sharing.

### **Conclusions**

Much is already known by service providers about what is needed for CYP with complex needs and considerable resources are already in place to meet those needs. Nevertheless, we need to know more about the number and needs of this group of service users and their families and a more consistent approach to the delivery of services is needed. Special efforts are required to ensure that there is good communication between the wide range of staff involved in delivering these services and that issues associated with equity and service gaps are identified and addressed. Finally, CYP with complex needs need good access to appropriately qualified staff who provide both routine care and the kind of specialist care that such children need in the community.

### **References**

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ISD (2006). Definition agreed by the Complex needs group December 2005. Edinburgh ISD, Scotland. Available from: <http://www.isdscotland.org/isd/3397.html#Analysis>

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# CHAPTER ONE INTRODUCTION

## Structure of the report

1.1 This chapter provides the background to the study, including the aims and objectives. It addresses the issue of the definition of complex needs and the numbers who are likely to fall into this category. It describes the workforce of nurses and allied health professions who work with children and young people with complex needs, gives a descriptive overview of services within Scotland and the 4 selected sites. The methodology of the project, including the selection of sites, is then described.

1.2 In Chapter 2, we provide detail from a Scottish perspective focusing on 4 health boards, in relation to children and young people with complex needs. In Chapters 3, 4, 5 and 6, we report on the data collected from the telephone interviews, questionnaires and focus groups. The data have been grouped and analysed according to 4 major themes:

- Chapter 3 looks at integration within and between services
- Chapter 4 investigates service capacity and capability (existing levels and potential future demands),
- Chapter 5 explores the degree of equity within service provision, and
- Chapter 6 highlights the communication and information needs of the Nursing and Allied Health Professionals (NAHPs) who provide services for children and young people with complex needs.

Chapter 7 draws together the key themes arising out of the document, and provides a summary and concluding comments.

1.3 The main body of the report is followed by a set of appendices (1-4). These are: review of international literature; interview schedule for telephone interviews with managers; questionnaire sent to practitioners; and topic guide for focus groups with practitioners.

## Background

1.4 Children and young people with complex needs are a very vulnerable group with an intricate mix of health and social care needs which represent a real challenge for those seeking to provide services. The children's sector workforce in Scotland currently comprises 222,000 staff, of whom approximately 27,000 work in the health sector. Of these, 18,000 fall within the remit of this study, i.e. they are within the nursing or allied health professions, though are predominantly located within acute care services (Children in Scotland 2005). These professions are not represented to any great extent in workforce figures for education, early education, childcare, social care or other children's services.

1.5 Data on the proportion of staff working with children with complex needs are not recorded, in part because this particular population of children is not identified as a discrete group within service provision. This is especially true of community based services where needs are met alongside those of all other children. This issue is becoming especially salient within the broader context of the "shift in the balance of care towards more preventive, continuous and, individual and planned care provided locally in the community by multi-disciplinary teams" (NES, 2007a).

## Aim and objectives

1.6 The overall aim was:

- To provide a picture of the NAHP services for children and young people with complex needs in a community setting, in Scotland.

1.7 The specific objectives were:

- To review the literature of models of service provision across the professions concerned, in English speaking countries, and examine these models with relation to the Scottish context
- To identify a number of health boards in Scotland and provide a descriptive picture of relevant services, the workforce involved and the issues facing the service

## Who has Complex Needs?

1.8 A wide range of terms are linked with the concepts of 'complex' and 'multiple' needs, used by various disciplines, sometimes specifically, and most often interchangeably. They include: 'multiple disadvantage', 'multiple disabilities', 'multiple impairment', 'dual diagnosis', 'high support needs', 'complex health needs', and 'multiple and complex needs' (Rosengard et al. 2007). Additionally, the literature refers to 'special needs', 'special health care needs', and 'high and complex needs'. The terms encompass children with a range of conditions and medical needs. A definition agreed by the Complex Needs Group, Scotland (ISD 2006a) is:

*“A child with multiple and complex disabilities has at least two different types of severe or profound impairment such that no one professional, agency or discipline has a monopoly in the assessment and management”.*

1.9 This definition is elaborated on still further in the summary statistics for the Support Needs System (SNS), which identifies a group of children with Multiple and Complex Disabilities (MCD) (ISD 2007). A child is defined as having MCD if he or she has:

- i. severe or profound disabilities in at least 3 of the following disability categories: motor impairment, hearing impairment, cognitive impairment, speech and language impairment, behaviour problems, feeding problems, additional chronic health needs  
OR
- ii. severe or profound disabilities in at least 2 of the following disability categories plus the need of at least 2 types of resources: therapy services, additional educational resources, nursing care needs, social care resources, mental health services

1.10 This publication uses the SNS data set to calculate the number of children with MCD across Scottish health boards and estimates the proportion of children with MCD relative to the overall population of children with Support Needs. The average proportion is 0.31% of children and young people below the age of nineteen years, which represents in the region of 18% of the larger group of children who have any support needs. Extrapolating from the Mid 2006 Population Estimates for Scotland (GROS 2007), there were 1,184,819 children of

nineteen and under, allowing us to estimate a population of approximately 3,673 children and young people with MCD in Scotland. These figures are likely to vary according to the criteria used and the time at which population estimates were made, but do give some indication of the number of children involved.

1.11 It is also likely that the SNS figures are lower than the Scottish Government figure of 7000 children considered to have complex health and social care needs (Scottish Executive, 2007, Action Framework, p. 41) because the system had only been implemented in 10 of the 14 Health Boards, and its use has been interrupted in some local areas because of administrative and/or medical staffing shortages. This same document maintains that this figure is steadily rising, which can be attributed to increasing survival rates of pre-term infants (McIntosh & Runciman, 2007), those born with congenital impairments and cancer (Kirk & Glendinning, 2002), and improved prognosis for children with chronic diseases, with over 85% surviving into adulthood (RCN, 2004).

### **Who works with children and young people with complex needs in the community?**

1.12 A wide range of professionals, carers and voluntary agency staff work with children and young people with complex needs in the community and the experience of individual children will vary considerably. Indeed, it has been suggested that disabled children with complex health care needs will have contact at any one point with ten different professionals and several agencies (Abbott et al, 2005). The agencies include health, social care services, social work and education, together with extensive input from the voluntary and non-statutory sector. The staff groups involved range from medical and health (nursing and allied health) professionals who provide services from hospital but maintain an outreach element to their services, either visiting the children in the home or recalling the children to hospital at regular intervals.

1.13 There are also medical and other health professionals who are based in the community but who have a role in providing support and care to the individual child in the home and providing or enabling access to community services. Community children's nurses (CCNs) are of central importance in the UK, as are a range of allied health professions. The allied health professionals in Scotland are:- Art Therapists, Dieticians, Drama Therapists, Music Therapists, Occupational Therapists (OTs), Orthoptists, Orthotists, Physiotherapists, Prosthetists, Podiatrists, Diagnostic Radiographers, Therapeutic Radiographers, Speech and Language Therapists (SLTs). It should be noted that, in the majority of the literature reviewed, and subsequent data collected for this project, 3 allied health professions appeared more frequently than any others, namely, occupational therapy, physiotherapy, and speech and language therapy, with occasional reference to the work of dietetics. This is not to say that other groups were not involved, only that their role was rarely highlighted in the literature.

1.14 While the health needs of children may be prioritised at specific times, the needs of the child or the young person go beyond those solely related to their health. Many of these children will have daily care needs which are often provided through social services and can involve levels of staffing from care assistants to very experienced social workers. Although the education of the child does not, strictly speaking, come under the remit of this review with its emphasis on health needs, it is clear that the management of the child within the school context can likewise have consequences for service provision and a knock-on effect



on medical and health needs. Thus, school nurses, parents, teachers and ancillary staff (teaching assistants) are all key elements of partnership working within the service provision for these children.

1.15 Finally, it is important to see the needs of these children from the perspective of the family as a whole. For most families, the presence of a child with complex needs will have a dramatic effect on the family dynamics. Parents are likely to have less time for other children and for themselves and this can lead to multiple secondary effects. Therefore professionals who manage the needs of the family as a whole, utilising a family-centred approach, are also an integral part of the picture. It is not always clear who will provide these services, with non-nursing and allied health professionals often taking on the responsibility as part of their remit. Nevertheless, a strong individualised, person-centred service is able to provide support whether it is therapeutic or focused on respite care. In practice it is rarely a question of one professional or another, but more about the combination required for a given child with a given condition, with the pattern of professionals differing in each instance.

## **Methodology**

1.16 This project was conducted in 2 inter-related phases. The first was a review of relevant global literature contextualising the findings with respect to Scotland. Additionally, Health Board workforce data and plans were reviewed. The second phase was an exploration of the nature, role and models of nursing and allied health professional services for children and young people with complex needs in community settings within 4 Health Board areas in Scotland.

### ***Phase 1***

1.17 Phase 1 of the project involved a literature review and analysis of national and health board data. The research team reviewed the relevant literature to explore the nature, models, outcomes and infrastructures of community healthcare provision for children and young people with complex needs in English speaking countries. An indicative search strategy is provided in Annex 1, along with the review itself. Databases searched included Cinahl, PsycInfo, Scopus, Medline and internet searching. In addition, the facilities of the NHS Health Scotland e-library were utilised. Abstracts were identified and, where appropriate, papers were obtained. Given the variability of the literature and time frame of the project, the research team employed focused data extraction sheets which provided a framework to underpin phase 2.

1.18 Key themes identified in the literature were then incorporated into the research tools described below, to be further explored with NAHP personnel in the 4 health board areas in Phase 2 of the project.

1.19 Existing numbers and types of personnel working with CYP with complex needs in a community setting were identified from the Information Statistics Division (ISD) workforce data for Scotland.

## *Phase 2*

1.20 Four health board areas were identified to undertake a more detailed exploration of the issues related to service provision for children with complex needs. The health boards were selected to provide a range across a number of factors: geography, type of population served, the birth rate, the level of provision in terms of acute services and the level to which they had designated specialist staff and services (respite care) for children with complex needs as shown in Table 1.1 below. We opted to retain the anonymity of the health boards by giving them alternative titles which will be used throughout the report.

**Table 1.1 Characteristics of the 4 Health Board case study sites.**

<b>Health board</b>	<b>Name of board</b>	<b>Location</b>	<b>Live births av. 50/1000</b>	<b>Acute service</b>	<b>Respite provision</b>	<b>Specialist provision</b>
1	Duncan	Urban	46	Children's hospital	Comprehensive	Comprehensive
2	Macbeth	Remote	53	Ward within a general hospital	Ad hoc	Comprehensive
3	Banquo	Rural	50	Children's hospital	Uncoordinated	Inconsistent
4	MacDuff	Rural/Urban	50	Children's hospital	Uncoordinated	Comprehensive

1.21 Phase 2 incorporated telephone interviews, postal and electronic questionnaires, and focus groups. Identified key professionals in the 4 selected Health Boards were surveyed, by telephone interview, questionnaire or focus group, to explore the topics identified in the literature.

### *Telephone Interviews*

1.22 Telephone interviews (see interview schedule in Annex 2), lasting approximately one hour, were conducted with seven senior managers (three from Duncan, two from Banquo, one from Macbeth, and two from Macduff). Each interview was recorded and transcribed.

### *Survey Questionnaires*

1.23 Whilst some information was available from existing organisational baseline data (e.g. ISD), obtained in Phase 1, a survey questionnaire was used to gather information about services provided by NAHPs to meet the healthcare needs of children and young people with complex needs. The questionnaire (Annex 3) was distributed to managers of children and young people's service providers, e.g. related paediatric services, hospital outreach services, Public Health Nursing/health visiting/school nursing, Children and Family services, Looked after and Accommodated Children services, outreach services and related paediatric services. The research team targeted lead managers and grass roots practitioners, using a range of available contacts and resources (including the senior managers interviewed by telephone, and relevant statutory and non-statutory bodies).

1.24 Specific topics addressed within the questionnaire included:

- The range of nursing and allied health professionals working with children and young people with complex needs in community settings
- The type of interventions, and any specific or specialist requirements e.g. crisis intervention, critical incidents.
- The variety of community settings in which the nursing and allied health professionals are operating
- The qualifications, length of time in post, expertise, experience, and ongoing educational needs and skill mix requirements
- The nature of unmet healthcare needs
- Issues that arise from management, staffing and funding arrangements
- Existing strategies for joint and integrated working between service providers
- Constraints and supportive influences related to service provision and partnership working
- Any recent or planned changes to existing service provision
- Exemplars of good practice

1.25 A total of 107 questionnaires were sent out, by post and email, following suggested contacts given by managers in the telephone interviews. A total of 33 completed questionnaires were received, giving a 31% response rate. The majority of responses were from Duncan and Banquo case study areas, with a much lower response from Macbeth and MacDuff. The MacDuff response was particularly low, with only 2 confirmed respondents returning a completed questionnaire. A number of factors (some suggested by NAHPs themselves) may have contributed to the low response rate: the timing of the survey carried out over a holiday period and amidst restructuring of the workforce; research fatigue, with the survey following the Community Nursing Review; lack of time due to the current workload of individual staff; and the length of the questionnaire.

## **Focus Groups**

1.26 Using data generated by the telephone interviews and questionnaires, a template for focus groups was developed (see Annex 4), to further explore and unpick some of the issues raised. Four focus groups were held within 3 of the 4 sites (2 in Duncan, and one in each of Banquo and Macduff). In Macbeth, external constraints on staff time, in conjunction with the logistical problems of assembling people in one location over such a large geographical area, meant that it was not possible to hold a focus group. Instead, 4 telephone interviews, covering topics discussed in the focus groups, were carried out with appropriate nursing and allied health practitioners.

1.27 The focus group participants were recruited through the senior personnel interviewed in each Board, and/or lead personnel within community settings, to reflect the diversity of service provision in the locality concerned. The focus groups included members of community health partnerships and other existing integrated service providers, to identify existing best practice, aspects of service provision and areas for improvement.

1.28 The focus groups were run by members of the research team, lasted for approximately one hour, and were tape recorded and transcribed.

1.29 Additional telephone interviews were used to follow up issues with practitioners who were not able to attend focus groups, or pursue specific points or issues in greater depth, and explore and clarify any anomalies or sensitive issues that arose from the focus group discussions.

## **CHAPTER TWO            THE SCOTTISH CONTEXT**

### **Introduction**

2.1     This chapter begins by summarising the key points of the literature review carried out for this study. Effectively this sets the scene for the Scottish context. The review itself is provided in Annex 1 and a full set of the references associated with the review are provided. The chapter goes on to provide an overview of workforce development plans within the 14 health boards in Scotland and then goes on to examine the profile of the four target health boards.

### **The review of the literature**

2.2     The reviewed literature covers a number of countries. Although we have focused on those which we believe to have most relevance to the Scottish scene it is apparent there are many ways of providing services to this group of children, young people and their families and that it is not possible to truly compare funding mechanisms and the extent to which differences are associated with socialised, public systems of service delivery or systems where there are private insurance based or mixed models of provision. There is considerable variability in the way that complex needs are defined. The literature is sometimes unclear about the distinction between services for those with complex needs and other children's services. Nevertheless there is a clear direction of travel away from hospital based services to more personalised and family centred community based services. Of course this does not mean that it is necessarily happening everywhere, merely that this shift is reflected in the literature. This family centred-ness requires creative solutions in terms of service delivery, especially in remote areas. Solutions in Australia may have direct relevance to some parts of Scotland. There is an increasing reliance on support workers and assistants to deliver care which has implications for specialist knowledge. Although the emphasis is often on the skills and outlook of the individual practitioners there are clearly widespread issues associated with service re-design which are systematic and require extensive managerial support. Although the views of parents and children are often mentioned as a part of the changes that have started to come through this was not reflected in the literature that we reviewed. Although most of the services described in the literature were distinct they often tended to include similar elements and it was difficult to contrast them directly. In order to extract key differences in models described we separated them out into three types (The Acute Care Model, The Community Care Model, The Child/Family Centred Model) and then identified a number of areas (Integration within and between services, knowledge and skills, equity of service provision, communication and information) which could be described as tests of whether a system could be said to work effectively. In practice because too little data, or at least too little data of the right sort, was provided in the majority of service descriptions it was not possible to compare across them directly.

### **Workforce planning in Scotland**

2.3 It should be noted that the way in which data are collated and presented by ISD Scotland does not allow for identification of those working specifically with children and young

people. Among nursing and midwifery staff, it is possible to determine those working with children in the community, or jointly in the community and hospital, and school nurses (numbering 382 in 2007). However, it is not possible to determine how many other types of nursing staff (e.g. Health Visitors, Public Health Nurses, District Nurses), are working specifically with children in the community. Similarly, for Allied Health Professionals, there is no way to determine how many within each profession work specifically with children. Available information does not evidence the numbers of NAHPs working with CYP with complex needs.

2.4 Each year the 14 health boards in Scotland are required to submit workforce plans for NHS staff, which we examined as part of the review. As far as was possible, given the nature of the way in which such information is presented, we extracted information relating to the 4 sites which would be directly relevant to understanding the way in which services are delivered to children with complex needs and their families. In the sections below we have separated out the nursing workforce plans from the AHP workforce plans

### **Workforce Trends – Nursing Staff**

2.5 The anticipated number of children's nurses required to fill vacancies and meet projected need is expected to increase by 3.2 percent each year in Scotland for the period 2006/7 to 2010/11. The demand for non-registered children's staff is expected to increase by 4.2 percent annually for the same period (figures from National Workforce Plan, Scottish Executive, 2006). While the numbers of pre-registration nursing and midwifery students in training are at an all time high (National Workforce Plan, 2006) the number of graduate completions for training in children's nursing in Scotland was 140 in 2005/6 which is a decrease from previous recent years (157 in 2003/4 and 172 in 2004/5) (figures from National Workforce Plan 2006). This could have implications in meeting future service demands.

2.6 Whilst the overall number of nursing and midwifery staff has increased over the past 10 years, it is acknowledged that there is a national shortage of community nurses. One board commented on a local shortage of trained nurses with no new permanent nursing posts being offered, and states:

*“sustaining both Community Nursing Services and Community Hospital Nursing Services in their current form over the next 5-10 year period is questionable. This means we need to start planning how we can provide the same level of service but in a different way. Locally there is a shortage of qualified nursing staff, and any posts are filled with nurses coming from another hospital within the region which simply transfers the staff shortage problem, it does not solve it” (NHS Dumfries and Galloway Workforce Plan, 2006, p. 96).*

2.7 The overall level of turnover in nursing and midwifery has reduced slightly over the past few years, but three of the four participant NHS boards had rates above the national average as of 2005/6, with NHS Duncan and NHS Banquo being consistently higher throughout the five year period, as shown in Table 2.1 below.

**Table 2.1 Turnover trend of nursing and midwifery staff**

	2001/2	2002/3	2003/4	2004/5	2005/6
National Average	7.2	7.3	7.3	6.7	6.8
NHS Duncan	9.1	9.9	9.1	8.2	8.3
NHS Banquo	8.4	9.4	8.5	8.0	8.4
NHS Macduff	7.4	6.7	6.4	6.1	6.8
NHS Macbeth	6.5	5.8	6.8	5.7	8.6

**Notes to table** Turnover is defined as the number of leavers divided by the average number of staff in post in year concerned. Source: ISD 2008.

2.8 NHS Boards' workforce plans indicate that there is indeed a need for a greater investment in Advanced/Nurse Practitioners roles and Assistant Practitioner roles (National Workforce Plan, 2006). The plans also suggest that care will be increasingly delivered by non-medical staff which will allow for more specialised nursing and midwifery roles. The proposals for the development of nursing roles often aim to meet the needs of a particular client group. Some examples of extended and specialist roles include:

- Extended Nurse Prescribing in Orkney as part of extending the scope of practice for Nursing in the Community. More core palliative care services will be provided by community nurses and a new combined social care and nursing role may be required to enable continued home care (NHS Orkney Workforce Plan, 2006).
- NHS Greater Glasgow & Clyde has launched an 18 month pilot of the Family Health Nurse involving a skilled generalist role, which practices a model of health rather than illness (NHS Greater Glasgow & Clyde Workforce Plan, 2006).
- NHS Dumfries and Galloway has indicated an interest in developing "innovative child posts and nurses with special interests e.g. Epilepsy nurse, Respiratory nurse" (NHS Dumfries and Galloway Workforce Plan, 2006).

### **The Community Nurse**

2.9 In order to respond to the plethora of current policy drivers, and to build workforce capacity for service development, there is currently an ongoing review of community nursing in Scotland in four pilot sites (Scottish Executive 2006). Although this process of review is not complete, one health board has commented that skill mix had been introduced into community nursing but that vacancies were becoming harder to fill (NHS Dumfries and Galloway Workforce Plan, 2006). Another board (NHS Greater Glasgow & Clyde 2006) reported that skill mix has been introduced to support Health Visitors/School Nurses, and Public Health Nurses.

2.10 Support staff are now recognised as valuable assets in multi-disciplinary teams and include nurses and in some cases, lay workers. New roles will include nurses providing minor illness services and possibly Family Health Nurses (NHS Greater Glasgow & Clyde Workforce Plan, 2006). In Shetland, where the difficulties of recruiting in this remote area can be a barrier to specialisation, there are plans to distribute paediatric skills throughout the workforce. At present, these skills are held by individual members of staff, such as children's nurses. Future options might include the additional training of District Nursing Teams, an additional children's nurse who would act as a link between community and hospital services,

a team of children's nurses working across primary and secondary care, or the CHP model of skills within each locality based team (NHS Shetland Workforce Plan, 2006).

## Workforce Trends - Allied Health Professionals (AHPs)

2.11 Over the past 5 years, there has been a general increase in staffing for both professional and unqualified staff (assistants) in most staff groups, particularly in physiotherapists and occupational therapists.

2.12 Delivering for Health (SEHD, 2005) highlights the increasingly important role of AHPs and the need for new ways of working. In light of this, NHS Scotland has recognised that further information is required about AHP activity and research is currently underway. The national 2006 census '*AHPs Count: Preliminary Results from the census*' (ISD 2006b) interviewed 5,955 practitioners to determine the nature, variety and magnitude of AHP caseloads. The total caseload for Scotland was 843,825 patients, with one patient being seen on census day for every 89 people in Scotland. The preliminary results also provide information on access to services, clinical conditions and care objectives for patients. It indicates that AHPs are involved in many stages of patients' care including prevention, screening, diagnosis, supplying equipment and education. A programme is currently in progress to develop data standards in order to better record, classify and measure the work they do (National Clinical Dataset Development Programme).

2.13 Demand for AHPs has been increasing over the last 10 years, primarily because of service delivery changes (National Workforce Planning Framework, NHS Scotland 2005). The impact of these changes on AHP services and roles is not clear for some health boards, but one NHS Board acknowledges that more rehabilitation at home will require greater AHP workforce and resources to support new initiatives (NHS Forth Valley Workforce Plan, 2006).

2.14 A significant number of NHS Boards have reported difficulties in recruiting AHPs especially where there are other employers recruiting from the same labour market such as other statutory, voluntary and private employers. The recruitment of paediatric physiotherapists and paediatric occupational therapists is also reported as challenging. Recruitment is difficult in single-handed posts and in more remote and smaller population areas such as the Highlands and Islands. The employment of newly qualified AHPs is sometimes not possible in these remote areas as supervision cannot be provided.

2.15 The turnover trend of AHPs has decreased between 2001 and 2006, but 3 of the 4 study NHS Boards have levels above the average, Macbeth in particular. (Table 2.2)

**Table 2.2 Turnover trend of Allied Health Professionals and Clinical Psychologists**

	2001/2	2002/3	2003/4	2004/5	2005/6
National Average	7.4	7.1	8.1	7.2	7.0
NHS Duncan	9.7	9.8	9.1	9.1	7.9
NHS Banquo	8.0	7.5	8.2	7.8	7.7
NHS Macduff	5.7	7.2	6.6	7.3	6.4
NHS Macbeth	6.8	8.1	8.5	8.7	9.1

**Notes to table** Turnover is defined as the number of leavers divided by the average number of staff in post in year concerned. **N.B.** Figures include clinical psychologists. Source: ISD, 2008.



2.16 An ageing AHP workforce was of particular concern to NHS Tayside, where one fifth of staff could retire within 10 years, potentially creating challenges in terms of succession and planning. There were no undergraduate programmes for AHPs in this region, reducing the range of opportunities, in contrast to those available elsewhere in Scotland.

2.17 Within the workforce plans, NHS Greater Glasgow and Clyde (2006) commented that there was no method to link the number of student training places to the number of new recruits required. NHS Dumfries and Galloway (2006) acknowledged the need to encourage part time and distance learning for mature people to ensure future workforce.

2.18 The need for the assessment and review of AHP roles was widely acknowledged, with many NHS health boards considering the enhancement or extension of roles. It was recognised that there were opportunities for AHPs to contribute to the community focused model and to become more integrated. For example,

*“an option which requires a full review is whether paediatrics should move and become a separate team with a separate service manager. This could become a joint service incorporating children’s services, school nurses, child protection and learning disabilities nurse or become a joint therapy service with Physiotherapy” (NHS Orkney Workforce Plan, 2006).*

## The case study sites

Data for this section were taken from the respective health board workforce plans, health and community care plans, and children and young people’s strategic plans for each of the study sites. Additional data were obtained from the General Register for Scotland.

### Macbeth

2.19 Macbeth covers 2,500 square miles, and has a population of approximately 147, 930. It has one town with over 30, 000 residents, three between 6 and 10 thousand residents, and all remaining towns and settlements have populations under 5, 000. The region is one of the most rural in Scotland. There are no large urban areas; almost half of the population live in areas that are classified as rural and over a fifth of the population live in remote rural areas. Over a quarter of the population live further than 30 minutes drive away from a large town.

**Table 2.3 Urban Rural Classification, Percentage of Population**

	Large Urban Areas	Other Urban Areas	Accessible Towns	Small Remote Towns	Small Accessible Rural	Remote Rural
	%	%	%	%	%	%
Macbeth	0	28.4	17.9	4.8	28.2	20.8
Scotland	39	29.1	10.4	2.8	13.1	5.7

2.20 In comparison with the Scottish population profile, the region’s current population profile is considerably different, with a larger proportion of older people and a distinctly smaller proportion of young people. The average age in Macbeth is 42.6 (compared to an average age in Scotland of 39.6) and the over 65 years population is likely to grow by 51% by 2024. There are currently 26,105 children aged 0–15 (representing 17.6% of the population) and 5,313 aged 16–18 (3.6% of the population). The birth rate is projected to fall

over the next 20 years from 1,400 births a year to 1,200 births a year. The children's population of 0–15 is projected to drop by 21% by 2024.

2.21 Using the Scottish Index of Multiple Deprivation as defined by the Scottish Government, Macbeth has 16 data zones that are in the 20% most deprived in Scotland. The number of people who live in these most deprived areas is approximately 12,238, which is 8.3% of the Macbeth population (compared to the national figure of 19.7% of the population).

### *Health Inequalities*

2.22 Compared with the Scottish population, the health of people in Macbeth is generally better than average. Mortality rates for the region are lower for a range of diseases in comparison with Scotland as a whole.

2.23 19.3% of dependent children in the region live in lone parent households and 14.4% of dependent children live in households with no adult in employment. The hospital emergency admission rate for children aged 0-14 years has been falling over the last 10 years. In 1995 it was nearly 6,000 admissions per 100,000 population, and in 2005 this had fallen to 4,400 admissions per 100,000.

2.24 Macbeth Health Board has identified the following patterns of ill health in children and young people which impact on the workforce:

- There is an increase in the survival of children with complex needs and inward migration possibly associated with the “inclusive” reputation of services in Macbeth, resulting in an increase in requests for education/training in a variety of settings.
- There are rising incidences of childhood conditions such as asthma, obesity and of children and young people experiencing a range of mental health problems including ADHD and Autistic Spectrum Disorder. Patterns of mental ill health are resulting in increasing demand to meet immediate and ongoing mental health needs of children and young people.
- Increasing workload in children and young people affected by parental substance misuse and growth in substance misusing young people.
- Children are high users of primary care for minor illnesses, surveillance and immunisations.
- Approximately 25% of all attendances at A&E are children and young people.
- Children are proportionately lower users of secondary care and very serious or life threatening illness is relatively uncommon.
- Changes to Out of Hours GP services appear to be a contributory factor to the increase in direct referrals to Hospital General Paediatrics between 8pm and 11pm.
- Growth in the number of children referred to services with developmental disorders as evidenced by the pressure on Paediatric Occupational Therapy and Physiotherapy Services.

## *Complex Needs*

2.25 The Support Needs System (SNS) records information about children with additional support needs across Scotland. Its aim is to monitor their progress and ensure they have access to services or support they require. From the 2006 summary, Macbeth had 13 children being assessed in SNS (5 with complex needs), and the 0-16 year olds represented 0.05% of the total child regional population. However, due to lack of resources to collect data, the figures are considered to be an underestimate of the true numbers of children with complex needs in the health board area.

## *NHS Services*

2.26 There is one Community Health Partnership within the health board with a supporting structure of 4 Local Health Partnerships (LHP), an Acute Services Team and links to the Joint Future Structure of Management Groups, Senior Management Group and Executive Partnership Board. The LHPs' principal partnership responsibilities are:

- integration between acute and area wide services
- the establishment and maintenance of effective community planning links with their respective Local Rural Partnership
- regular contact with Area Management colleagues within the local authority, capitalising on the existing NHS Partnership Framework across the health board area
- links to the Joint Future Management Groups and Integrated Children's Planning Mechanisms
- strengthened links between health and social care at local management levels
- strengthened links between the NHS and the Voluntary Sector

NHS Macbeth is committed to developing an integrated care model of service delivery in partnership with other agencies in the statutory, non-statutory and independent sectors, to better provide a more client-centred service.

## *Children's health services*

2.27 NHS Macbeth child health improvement programme is divided into "Early Years" and the 3-18 year age groups.

2.28 The "Health Improvement Regional Programme- Early Years" aims to improve the health and well being of young children and focuses on Accident Prevention; Breastfeeding; Dental Health; Emotional Well being; Nutrition; Obesity Parenting; Physical Activity and Play.

2.29 The main focus of work of the "Education and Young People 3 – 18" programme is the development of health promoting schools; health plans for Integrated Community School cluster; and national and local health improvement programmes aimed at young people. Specific areas of work within the programme include being active; food in schools; tobacco control; dental and oral health; alcohol and drugs education; sexual health and relationships; provision of quality physical education; mental and emotional health and wellbeing.

2.30 Speech and Language Therapy (SLT) is an area-wide service managed by a "Heads of Service Management Team" encompassing Special Educational Needs, Paediatrics and

Adults. This Management Team is directly managed by the Nurse Director, and is further delineated into 5 teams, one within each Local Health Partnership and one within the hospital. Each locality has a Co-ordinator who directly links with the Heads of Service Management Team.

2.31 Individuals who require the SLT service are seen in a variety of locations including hospitals (community and acute); rehabilitation centres; health centres and clinics; social service locations and their own home. The service predominantly receives referrals from GPs - Medical Staff / Consultant; Education - Other AHPs; Social Services; Self referral; Health Visitors - Parent / Carer / Other

#### *Nursing and AHPs working in a community setting*

2.32 There is a need for resources to develop Community Services (opportunity to release resources from acute setting are minimal through sustaining a 24 hour acute service).

2.33 Supporting all demands from partners for active participation in the many multi agency children's structures is increasingly becoming an issue, as nearly all child health staff have to do this over and above their clinical responsibilities.

2.34 Recruitment of suitably qualified and experienced District Nurses (DNs) and Health Visitors (HVs) and Public Health Nurses in the local setting is challenging. Vacancies have been rare for DN's but for HVs the picture is different, although this is in part due to a significant number of interesting secondment opportunities being filled by HVs.

2.35 One area has a high proportion of vulnerable families and 'at risk' children and suffers from a distinct shortage of HVs and a high level of work related illness. Of the 4 staff members over 55 in this category, 3 are qualified HVs and one is a staff nurse. The implementation of Hall 4 has identified the need for a change in the HV team profile with the need to increase the proportion of Public Health Nurses, with a clear role of Health Visiting and/or School Nursing.

#### *Education and training*

2.36 The following points to be addressed regarding education and training were reported in the Workforce plan:

- Currently no assessment against competency framework in Nursing.
- Competency frameworks are worked towards and signed off in Physiotherapy and Occupational Therapy.
- Current limited number of candidates affects the willingness of Higher Education to provide local training.
- Develop staff with the right skills to meet Children's, Young People's and Families needs.
- Ongoing requirement for updating of paediatric resuscitation skills across a range of staff in many setting
- Need to develop and maintain skills in recognising the ill child, if 'out of hours' centres are to provide access to children less than 12 years.

## ***Banquo***

2.37 Banquo health board area covers 3360 square kilometres, and encompasses three local authority areas. It has a mixed rural and urban population of 525,936 people. Almost one quarter of the population is aged 0-19 years (126,003 out of 525,850). This proportion varies slightly across the three local authorities, with the main city having the lowest percentage (21.7%) of children, one local authority area the highest (25.8%). The main city in the region has a population of 206,600, of which 65,972 are aged 25 and under, representing 31.9% of the total population. This is slightly higher than the Scottish average of 31.3%.

2.38 The population of Banquo is expected to fall by 3% between 2001 and 2011. However, this is the expected decrease in the total (all ages) population. The child population is predicted to decrease much more rapidly, particularly among pre-school and primary school age children, and particularly in the city. The number of primary school children is expected to fall by more than 20%.

## ***Child Health***

2.39 Socio-economic factors that influence child health indicate that the region is an area of 'extremes'. While the main city has low unemployment figures, high earnings and good housing there are simultaneously high levels of drug misuse, housebreaking, domestic violence, and a high rate of children on the Child Protection Register.

2.40 The Child Health Needs Assessment Report (2003) by NHS Banquo identified the following significant health trends affecting services in the region:

- There are an estimated 12, 587 0-19 year olds in Banquo with mental health problems. Referral rates to child and adolescent mental health specialties have increased in recent years and have now overtaken the national average rates.
- The teenage pregnancy rate has been decreasing nationally for some years, and the rate in Banquo is the lowest of all the mainland Health Board areas.
- The increase in type 1 diabetes in the region is of particular concern. This follows a national trend. If the incidence of type 1 diabetes continues to rise, there will be increased pressure on resources (there is currently one consultant, one diabetes nurse and 0.5 dietitian) and there will be little opportunity to provide services closer to patients' homes. Increased children's diabetes nursing is seen to be a priority for this service, with generic children's community nurses (if they are put in place) having a valuable role in delivering care locally.
- Banquo has a high and increasing incidence of Inflammatory Bowel Disease among children.

## ***Complex Needs***

2.41 From the 2006 Support Needs System (SNS) summary, Banquo had 4373 children being assessed in SNS, and the 0-16 year olds represent 7.0% of the total child regional population.

### *Children's Health Services*

2.42 The Combined Child Health Service provides acute and community child health services across the region (and to some children from neighbouring regions). The Service was established in 1999 and provides all secondary and tertiary acute paediatric services. Child Health is becoming increasingly a multi-agency service, and there are 3 Community Health Partnerships (CHPs). The service aims:

- To provide seamless care to children and their families
- To provide child-centred care
- To provide facilities which are child and family friendly
- To provide staff who are paediatrically trained

2.43 Acute care is provided at an urban children's hospital and a regional hospital. Acute care is currently provided up to 14 years of age, although there is some flexibility with this for individual children. All aspects of out-patient, in-patient and day-case care is provided. The children's hospital is a teaching hospital so undergraduate and postgraduate teaching takes place. Community care is provided at various locations:

- A pre-school Assessment Centre for children with special needs
- Schools across the health board area
- Health centres across the health board area
- Child Development Teams across the region, providing medical and therapeutic care to children with special needs

### *Workforce Issues*

2.44 Planned key changes to staffing and redesign of services include the introduction of new or enhanced roles specifically for NAHPs.

2.45 There is a need to re-skill and re-shape the CHP workforce. Any change in numbers will be small and focus on nursing, support worker and AHP roles. There may be a small increase in assistant/support worker roles and for those with a multiple specialty based on up-skilling and re-skilling staff and not increasing nursing and AHP workforce numbers (ibid p23). City CHP changes include: Development of leaders for a Nurse/AHP led intermediate care/rehabilitation service, Changing roles of GPs, Practice & Community Nurses and Pharmacists in chronic disease management and complex case management. Regional CHP workforce plans indicate a shift in nursing and AHP from acute to primary care.

### *Urban Integrating Children's Services*

2.46 The overall service aim is to help and support young people make a successful transition into adulthood. The Multi-Agency Vulnerable Young People's Service has been developed in response to new regulations and guidance on services for young people who cease to be looked after by the local authority.

2.47 A strategic training and workforce development group has formed and is developing the multi-agency training framework 'Learning Together'. A training database has been set up to provide a range of information for monitoring and evaluation purposes. All partner agencies involved in Changing Children's Services have acknowledged the need for appropriate multi-agency training to support the workforce in achieving better outcomes for Scotland's children.

2.48 In response to this need, a high-level Workforce Training and Development Group has been established, chaired by the Project Director of Children's Services. The group has representatives from the Children and Young People's Services Management Group, and professional and organisational staff development personnel from within the local authority, the health board, the local university and the voluntary sector.

### ***Duncan***

2.49 Duncan covers 4732 square kilometers, and has an estimated population of around 800, 000 people, comprising 15.6% of the total population of Scotland. According to the General Register Office, Duncan is expected to have the largest projected increase in population between 2004 and 2024. Duncan is also one of the few NHS Board areas that are expected to have an increase in the number of children aged 0-15, compared to a nationwide decrease by 12% by 2024. It also has the largest projected increase in the population of working age in Scotland. There are approximately 180,000 children and young people (0 – 19 years) resident in the NHS Duncan Health Board area. The population of this group has fallen slowly over the last few years and is projected to fall to just below 175,000 in 2020.

### ***Health inequalities***

2.50 Although Duncan is relatively affluent, the disparity in health between the most affluent and the least affluent is striking. The extent of these inequalities is emphasised when looking at health indicators such as breastfeeding, teenage pregnancy and low birth weight babies (Source DPH Annual Report 2004).

2.51 Young carers are an 'inequalities group' whose numbers have in the past been underestimated. The National Census of 2001 identified 1,662 children and young people in Duncan under 16 who provide care to a parent or other family member suffering from ill-health, disability, mental health problems or drug and alcohol addiction problems. However it is widely accepted that the true number of young carers is considerably higher, especially when the care of younger siblings is taken into account. Estimates suggest the figure could be as high as 5,000 for one city. There were 436 children on the child protection register and 1,990 'Looked After' across Duncan in January 2005.

### ***Complex Needs***

2.52 From the Support Needs System (SNS) 2006 summary, Duncan had 2924 children being assessed in SNS, and the 0-16 year olds represent 3.1% of the total child regional population.

## *NHS Services*

2.53 NHS Duncan has 5 Community Health Partnerships, one of which is a Community Health Care Partnership (CHCP). Within the major city, there are also 5 Local Health Partnerships (LHP), which are responsible to the CHPs for ensuring the delivery of services locally to patients in their areas. Each of the LHPs has specific responsibility for the coordinated and cohesive delivery of services in its local area providing Health Visiting, District Nursing and Mental Health services and working closely with GP Practices, pharmacies, dentists, opticians and voluntary organisations.

## *Children's Health Services*

2.54 There is a children's hospital in the major city, which also provides service to children outwith the region. One area has a Child Development Centre, where education, health, social work and the voluntary sector work in partnership and on-site to provide a comprehensive range of services for children with special needs from birth to school leaving age. Speech and language therapy, physiotherapy, music therapy, and occupational therapy are provided from the centre, and school nurses and a CCN are based there also. Another area has a Community Team, based in a hospital, which provides services for children with neurological and complex needs. There is also a learning disability team, which has a Community Disability Learning nurse working specifically with children.

2.55 Within Duncan, school nurses and AHPs work very closely together, for children in a variety of settings such as children's centres, residential services, schools and health centres. Resources and services vary across the region, and there is evidence of long waiting lists for occupational therapy, and to a lesser degree, physiotherapy. There is an Additional Support for Learning Inclusion Team in NHS Duncan which provides a holistic problem solving approach to the management of children with additional support for learning needs. The team promotes joint working practices across health and education teams, social work and voluntary organisations in collaboration with children and families. Members of the team can include OTs, Education staff, physiotherapists, mental health professionals, speech and language therapists, nursing staff, therapy assistants and dieticians.

## ***Macduff***

2.56 Macduff encompasses 3 local authority areas, covering an area of 500km<sup>2</sup> which incorporates a thinly populated rural region. The overall population density is currently 51 people per square kilometre which is lower than the Scottish average (65 people per km<sup>2</sup>). The current population is 386,600 and is projected to decrease by approximately 4% by 2024 compared to the projected 1% decline for Scotland as a whole. The population of Macduff is ageing, for example the 65 plus age group is estimated to grow by 0.17% by 2014.

2.55 In 2001 there were 93,081 children under 20, represented evenly across the three local authority regions. Those under 20 years old currently form 23% of the region's population. The population aged under 20 years in Macduff is projected to fall by 12% over the next 15 years, mirroring the projected Scottish picture of a 12% fall.



2.58 Unemployment in the region has fallen to its lowest level over the past decade, but one city contains some of the most deprived areas in Scotland, where over 50% of children in the city live. One region has low unemployment levels and is a relatively affluent area, pockets of deprivation also exist in the city and in remote areas. There are also pockets of deprivation and rural deprivation.

### *Child Health*

2.59 Life expectancy in Macduff is increasing and is higher than the national average. NHS Macduff has identified key health outcomes affecting children and young people arising from its population profile. Within deprived communities, these include higher rates of teenage pregnancies, abortions, new episodes of sexually transmitted infections and a large increase of smoking in 13-15 year olds. There were also higher rates of children under 9 presenting with asthma.

### *Complex Needs*

2.60 The Support Needs System (SNS) records information about children with additional support needs across Scotland. Its aim is to monitor their progress and ensure they have access to services or support they require. From 2006 summary, Macduff had 926 children being assessed in SNS, and the 0-16 year olds represent 2.0% of the total child regional population.

### *Children's Services*

2.61 There is a multi-disciplinary Child Development Centre for children with developmental delay and disabilities. The centre provides pre school and school age children and their parents with: a multi-disciplinary assessment resource; an outpatient paediatric therapy resource; an integrated therapy nursery; and outpatient clinics. Services are provided by doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, dieticians, nursery nurses, nursery assistants, clinical centre co-ordinator and other agencies as appropriate.

2.62 Community Paediatricians provide a secondary, specialised service to children with a range of additional needs, developmental disorders and disabilities. The service has a statutory responsibility to all children (up to 19 years) through the Education and Children's Acts (includes Record of Needs). It provides assessment, diagnosis and follow-up of children with special needs including: learning difficulties; physical difficulties; visual impairment; hearing impairment; emotional/behavioural difficulties; chronic ill health. It also provides for children in need, who are at risk, in care or disadvantaged.

2.63 There are 3 Community Health Partnerships. In 2002, 6 key areas for future integration within the context of CHPs were identified. These were school health services, Hall 4, Community Paediatrics, Looked After and Accommodated Children (LAAC), Children with Complex Needs and Child and Adolescent Mental Health Services (CAMHS). The key areas are included in the three children's services plans and in the Macduff Child Health Strategy.

## **Summary**

2.64 As can be seen from the above descriptions, the 4 case study areas each raise specific issues which challenge the range and complexity of service provision. For children and young people with complex needs, their families and carers, differing levels of resources impact on service accessibility, acceptability, affordability and equity. The workforce composition highlights needs related to community service planning and delivery. Workforce and Children's Services Plans indicate the need to address transitional services between acute and community care; staff retention; education; specific expertise and experience related to children and young people; and integrated service delivery.

2.65 The next chapter will look at the integration within and between services from the perspective of the study participants.

## CHAPTER 3      INTEGRATION WITHIN AND BETWEEN SERVICES

### Introduction

3.1      This chapter looks at how services are provided in the community and specifically, the way in which different elements of any given service interact. It also explores the extent to which the different services provided by health, education, and/or social care, are integrated.

### Service Overview

3.2      Study participants from the 4 case study sites highlighted an eclectic array of approaches to service provision in the community for children and young people (CYP) with complex needs. Service managers were asked about the composition and complement of staff providing care. Their responses indicated a wide variation within each area reflecting the varied population needs, geography and organisational structures. In addition, questionnaire responses from practitioners indicated the diverse range of professionals with whom they worked or liaised. Collaboration and partnership working was influenced by geographical factors and organisational structures. Analysis of data revealed that there were multiple integrated approaches to care and providing services.

### Partnership Working

3.3      All those interviewed described high levels of liaison, collaboration and sometimes integrated working with other service providers, such as education, social services, and acute care. It was felt that there was close partnership working and integration with voluntary agencies within children's service provision, particularly relating to child protection, and respite care.

3.4      In general, participants within each of the 4 case study sites reported positive views with regard to partnership working, and cited increased multi-professional and multi-agency working:

*“One example of really good practice ...[is] the one-stop shop clinic opportunity for the families where they get one appointment, at which there's an orthopaedic surgeon, perhaps the spinal specialist twice a year, the dietician, physiotherapist, paediatrician, wheelchairs, orthotics, and everything can be dealt with in one session .. And that's a wonderful example of good collaborative work” (Physiotherapist, MacDuff).*

3.5      This was again highlighted within health and social care, and within the transition from primary and secondary care. In Banquo it was reported that there was:

*“lot of good partnership working with primary and secondary care; because there is no CCN service, we have to rely on the goodwill of District Nurses (DNs) who aren't paediatric qualified or trained, to take on a lot of the duties ... There's a huge amount of partnership working – when any of the specialist*

*nurses see children in hospital, they liaise with Health Visitors (HVs), General Practitioners (GPs), we invite everyone into multidisciplinary team meetings, do a lot of liaison and communication” (CCN, Banquo).*

3.6 Allocation of resources was shown to facilitate positive collaboration:

*“There are certain schools with resource allocation, where the children have a wonderful experience: where there is lots of sharing, lots of education, lots of good, good collaboration between health and education staff ...” (Physiotherapist, MacDuff).*

3.7 Within Duncan, professionals reported working towards an integrated system. Multidisciplinary working was more prevalent among grass root workers, ensuring success and consensus regarding shared goals by working together. This was less apparent at managerial level. The majority of frontline nursing and allied health professionals agreed that there was evidence of joint working between hospital and community care services for CYP with complex needs. Similarly, most respondents also believed that statutory and non-statutory/voluntary organisations collaborated and worked in partnership to deliver services. Nursing and allied health professionals also believed that service providers worked together toward shared and agreed goals, while maintaining their autonomy. However, practitioners were not so confident that these organisations were actually addressing problems, with opinion being split almost equally between those who disagreed, and those who agreed with the questionnaire statement, “All service providers for children with complex needs address issues of overlap, duplication of services and gaps in service provision”.

3.8 One participant (Lead School Nurse, Banquo) expressed a desire for a more strategic view to be taken, whereby one key person would be in charge. This person could then pull everyone together to map out resources in relation to needs. This participant went further, recommending that it was necessary to employ a degree of funding rationalisation across sectors, so that everyone was working together as a team, rather than fighting amongst themselves for budgets. This view was echoed by a colleague, commenting on the local Child Health Improvement Partnership (CHIP):

*“We have all the bits of the jigsaw, but we haven’t quite worked out what the picture is”*  
Paediatric physiotherapist, Macduff.

Another participant said

*“It doesn’t feel like there’s a strong strategic lead around children”*  
Head Speech and language therapist, Banquo

This viewpoint was echoed by others, and is explored further in Chapter 6.

3.9 In Duncan, an example was given of partnership working, focusing on a comprehensive service level agreement (SLA) between Speech and Language therapy (SLT) services and education. This had enhanced the SLT service provided in the special schools, across the three local authorities, and resulted in increased contact with the school nurses. This service also had access to community nursing staff based at the children’s hospital when required. The Additional Support for Learning Act (ASL) had acted as a driver in promoting this type of working together. Another example was in Banquo, where implementation of this

policy facilitated employment of physiotherapists by the local authority education department to work in some of the schools.

3.10 The use of care pathways was perceived to be beneficial to integration and coordination of services, as described by one coordinator in Duncan:

*“... provision for early years has a well structured pathway, where as soon as children are identified ... we can get services started ... we work very closely with preschool, home teaching, education, and with all the local children’s providers, so that we get them the help that they need, when they need it. We work in a joined up way ... the integration and coordination of services starts quite early on”*

### **Working with other professionals**

3.11 Questionnaire respondents were asked to list all the health professionals with whom they worked. Over a quarter of practitioners managed staff, while a similar percentage provided direct clinical care, with many respondents reporting both. Staff who were managers were often responsible for managing more than one type of professional carrying out a specific job or role, e.g. a chief nurse in Duncan managed community children’s nurses, Child and Adolescent Mental Health Services (CAHMS) nurses, public health nurses, public health practitioners, specialist children’s nurses, and midwives. Comments indicated that such working relationships were flexible, and involved all those required for the individual child’s needs:

*“We work with any colleague involved with a child or family as appropriate”*  
Lead SLT, Duncan

*“work is not always directly with all above staff but communication is made regarding CYP”* Music Therapist, Duncan

*“... we come into closer contact with some more than others”* Paediatric Physiotherapist, Macbeth

The category of ‘other’ staff that respondents managed or worked with included carers for ventilated children, community learning disability team, nurse consultants, child protection lead nurses, community paediatricians, nursery nurses, acute and community link nurses, GPs, school doctors and podiatrists.

3.12 Social work services were frequently cited by respondents as a resource, followed jointly by education and respite services. NAHPs also had contact with care agencies, carers’ centres, child locality teams, leisure services, learning disability teams, CAMHS, sexual health professionals and home visiting teachers.

3.13 Partnership working was reflected in NAHPs working with colleagues from the social care sector in relation to advice, child protection issues, counselling, adaptation, equipment, assessment and review of children and young people (CYP), respite, benefits, and crisis support. Several cited in addition that they worked with social work teams for children with disabilities, Family Focus/Support Workers, children and family centre staff, OTs based with social services, as well as respite and housing services.

3.14 Respondents reported working with a variety of professions within education. This included teachers for “staged assessment intervention/coordinated support plans”, education psychologists, area managers from learning support, and specialist teachers for hearing and visual impairment. The Inclusion and Equality department, for coordination of services for the ASL Act was another resource listed. One professional had access to pupil support departments within the local authority. An AHP noted that they worked with the educational sector only if requested, and did not carry out screening, as school nurses were trained to do this. Contact with professionals within social justice was not common, with one person only, a Paediatric Team Lead (Banquo), stating that they worked with police.

3.15 NAHPs were in contact with a variety of organisations and service providers that assisted carers. Voluntary sector organisations were most frequently cited, and included Barnardos, Befriend a Child; Befrienders Project; Child Brain Injury Trust (CBIT); Children 1<sup>st</sup>; CLIC Sargent (cancer care); Contact a Family; Down Syndrome Society; Homestart; Marie-Curie; National Society for Autism; PAMIS (organisation for people with profound and multiple learning disabilities, their family carers and professionals who support them); Princes Trust for Carers; Scan; SNIP (Special Needs Information Point); Spina Bifida Association; SureStart; Signpost; and Whizz Kidz.

3.16 NAHPs also worked with non-statutory/voluntary agency staff in relation to respite provision and activities such as sports and developmental play. Some were involved with parents support groups such as a parent management group for out of school care and a parents’ inclusion network.

### **Skill mix**

3.17 Integration within and between services raised the issue of skill mix, in relation to the range of professionals and their differing experience and expertise. Changes in skill mix were utilised throughout the 4 study sites, in differing ways and in different venues.

3.18 In Duncan, for example, they were increasing skill mix, enabling support workers to carry out the therapies usually carried out by occupational therapists (OTs), so that OTs were able to carry out more consultations and assessments. A similar approach was being undertaken in MacDuff;

*“ ... across physio and OT, we’ve been adopting a skill mix approach. We’ve managed ... with short term funding ... to look at new ways of working, and were successful in mainstreaming that initiative in one part of MacDuff, Region X particularly, but not Town Y. That’s proven a very good model of using a support worker to support the children within school settings and home settings, and releasing the highly qualified staff to do the assessments and specialist side of work for these young people”* Paediatric Physiotherapist, MacDuff.

3.19 Community nursing within MacDuff did not utilise support workers such as health care assistants within teams for a specific child, unless they were joint funded, for example, by education. However, a workforce planning tool was being piloted early in 2008, which

would assist in determining the required skill mix. An example of positive integrated working was shown in another region:

*“We have a nursery nurse that’s based here, she works with families, she takes on ideas from the therapists, she works with everyone”* (CDC Coordinator, Duncan).

3.20 The majority of SLTs, physiotherapists and OTs worked with technical instructors (TIs) who have superseded assistants, and have a higher degree of autonomy.

*“This person has actually worked in adults, but has taken to paediatrics very well. I think what she has been able to do [the work] and what she’s taken on far outweighs the amount of time we’re having to spend supervising, so it’s been a big success”* (Physiotherapist, Duncan).

3.21 Another reported benefit included being able to recruit administrative support as part of the savings associated with skill mix, *“... a basic grade had left, her post was eventually split into TI hours and administrative assistant hours, and that takes a huge workload off us”* (OT, Duncan). Improved administrative support was seen as very beneficial, as it would reduce time spent on administrative tasks, and increase hands-on time.

3.22 However, some participants were keen to point out that there was little advantage in appointing greater numbers of staff, with fewer skills, compared to fewer staff with more experience:

*“We use non-qualified staff, technical instructors to make up the shortfall for more routine work that therapists themselves don’t have to be doing. But can only go so far – there’s no point saying you can have 10 more technical instructors when what you really need is an experienced Senior 1”* (Paediatric physiotherapist, Banquo).

3.23 Deskillng of the workforce was a concern raised elsewhere,

*“... the concern was that they would look at a Senior 1 post, and replace it with a full-time post, but at a level that’s way below ... if we had a junior, or more TIs, it would be great, but my worry would be that you would be taking away more senior staff, and losing skills”* (Physiotherapist, Duncan)

3.24 Suggestions related to skill mix change included improving the availability of suitably qualified and skilled agency staff with appropriate core skills for children with complex needs, within community nursing. This would also support earlier discharge from hospital. A Chief Nurse advocated *“general support workers who would support CYP and families along care pathway”*, suggesting that this could be implemented through joint planning; joint training; joint working; and shared/pooled budgets.

3.25 A consistent theme in “Building a Health Service Fit for the Future” (Scottish Executive 2005c) and “Delivering for Health” (Scottish Executive 2005b) has been the need for the NHS in Scotland to change and adapt in response to the rapidly changing patterns of health care needs. This challenge, which is particularly pertinent to CYP with complex needs, requires innovation and flexibility across the spectrum of activities that support the redesign and advancement of services. To deliver a “better, quicker, closer and safer” service (Action

Framework, Scottish Executive 2007), education, training and development is one specific area which needs to be addressed.

3.26 One suggestion related to health service provision within schools, particularly concerning hands-on clinical treatment, such as catheterisation. A service manager in MacDuff suggested that instead of each individual school advertising for an auxiliary or care assistant for, say, 15 hours, and somebody else for 20 hours, a core group of around four or five multi-agency trained workers covering all schools could be established for a specific region. These workers would be trained in all the relevant procedures (which could be added to as required), and would be named workers for individual children, which would give added value to them and their families. This approach would remove the problem of finding staff for small numbers of hours across a multitude of different sites. It would be important for these particular staff to be remunerated appropriately according to their skills, which would hopefully promote stability within such a team of workers. Establishing and sustaining workforce education and training will be further explored in Chapter 4.

### **Recruitment and retention issues**

3.27 Recruitment and retention were cited by many as the most important workforce issues currently influencing service provision to CYP with complex needs. As the vast majority of nursing and allied health staff was female, this had obvious implications with regard to maternity leave. For example, SLT services in Duncan currently had just under a fifth of its staff on maternity leave, and physiotherapy also reported a high level of maternity leave, although there was an assumption that staff on maternity leave would return within a given time. Generally, owing to resource constraints, such as availability of personnel and economics, managers felt unable to provide backfill, or temporary replacement staff, which had resulted in vacancies lasting six months or more, which in turn impacted on service provision. This also affected waiting lists in the areas where these existed.

*“In OT team, there are always people off on maternity leave, which has an impact on waiting lists/times, so children go on a priority system, that’s ongoing. Probably the same in other teams?” (OT, Duncan).*

*“At the moment someone on maternity leave and somebody on sick leave. Sometimes we have posts/bits of posts that are left, there seems to be a hold up getting the go-ahead to fill the job so we can have posts uncovered for periods of time. At the moment we’re getting part of a job filled, but that’s been vacant for a few months. Lots of female part-time workers” (SLT, Duncan).*

3.28 Within MacDuff, it was reported that there were problems regarding recruitment and retention within the paediatric community nursing service, where it was stated by a manager that there were currently high levels of sickness absence. To address this, a number of agency staff were employed, and existing staff worked additional hours. There was more demand than service availability.

3.29 One manager in Duncan commented that physiotherapy was felt to have high levels of retention, and experienced a large number of applicants for lower level jobs, *“For a few months’ fixed term temporary contract, I got 36 applicants – so recruitment is no problem at*



all". The shortage of physiotherapy posts meant it was generally difficult for newly qualified graduates, without appropriate community paediatric experience, to find a first post. It was considered more problematic to recruit sufficient senior staff, and it was felt that this in part may have been wariness of moving jobs because of the challenge posed by Agenda for Change.

3.30 It was felt that Agenda for Change grading had caused problems with morale, and in some areas, had had a negative influence on staff retention. Participants in one area believed that to challenge allocated grades would take time away from the clinical caseload, and that it had the potential to engender ill-feeling against fellow colleagues who may have received a higher grading. In another region, it was believed that the banding for SLT and OT had disadvantaged staff compared to the rest of Scotland, and that this had led to a reduction in applicants. Additionally, it was felt that the children's ward in the regional hospital in Macbeth might struggle to appoint CCNs, as their counterparts in a neighbouring UK region had been awarded higher bandings.

3.31 It was reported that Banquo had a generally stable workforce, and a high retention rate, although there were some issues regarding retention in rural areas. Additionally, there were recruitment problems for health visitors within the CHPs, whereby one large area currently had no HV and the post was being covered by others. Another manager stated that they felt it was difficult to recruit staff to paediatrics, as there was a gap between the entry level for each profession and new graduates, in that they lacked skills, training and expertise. There were also implications regarding an ageing workforce, who had a greater degree of expertise, but who would leave a greater gap when they left or retired.

3.32 Additionally, many female staff worked part time, which could make it more difficult to recruit, given the small number of hours which made up a number of job vacancies:

*"The one problem we have in paediatrics in particular is a lot of more senior posts are part-time, and it's very hard to fill a part-time post with a young, keen whippersnapper, who wants full time hours. That's our next problem – rather than corralled into 18 or 26 hour posts, you know you could fill it if it was full-time, or standardised part-time. But it is never quite the way round you want it to be"* (Paediatric Physiotherapist, Banquo).

3.33 Financial support to assist filling long-term vacancies did not necessarily resolve the problem:

*"We've had 'hard to fill' money from the Scottish Government for a 'more than 6 months' vacancy, and the post was still vacant for 2 years. Have somebody now, but pure fluke – somebody from Australia phoned up because her boyfriend was moving here. Virtually everybody who is coming to our department is coming from New Zealand or Australia, it's not local people we're growing, because there isn't the infrastructure and support to be able to do that"* (Paediatric OT, Banquo).

3.34 Lack of paediatric experience can pose problems regarding recruitment, and some of the allied health professions used rotational posts to address this issue.

*“I could not fill a Senior I post, so I promoted it to a Senior II rotation, so I get staff rotating through the main hospital, and they get an opportunity to do paediatrics, which was never there before. As a result, if I have a vacancy, I’ve got Senior II s battering down the door, ‘would you like a paediatric?’” (Paediatric Physiotherapist, Banquo).*

3.35 However, rotations did not always include paediatrics, and for one or two, this was viewed positively, particularly with regard to students:

*“From an OT point of view, when I get students, my advice is to get a basic rotation within the wards, even if it’s in adult, and get the basic grounding and philosophies around OT, before even thinking of coming to paediatrics” (OT, Duncan).*

*“The difficulty that we would have, from a paediatrics point of view, rotation is only for 4 months, and we would fight against somebody saying we would have a junior for 4 months, because it would be a massive workload for us, and would diminish the service.” (Physiotherapist, Duncan).*

However, this has implications for educational and experiential opportunities, and will be raised in Chapter 4.

3.36 In one area, recruitment issues were also eroding confidence in the provision of therapy services, particularly for CYP,

*“from acute (inpatient) perspective, difficulty is feeling confident that children will have their needs met adequately in community and major problems with delayed discharge due to recruitment and retention problems” (Physiotherapy Team Leader, Duncan).*

One OT elaborated on the problem, saying there was a lack of OTs with experience and a real difficulty introducing skill mix due to remote working. Additionally, there was a shortage of senior staff to supervise, and finding time to supervise new staff was difficult for some therapists.

3.37 One manager in MacDuff mentioned problems in succession planning, due to a lack of suitably qualified staff, which affected rotation within the AHPs:

*“Paediatrics is a unique activity, requiring high levels of autonomy and experience. Need to build in rotational experiences, so staff are exposed to multi-disciplinary working, and skill mix”.*

## **Resources**

3.38 Difficulties in recruiting and resourcing health care staff have already been acknowledged, but equally problematic for professionals was the recruitment, and retention, of carers for children and young people with complex needs.

*“Recruitment/retention of carers is a nightmare, but that’s not just a Banquo picture – it’s Scotland wide. I think City E is quite bad in that it’s very difficult to recruit/retain carers to look after a sleeping ventilated child overnight. And they’re relatively low paid, and have a lot of responsibility” (CCN, Banquo).*

3.39 Participants in Duncan reported that they would like more trained carers, however, one interviewee raised the topic of public expectation, stating that some families had been allocated a registered nurse in the past and were reluctant to use a carer without the equivalent background or specialist knowledge. Currently, a combination of trained carer and registered nurses were used for new care packages, where possible. It was stated that they were trying to move away from 24/7 packages of care, where there was always a professional in the house, as it was felt that it was important for families to have some time alone with their child. Occasionally there were problems with the provision of home-care packages for ventilated children, enteral feeding and oxygen dependent children, owing in the main to the difficulty of recruiting and retaining staff to support and deliver any new care packages. Additionally, an issue was that:

*“Staff find it difficult working in the family’s home, and the pressure from the families ... never getting a break - families tend to view them as ‘their’ nurse/carer, and expect them to do whatever they tell them to do. It’s a sense of isolation ... working in people’s homes” (Manager, Duncan).*

3.40 Asked about the opportunities to address barriers to service delivery, a manager referred to resource implications:

*“I think we need to have an agreement across Scotland on how home care packages are managed, and whether or not that’s out of a central budget – that’s the one thing that concerns everyone. Not having an adequate budget. And then if the child moves, then. I think that’s a big issue. There’s no consistency across Scotland on how we manage these children – that’s a big problem as well because inevitably these children get to meet one another and talk..... They all do good bits of work, but if they pulled it all together... get some sort of national perspective on it.” (Manager, Duncan).*

3.41 Challenges to integration within and between services were posed in relation to the supply and demand of equipment and the allocation of specific budgets from individual service providers. In MacDuff, additional care, when required for CYP with complex needs, was provided by the District Nursing service. This service was not child specific, as it generally provided for adults and children. Issues relating to obtaining equipment, and questions as to who was the provider for children and young people were raised as a result. A physiotherapist in Duncan mentioned that while previously they had held a budget for equipment, it was now held centrally, with equipment obtained from the community store. This had resulted in increased bureaucracy, with all requests having to be justified and then approved, by managers, and an increased length of time to get equipment into the home environment. This process was echoed by a nurse director (Banquo) who stated that:

*“if there’s a child in the high dependency unit being transferred from Glasgow, who needs to go home on long-term ventilation, I have to go cap in hand to the Health Board to get funding for this child. [There’s] no specific budget for this. That’s how it*

*is. I've never been refused, but it all takes time, and all the while, the child remains in hospital".*

3.42 In Banquo, where equipment was not centralised, a paediatric OT stated that equipment for children was put away into stores, and not catalogued or circulated, so that no-one was sure what equipment was available.

3.43 There was also some degree of uncertainty as to who should hold the budget, particularly in relation to mainstream schools and the equipment required there. Macbeth had an Alternative Communication Equipment Committee, which had representation from SLT, physiotherapy, education and social services. Each of the services contributed some monies annually, thereby pooling resources. Within SLT, children and young people were assessed regarding their equipment needs, and the request was then passed to the committee for approval. It was reported, that on balance, it was very rare that requests were turned down. The benefits of working in partnership supported the equitable distribution, accessibility and timeliness of supply of equipment. Frontline practitioners mentioned organisations providing support with equipment, such as Integrated Community Equipment Services and Westmarc (West of Scotland Mobility and Rehabilitation Centre) for wheelchairs and seating.

3.44 Some managers spoke of innovative ways in which they occasionally were able to address some of the problems in obtaining equipment, but emphasised it was only their position and autonomy that allowed them to facilitate this.

3.45 A concern was raised by a manager in Macduff relating to equipment being located in the home, and whether staff would be sufficiently trained to use it. This was with regard to the fact that children now had much shorter hospital stays, and were moved much more quickly into the community, where a lot more equipment was held. It was felt that staff, particularly those working with adults, might not have the skills and expertise to manage that. This issue related to knowledge and skills is further explored in the following chapter.

3.46 Overall, the suitability and currency of equipment was generally not considered a problem:

*"I would say that from our service, we are lucky, we have equipment, and we have a budget for specialist equipment, and none of our children has been refused. We're able to buy good quality modern equipment to meet the needs of the children."*  
(Physiotherapist, MacDuff).

## **Funding**

3.47 Funding as a topic generated a lot of discussion, as it was one which affected everyone to a certain degree. Often, funding, when available at all, was of a short-term nature, which was felt to create problems.

*"I think that the Scottish Government, whatever political party, have a lot to answer for with the short-term funding. If they would just invest in the core services and the infrastructure, instead of the confusing mist to try to get funding, even to provide school nurses with BP machines. Things that should just be resources that are there. Scottish Government needs to do a bit more*

*joined up working. Really not short-term funding – it raises expectations” (School Nurse, Banquo).*

3.48 In general participants were not overly positive about short-term projects, or the hiring of staff on a temporary basis, as this generated feelings of anxiety, on the part of the staff, and for the children and young people they supported.

*“My job, though for severe and complicated needs, is actually a project, not a permanent post. The original project was for 2 years, extended by one year. The exit strategy was that I was meant to pass on my skills and knowledge to the mainstream school nursing team so they could carry on the work that I do, but never really an option even from day one. Their workload is huge, there’s no way they’d be able to take on the stuff that I do as well. So my job is only secure until end of March 2008. Colleagues are trying to secure funding to make the job permanent, otherwise I’ll be looking for another job” (School Nurse, Duncan).*

3.49 Contradictions and inconsistencies in relation to funding were evident, which consequently generated problems in recruiting staff:

*“Can’t attract people for short term posts either because by the time you get the money, you’ve only got 6 months left, so frustrating” (School Nurse, Banquo).*

In this region, short-term funding was no longer permitted to be used for employing staff, owing to concerns that it might lead to expectations of commitment for long-term funding which the budget could not then accommodate.

*“In terms of employing people, NHS Banquo won’t let us use short-term funding. There’s a complete veto on it – “they’ll go bust” and “they won’t be able to continue it”. We’ve suffered with other Health Boards who have used that, and then get it continued. There’s been no new development for posts up here for forever, because we’re not allowed to use short-term funding, which is often how people get posts established. And we still have a lot of nurses and other employees who are on ‘soft’ money, they’re not in the core budget” (Paediatric Dietician, Banquo).*

### **Sustainability of services**

3.50 The move to caring for children and young people with complex needs in the community has not been without problems. As one participant noted, commenting on the financial implications:

*“It would be nice to think that the budget is following the children out into the community, because parents need that support, they’ve got their children at home” (CDC Coordinator, Duncan).*

Financial concerns, along with static staffing resources, meant that in some areas staff were under a great deal of pressure.

*“I have concerns that there is already a lack of capacity in the community. Unless there is some drift of resource from acute to community – it’s unsustainable now, really, we can’t do any more unless there is some funding. There are more and more children with special or complex needs in the community, but there’s been no resource to support that, up to now” (Lead Nurse, Banquo).*

*“The Child Locality Team (CLT) run on goodwill... no financial support. Lack of coherence and sustainability for the future.” (Manager, Macbeth)*

3.51 Capacity was mentioned time and again; a Lead Nurse said it was the main issue for nursing and that there was a huge lack of capacity especially within school nursing. The same participant noted that:

*“Agenda for Change has negatively impacted on the workforce by undervaluing experienced staff losing such staff to Health Visiting etc.”*

The lack of capacity was also felt to be the main problem facing therapists in Macbeth; a paediatric therapist commented there was no *“capacity to meet demand”* although they had got capable staff they faced *“too high a workload”*. In Duncan, a clinical nurse manager mentioned lone working, recruitment and retention difficulties, and access to IT, as issues creating difficulties with sustainability and capacity building.

3.52 Proximity to a hospital was a factor mentioned by one participant as being relevant to sustainability of service provision:

*“If you have a children’s hospital within a city, part of the Health Board, then it’s still very much up to that organisation to provide all of the care for the children in the community. NHS Banquo still doesn’t have an established community children’s nursing team.” (Manager, Banquo)*

Some participants felt that certain services were very thinly spread. AHPs, physios, dietitians and OTs particularly tended to provide core interventions, but many of the therapists were of the view that children did not benefit from this level of service. *“It’s like spreading the jam very thinly so that everyone gets something”* (Paediatric Physiotherapist, MacDuff), and in another region, specialist children’s services were non-existent:

*“In Banquo, right across the board, there is no community children’s nursing service. It doesn’t seem to be a priority. There are hundreds of children coming into an acute hospital setting, travelling hundreds of miles every year to come in and get nasogastric tubes passed, gastrostomies put in, bloods taken for central lines – the service here is diabolical compared to Duncan, they’ve got 5-6 whole time equivalent CCNs. Everywhere else can provide a service” (CCN, Banquo).*

3.53 Lack of administrative support was a big issue, described by one manager as *“a management nightmare ... have one person for 3 days ... looking after 50 staff, it is absolutely impossible”* (Physiotherapy Manager, Duncan). It was felt that many staff lost time for clinical input by having to undertake administrative tasks, a point made earlier in 3.21.

## Service Organisation

3.54 Within this study, the overall picture, as evidenced by the research data, was that most services were managed within a combined children's health service. Services for this particular population were administered in a variety of ways. Services included a combination of hospital and community services and were dependant on available resources.

3.55 The composition of the workforce appeared to reflect availability, expertise and experience, in accordance with the local demographics. Service providers were described within teams, variously identified as Children's Locality Teams (CLTs); Community Health Partnerships (CHPs), Child Development Teams (CDTs), Child Development Centres (CDCs), Children's Community Nursing Teams within combined Child Health Services, and Outreach teams. The composition of nurses and allied health professionals differed within teams.

3.56 The Child Locality Teams in Macbeth were promoted as a model of excellent practice for the Integrated Assessment Framework (also known as GIRFEC, Scottish Executive 2006c). Teams of between 8-10 professionals, comprising physiotherapy, OT, speech & language services, community children's nursing, community paediatrics, meet on monthly basis. As part of the regular meetings, the teams have the opportunity to review the needs for training and competencies for those working with children with complex needs. This model had since been emulated in several other areas. A manager in this health board area had also been put forward for a Scotland OT service award for the integrated approach of the OT services in the area.

3.57 The impact of organisational change with respect to children's service provision was highlighted:

*"there seems to be a lack of responsibility at the moment of the Community Health Partnerships (CHPs) to really consider the needs of children in the community. ...I think it's historical. As with a lot of services in the NHS, there's been so much movement ...we've had the dissolution of the Trust status, and then evolution of CHPs, so prior to that, from a historical point of view, children's services have been moved from primary care to secondary care, they are a part of the acute sector, and now within one of the CHPs. There has been so much movement that I think sometimes the needs of children are forgotten" (Manager, Banquo).*

3.58 In the light of 'Delivering a Healthy Future' (Scottish Executive 2007, p.60), the above quotation raises questions in relation to one of the key milestones, which highlighted the need for prioritising a strategy for children's services' Managed Clinical Networks (MCNs) (to be agreed in the National Delivery Plan 2008). In the same document, this point is again raised with regard to the Report of the Public Health Enquiry into Children's Heart Surgery at the Bristol Royal Infirmary,

*"It seems so obvious, it hardly needs to be said: just as children differ from adults in terms of their physiological, psychological, intellectual and emotional development, so they differ in their health care needs" (DoH 2001).*

3.59 In one region, the view taken by CHPs was that professionals, in addition to working with adults, were confident and competent to care for children and young people, but one manager commented that *“one of the battles I have with my colleagues within the CHP is to get a community children’s nursing team established”* (Manager, Banquo).

3.60 Child Development Teams included broad representation from NAHPs and, in addition, crossed sectors with representation from the local authority, social work, education and clinical psychology. A service manager took the view that this structure afforded the opportunity to continuously review training needs and competencies within each team. Another manager commented *“it is felt that CDTs play a pivotal role for children with complex needs”* (Manager, Banquo).

3.61 Questionnaire participants were asked to give an example of a service which they felt to be particularly effective, and the reasons why. A physiotherapy team leader in Duncan felt that the physiotherapy service provided seamless care from inpatient to community, thus bridging the gap for children requiring intensive input, whilst overcoming divisions between hospital and community. A Senior OT in Macduff was positive about the organisation of a local Child Development Team which was locally based, and specifically worked with children from birth to pre-school. Staff worked with families and school services, focusing on close working relationships within their immediate locality. A Music Therapist (Duncan) chose a primary school in Region A, Duncan, because it was an example of *“best practice between health, education & social services staff to meet the needs of children”*, with clearly improved health and social outcomes.

3.62 Nurses’ responses regarding integrated services reflected the diverse contextual aspects of service delivery. A Community Child Nurse Service in Town C, Macbeth, was highlighted because they played

*“a vital role in the coordination of services for client group. Provide education/training. Links with other agencies, services etc.”* (Nurse Manager).

A child development centre in Duncan that used the ‘Team around the Child’ (TAC) model of service delivery (Limbrick, 2007) was commended because of *“early identification/diagnosis/early integrated multidisciplinary assessment framework; coordinated care planning; a key worker. Working in partnership with parents/groups”* (Chief Nurse, Duncan). One nurse also mentioned “Care Coordination” because of “joint working, family/carers involvement” (Clinical Nurse Manager, Duncan).

3.63 Whilst the remit of the research project did not include gathering the views of children and young people, parents, family or carers, children and young people, user involvement was highlighted by respondents: A lead school nurse reported that issues were tackled in a multi-disciplinary way with the family ‘in the driving seat’. A Public Health Nurse in a special school mentioned working in partnership with parents. “Effective integration within and between services was again emphasised,

*“There is good liaison with social work colleagues in the child and family centre generally, and specifically between key worker and therapists working with individual children.”* (SLT Manager, Duncan).



## Models of Service Provision

3.64 Operationalisation of service delivery was dependent on organisational systems which supported health and/or social care service provision. These systems were influenced by government policies, target setting, and quality assurance mechanisms.

3.65 Discrepancies in the operationalisation of adult and children's services raised the issue of target setting, and the relevance of age-related need.

*"When it comes to children's services, there aren't as many targets for them. There aren't huge waiting lists for children. Age – there may be issues, for example, within CAMHS – there aren't targets – you can be on that list for 2 years, but the census isn't taking account of that because it isn't being raised as an issue." (Manager, Banquo).*

3.66 With regard to the Integrated Children's Service Plans, the planning process determines local needs for services and support; how local agencies and organisations will work together to deliver and develop services in response to these needs; the most effective use of staff and other resources; and how services will be monitored and evaluated in terms of the outcomes for children, young people and their families. A shared local ownership of the Integrated Children's Service Plans and the planning process aimed to ensure the best possible outcomes for children and families (Scottish Government, 2007, p.29). The evaluation of the Integrated Children's Service plans would be of great interest to both grass roots practitioners, as well as the children, young people and their families and carers, and it is hoped that these will be disseminated accordingly. Research participants eagerly awaited the outcome.

3.67 An overall viewpoint was reflected in the following comment regarding integrated services and good practice;

*"... basically there's a lot of work, but again there's some really good work, and some good teams coming together, focusing on inclusion and all the other recommendations that the Scottish Executive are saying we should be doing". (Head SLT, Macbeth)*

3.68 One manager felt that the Additional Support for Learning (ASL) Act had changed the way the SLT service was provided, and that they were now developing a different model of practice. Where previously they would be based in special schools, in keeping with Social Inclusion policies, there was now a requirement to provide services wherever the child was educated. SLT services in Duncan were endeavouring to roll out their Therapy Inclusion Programme (TIP) to education colleagues, as they needed to be involved, but this would require a lot of training. An Exceptional Needs Service had been developed in Duncan, with representatives from health and social services within local authorities. It met monthly to look at packages of care and to decide what was required, and determine what proportion of care would be funded from health, and what proportion from social services. The group aimed to ensure equity across the region, and was felt by managers and staff to be a model that worked well.

3.69 Referring to the utilisation of a monitoring framework, the transferability of this was noted:

*“Education have the lead, it’s a common inspection framework that health services would need to use ... which is key within schools, and ASL etc. ... incorporates your social and environmental difficulties. ... we used it as an example with the looked after children, and the outcome was spot-on! We didn’t need anybody outside to give us our action plan. Complex needs could be another [way to use the framework] .” (Service Manager, Macduff).*

3.70 Audit and quality assurance processes were commented upon. One participant indicated their interest in

*“ ... the self-evaluation of children’s services. I suppose they’re rationalising what the inspectors are doing instead of spending such a huge amount of time on inspection, the self-evaluation provides the hot-spots, and the inspectors can use that. But the interesting thing about it on the multi-agency front, you end up whereby the professionals are almost more critical than the inspectors. (Service Manager, MacDuff).*

## **Models of Care**

3.71 Models of care offer systematic, logical frameworks or tools, underpinned by principles which support practitioners to make professional decisions and clinical judgements. An eclectic array of models was in use in the case study sites. Specific elements of these models were adapted to respond to the particular local contexts and circumstances, providing opportunities to develop practice with a sound evidence base.

3.72 The most common model of care mentioned by participants was one with an individual child, person or family centred focus:

*“We are solution-focused rather than resource-focused ... In our shared planning meetings, we try to have the family as the focus ...they felt that at these meetings, their child was a person, not a diagnosis, and that they had had a say in what was decided” (Lead Officer, MacDuff).*

Within this overall agenda, certain supportive clinical tools were used, some of which were more occupation specific than others. SLT services in Duncan had implemented their own prioritisation tool, developed in one of the special schools, and then rolled out to the other special schools in the region. This model for managing demand or prioritisation provided transparency regarding decisions made by the therapists, who were often required to share their decision making with education colleagues, and sometimes parents, whilst depending on learning assistants to deliver the programme.

3.73 AHPs within several sites utilised the Kate Malcomess Care Aims structure (<http://www.careaims.com>), which offered staff a framework for clinical decision making, focusing on case management, duty of care, and discharge planning. It gives professional ownership and credibility regarding decisions made about care to each child, as shown in the following quote.

*“It’s a very good way of gathering your evidence, either to treat or not to treat, it’s good for those parents who want you for 18 years! And it’s good when the children have very complex problems. Sometimes it’s difficult to see exactly what bit an OT or a physio can actually help with, and sometimes you get so sucked in, you lose that focus of “What am I doing here, am I making a difference?” It’s good at channelling your thoughts”* (Paediatric OT, MacDuff).

3.74 One region in Duncan was gradually introducing the Care Aims package, and already used it with mainstream children, in a multidisciplinary capacity. A large amount of teaching surrounding the Care Aims model had been given to all concerned in MacDuff.

3.75 Another approach, which was still in its infancy, though more common in England, was the Team around the Child (TAC) (Limbrick 2001; 2005; 2007), which moves away from the traditional medical model, and focuses on determining the staff complement required to address and meet the child’s specific needs. This model was being used successfully with a small group of pre-school children in Banquo, where a team had been identified, joint goals and aims had been established, and a key worker appointed, which was the crux of the approach. MacDuff also had unofficially adopted this approach, and was planning to use it within one of the regions, once the new care coordinator was in post.

3.76 Occupational Therapists in MacDuff were introducing the Maroondah model (Australia), which was described as

*“ ... a more collaborative approach with parents and education staff. Instead of them becoming very dependent on us as the therapist to come along and provide and solve everything, it’s putting the onus back on them, and enabling them. We start them off, train them and show them what to do, and they’ll participate, go away and do homework, and then come back in. Taking the onus off the one-to-one”.* (OT, MacDuff)

3.77 Some participants reported taking an eclectic approach, mixing and matching tools and models according to what fitted with their resources.

Others mentioned approaches and/or policies rather than specific models, such as a “developmental approach”, Getting it Right for Every Child (Scottish Executive, 2006b), and Hall4 (Hall & Elliman, 2006). A podiatrist stated that no model was applied, instead they used a “general patient-centred approach”.

3.78 In MacDuff, HVs were all trained in a child development programme and used the ‘Integrated Urban Model’ (Barker, 1984) of health visiting. There was reported difficulty implementing the Family Health Needs Assessment (Sanders, 2002) in that there may be some children with complex needs who were recorded as requiring “intensive” input who were not receiving intensive levels of HV or school nurse service, but who might be receiving it from another service. This related to difficulties around Hall4, a child development programme, which prioritises services based on “core”, “additional” and “intensive” activities. Different regions interpreted terminology differently, resulting in a lack of uniform approach. Some regions had employed more HVs, e.g. if children were on “additional” support, they were required to be visited more frequently. School nursing did not follow a particular model or framework, but was driven by a work plan, regarding, for example,

immunisation, and used evidence-based health promotion strategies within the constraints of the educational curriculum.

3.79 Nursing staff in City A, Duncan had been piloting a “Care Coordination Model”, funded by Children’s Services, and as a result, the majority of families had a key worker as the main contact, which was reported by interviewees to have made a positive difference from the family’s perspective. Several managers stated that for children with complex needs, there was a lot of information about models, but that they were all different. One manager described an attempt to address this issue:

*“There isn’t one that we all recognise with consistency. We now have a project funded by the Well Child charity, and the person who is doing that is looking at all the different models, with a view to hopefully agreeing on one that will include risk assessment, and look at how we determine what sort of care package and the level of input these children require – so that it’s an evidence based model. That’s difficult for parents – so trying to get some consistency is required.”* (Manager, Duncan)

Although there was reference to evidence based practice, there was little acknowledgement of evaluative processes, methods, or knowledge related to evaluation in general.

## Key Points

- There was a high level of commitment to joint working both within and across service providers (health, education, social work and third sectors); however local services require a wide range of strategies and approaches towards integrating services;
- Despite their commitment, there were differing opinions as to whether all service providers for children with complex needs addressed issues such as overlap and duplication of services, and gaps in service provision;
- There was an awareness of the need for change but some concerns about the existence of the development and planning of strategic management; this related to decision making and resolutions;
- Skill mix is essential to the development of integrated services but anxieties were expressed about the trade off between fewer staff with higher levels of knowledge and skills versus more staff with less knowledge and skills. Similarly additional fears were expressed about the overall “deskilling” of the workforce;
- Sustainability and capacity building related to recruitment and retention needs to be addressed. A number of reasons were identified which could clearly impact on the way in which services were delivered:
  - Staff perceptions of unfair and variable job evaluation under Agenda for Change were raised as an issue, with potential impact on staff recruitment and retention.
  - Staff on maternity leave, without cover, was highlighted as a particular problem for ongoing provision of services in some organisations; as maternity leave is predictable in advance, and can therefore be planned for, there is a need to review HR policies to identify scope for improving the options available on staff cover
- The potential to redefine resources across acute and community health care, social care and education is becoming more acceptable, with adaptable boundaries evident in some cases. This, however, is thought to require an infrastructure which supports collaborative intersectoral (health, social care, education) strategic management addressing resource implications e.g. funding, skill mix change.
- Considerable concern was expressed about the complexities of funding, particularly the tendency for short term funding, which may be unsustainable. There was a perception that many initiatives related to service delivery relied heavily on the good will of staff rather than appropriate resources;
- There was widespread recognition, from both a policy and practice perspective, of the need for the provision of child and/or family centred care. For many services this is a direction of travel rather than a place that the service had reached.

## **CHAPTER 4      SERVICE CAPACITY AND CAPABILITY**

### **Introduction**

4.1      An adequate and competent workforce is fundamental to successful delivery of comprehensive services for children and young people with complex needs. Investment in education, training and professional development is essential to creating such a workforce. It is vital that the skills and competencies of this workforce, at all levels of service provision, meet the health needs of the population served and this represents a particular challenge for those delivering services to children and young people with complex needs.

4.2      The NES Corporate Plan (NES 2007a) supports preventive, continuous, individual and planned care, provided locally in the community by multidisciplinary teams. Its purpose is to enable service redesign and support the shift in balance between primary and secondary care. A National Stakeholders' Alliance (NES 2007a) has been established to bring together representatives of all providers and users of clinical skills training facilities, to develop and deliver a unified approach. This will be facilitated by a Managed Educational Network strategy (NES 2007b).

4.3      Team based education is viewed as leading to effective team working that produces the best outcomes for patients. The Scottish Government e-health programme will support this through the implementation of services for improving knowledge, and Quality Assurance Frameworks. The NES Knowledge Services Group will work with stakeholders to produce a coordinated national strategy, encompassing e-learning. Ongoing research will focus on NAHPs' interventions and practice to develop the evidence base.

### **Working with children and young people with complex needs**

4.4      Within the 10 Boards with available data, 14,806 children and young people had assessment data recorded on Support Needs System (SNS). Of these children, 80.2% had at least one disability (mild, moderate or severe) recorded and 35.7% required at least one type of service (ISD 2007).

4.5      Most participants in this research reported working with more than one client group, with a minority working exclusively with CYP with complex needs. Participants were asked to describe the children and young people with complex needs with whom they currently worked. Nurses and therapists worked with CYP with a variety of medical conditions, necessitating a large range of skills and knowledge.

### **Developing and maintaining knowledge and skills**

4.6      Maintaining skills was sometimes felt to be a problem, particularly when they related to a specific condition or were highly technical. This resulted sometimes in staff being given training on a "need-to-know" basis, instead of regular ongoing education and training. One respondent (Lead Nurse, Banquo) said they were not keen on upskilling generic workers, such as HVs and school nurses, just for a particular episode/condition, as it was difficult to maintain the skill in the longer period.

This view was echoed by another manager:

*“[Staff] can’t be expert for every condition, and on the generalist example, if you all do the training, as we’ve done for syringe drivers and everything else, and you don’t use the syringe driver in 6 months, you may as well start the training again. So effectively you’re just wasting your resource. Generally, it’s the same if a DN gets a serious kidney patient - then accelerate the learning, and use your resources, and do the partnership bit, and bring your expert resource alongside you, so that you’re both dealing with the family. That could be the only sustainable model, especially if you don’t want diagnosis for everything. The training is difficult to maintain and sustain” (Service Manager, MacDuff).*

4.7 The implications of the Community Health Nursing Review are pertinent to the above comment, in relation to specialist and generalist roles within the workforce. Within this particular region, AHPs had developed another way to address the problem of maintaining specialist skills and knowledge:

*“We have a model within physiotherapy where we’re quite fortunate to have a highly trained staff group at the moment, but each of the very specialist practitioners has a specialist interest area, where they are our expert, e.g. on neuromuscular conditions, and although all of the staff group will tend to have these children on their caseload, they’ve got one point of contact who is perhaps the contact in the Scottish forums, or working on the pathways” (Physiotherapist, MacDuff).*

4.8 The opportunities for staff and students, to acquire and maintain skills were felt at times to be limited, or at risk, frequently as a consequence of the numbers of available and appropriately qualified staff. In Duncan, an OT Technical Instructor was facilitating groups in schools, in order to support access to curriculum. Children presenting with varying degrees of motor coordination difficulties, and fine motor developmental delay were provided with therapeutic activities, coordinated by the OT technical instructor. Planning and support was provided in collaboration with specialist OTs and educational staff, thereby achieving joint targets. This ensured service sustainability, but reduced opportunities for new staff members who are fully qualified OTs to participate in all levels of service provision.

4.9 In the same area, concern was raised that because ‘Best Practice’ for a specialised treatment, in this instance Bobath (an approach to the management of children with cerebral palsy to encourage and increase mobility and function), determined that monthly input was as effective as weekly input, staff therefore had less opportunity to use and consolidate their skills. Consequently they had less opportunity to see the child and parents. Whilst this practice may be better for the children in the long term, it may not be so good for the existing staff, and future students in obtaining, maintaining and expanding their experience and skills.

4.10 One way of addressing the above concern can be seen in the following example. Within one region in Banquo, capacity and demand for SLT services was planned on a yearly basis, for the year ahead. Core to that planning was that:

*“someone works with you as a therapy partner... something that all therapists in Banquo are trying to do more – make sure they’re not working in isolation, that they have someone they can skill up and work with, and there is a ‘key therapist’ as part of that system ... we work in groups, with two therapists and therapy partners ...that’s parents or a carer or a school auxiliary or whatever with us in those groups, and the programme is tailored for each child individually. Can pair up more and less experienced therapists, so can keep our skill mix going that way, and support therapists who are maybe very part time with their CPD” (SLT, Banquo).*

This was of particular importance in an extensive rural area, where providing support for staff covering a large area could be problematic, and lack of it may lead to sickness and stress. Having trained, skilled staff could pre-empt this.

## **Education, skills and competencies**

4.11 Confidence and capability were raised as issues. Within MacDuff and Banquo, respondents felt that it was necessary to have staff with paediatric qualifications and skills:

*. “ ... and although we’re all based in Hospital X, the majority of our work is out in the community, and we all just do paediatrics, we’re not doing a mixture of paediatrics and other services” (OT, MacDuff).*

*“Paediatric nurses are necessary. And I would say paediatric AHPs as well. We have specialist skills that our counterparts in the adult world wouldn’t have ... we always put the term paediatric in front of our title” (Paediatric Physiotherapist, Banquo).*

4.12 However, in another region, it was not felt essential to have paediatric trained staff, with one school nurse in Duncan noting that skills and knowledge could be passed to anyone, whether or not paediatric trained, if there was the capacity.

4.13 Non-paediatric trained staff may not always have confidence, and may feel that they are lacking in skills and knowledge, when working with children, either in front of their colleagues or, equally, in front of parents and carers.

*“They also feel vulnerable with the parents, because they have an expectation of knowledge re their child’s condition. A lot of people then think, “I don’t want to show my ignorance in front of them”, it’s not that they don’t want to be supportive” (HV, Duncan).*

4.14 One participant suggested that staff do sometimes feel deskilled, but with support they can do the job. However, it was acknowledged staff may feel out of their depth, particularly in challenging situations with vulnerable or chaotic families and/or child protection issues.

4.15 It was felt by some participants that school teaching staff, in particular, were on occasion allocated tasks for which they were not necessarily trained. There was an expectation within school educational systems that ‘health’ would deliver for health-related procedures. Teaching staff undertake education about healthcare needs on a voluntary basis.



It is deemed to be the remit of health care staff within schools, that they provide any required health education or training for those caring for children and young people with complex needs. This then presents conflict and challenges to service provision from nurses and allied health professionals.

4.16 Participants were asked to comment on healthcare staff's knowledge base and skills, to enable them to care and provide services for children and young people with complex needs. Issues relating to education, qualifications, training, continuous professional development (CPD), and implications for workforce were highlighted as follows:

*"I think that the community paediatric nurses have [qualifications], because that's their bread and butter. The DN service, not many have paediatric qualifications, and those that do tend to act as a resource, or they just don't have the capacity to take on the additional work; they don't have the skills."*  
(Manager, MacDuff).

4.17 As one manager commented, there was a plethora of nursing staff involved in delivering direct care to children with complex needs in the community, ranging from paediatric community nursing services, hospital based District Nursing services which provided palliative care, to some care to children with complex needs. Additionally, Health Visitors also supported families, particularly for children under five, where they *"do a lot of signposting"*. The respondent went on to say:

*"If I was being pragmatic, I would say in an ideal world, children should be looked after by children's team, however, I also have to be realistic. I think it is crucial therefore that these people, if they're not children trained, have the training to equip them, and also that they have the support and someone to go to if they don't know"* (Professional Lead Manager, MacDuff).

4.18 The issue of specific children's teams was further explored by this manager who highlighted that demand was constantly growing, with increased shorter stays and earlier discharges into the community, alongside an increased use of specialised equipment. This poses problems for staff, such as District Nurses, who are delivering predominantly adult services, and who therefore may not have the skills and expertise to manage children.

4.19 However, for CYP with complex needs in the community, the difficulty in recruiting staff, and opportunities for their education, skills, training and developing expertise was emphasised. Some health professionals, such as SLTs, had the opportunity to work with children from the beginning of their career, while others cared predominantly for adults. One manager, providing an overview of AHPs, suggested developing specific resources to provide knowledge for the care of children and young people with complex needs, thereby increasing the level of expertise for all AHPs providing services.

4.20 Within the Child Development Teams in Banquo, there were plans to appoint therapy assistants, as there was some evidence to suggest that *"staff who are appointed as assistants then go on to undertake training to become qualified"*. As part of the staff nurse development programme, children's nurses were spending time in the community to expand their knowledge and skill base (c.f. Flying Start, <http://www.flyingstart.scot.nhs.uk/>).

4.21 One manager indicated concern that their link higher education institution no longer offered a community nursing degree. This observation has particular significance in relation to the current Community Nursing Review (Scottish Executive 2006a) within Scotland, and consequences for the workforce, and equally importantly, service provision.

4.22 Duncan had developed a bank of competencies for paediatric physiotherapy, including competencies for the technical instructors. The number of technical instructors has increased quite significantly in the past few years, and are considered a good resource. Additionally, some nursing staff had gone through training in hospital respite care. Programmes of care for individual children were reviewed annually at appraisal, so that staff could determine training needs that may have arisen with regards to a specific child. Wherever possible, nursing staff worked on more than one package of care, so they experienced variety and the chance to learn new skills.

4.23 In MacDuff, many staff working with CYP with complex needs received training/education on a 'need to know' basis, whereby they might go to a hospital ward to receive training about a specific condition and related equipment to be used in the community.

#### **Recent/future role change**

4.24 Over half of frontline NAHP practitioners indicated that their roles had changed in the past year, generally in response to organisational change. Some had increased responsibility for managing additional types of staff, such as secretarial staff, drop-in centre and care co-ordination staff, and school nurses. Few respondents mentioned significant or progressive role development or extended scope of practice, despite several citing an increased number of specialist referrals and increased demand for specific services.

4.25 Two frontline NAHP practitioners indicated professional needs related specifically to the provision of care for children with complex needs. An Integrated Service Manager stated that a complex care nurse post was being developed, while a CCN in Banquo stated that there were increasing numbers of children who were technology dependent, but was unable to specify plans being developed as a response to this.

4.26 The majority of questionnaire respondents stated that there were no plans to change or extend their role in the future. However, a Lead Nurse, School Nursing in Banquo stated that her role would change to encompass the ASL Act, and was underpinned by the local Children's Plan. A Clinical Nurse Manager in Duncan explained there would be a review of nursing staff working with [a non-statutory organisation], with a view to developing a Service Level Agreement (SLA) for provision in future. It was suggested that future change could be dependent on funding. A Macduff Project Manager stated they were applying for additional funding to increase staff so that additional places for CYP could be supported, while a Looked After and Accommodated Children's (LAAC) Nurse in Banquo said her post was only funded for 6 months and was unsure whether funding would be extended.

4.27 In general, future role changes were deemed to be reactive, rather than proactive, and dependent on policy and funding. For those working with CYP with complex needs, increasing and maintaining knowledge and skills was deemed an important issue. Several staff indicated that their workforce was under review, or that a training needs analysis or mapping of services was taking place. Others mentioned that they had personal development

plans (PDPs), for example, *“staff have PDP which identifies needs. The service tries to respond to this and to provide access to training”* (SLT, Duncan).

### **Sustaining and developing clinical practice**

4.28 Clinical practice was developed and sustained through a variety of methods; CPD/PDP and clinical supervision were the methods most frequently mentioned, followed by peer support, staff appraisals, needs assessments, audits, in-service training, joint working, regular courses, training, best practice guidelines, rotations and self directed study, among others.

4.29 Some practitioners received more support than others. One Senior Banquo OT reported that senior staff were offered regular CPD opportunities to develop service protocols. One podiatrist in Banquo, with regard to CPD, stated they were largely self reliant, undertaking self study, reflective practice, and learning from others. The support of peers was particularly valued by some. Another form of CPD felt to be very effective was self-evaluation:

*“It was a really good model, there is no hiding. You have to have the evidence there to prove what you’re saying about yourself. And then out of that comes the recommendations.”* (Paediatric Physiotherapist, MacDuff).

4.30 Comments by some of the practitioners indicated that staff may face problems in sustaining and developing clinical practice e.g. *“can be difficult as many lone workers, unsociable hours”* (Public Health Nurse, Lead Special Schools). One professional found that clinical practice was sustained *“with great difficulty - and only by luck that to date there has been a very small staff turnover”* (Head OT).

4.31 Suggestions pertaining to staff and service development included, *“Developing education solutions/programmes; changing the mind set within paediatrics/child health; and for AHPs to bridge with “mainstream””*. (Manager, Banquo). This comment raises issues which focus on current education provision, and the need to respond to cultural, attitudinal and organisational developments.

### **Education and training**

4.32 Frontline NAHP practitioners were divided over the issue of education and training of staff, with an equal number of AHPs disagreeing and agreeing with the statement *“There are appropriately educated and trained staff to deliver effective services for children and young people with complex needs in the community”*. More nurses than AHPs were of the view that there were sufficient education and training programmes to meet community staff requirements.

4.33 Over two thirds of frontline NAHP practitioners had attended training relating to CYP with complex needs within the last 2 years. Training often related to specific medical conditions such as acquired head injury, autism, visual problems, cystic fibrosis, diabetes and long term chronic conditions. Child protection training was frequently mentioned.

4.34 When asked to list CPD/education/in-service training that would enable them to work more effectively with CYP with complex needs, nurses highlighted the need for training in relation to meeting the needs of parents and families. Examples included parenting issues specifically relating to CYP and teenagers with complex needs; family expectations and dynamics; and grief and loss. AHPs listed specialist training, such as the use of augmentative technology, sensory integration, Bobath and postural management. Nurses and AHPs also recognised a need for training on joint working. In Banquo, one participant sought education on patient involvement, sharing information and joint working, while a public health nurse lead within special schools saw the need for joint training with child/adult social work staff.

4.35 An increasingly large component of the NAHP professionals' working lives involves training other staff, such as school nurses, health care assistants, and also carers and family members:

*"I think from our point of view, the way we work is certainly changing – our role now is a lot more about enabling others to carry out the therapies, passing it on to carers, to schools, to more junior members of staff, and act in a more consultatory level" (SLT, Duncan).*

4.36 The vast majority of frontline NAHP practitioners provided training for carers/parents and/or families. The implications of this highlighted an increased workload and a widened scope of service provision. Consequently, current service provision incorporates additional support staff, such as technical instructors, or health and social care assistants.

### **Barriers to training**

4.37 Over half of those who responded to the questionnaire listed barriers to attending education and training.

### **Funding**

4.38 Securing funding, procuring designated budgets and protected time for educational programmes were raised as issues:

*"Mandatory training has increased dramatically. There are plenty of opportunities, but it's trying to get funding, and then trying to get time" (CDC Coordinator, Duncan)*

Restrictions due to lack of finance and funding were repeatedly mentioned by staff:

*"financial constraints due to Boards having to save money and balance the books- training budget has suffered. No backfill, school nurses working term time only and a woeful lack of capacity/lack of funding for training" (Lead Nurse School Nursing, Banquo).*

A project coordinator in the same area stated:

*"all good training is largely centred on Glasgow or Edinburgh. Financial cut backs do not allow travel out of Banquo. Have to plead your case very strongly. This really limits opportunities for training".*

4.39 According to one speech and language therapist, opportunities were restricted by financial constraints, with limited budgets and budget freezing.

### *Location of training*

4.40 A Nurse Manager (Macbeth) pointed out that the location of training, in relation to travelling and distance, created problems for staff. Another manager in Banquo felt that it was hard for staff in the more remote areas in Scotland to access CPD, and a project coordinator found that the distance of “3.5 hours each way to attend central belt training” led to “a long tiring day”.

### **Time**

4.41 The lack of time available to attend training was the next most frequently listed barrier. A physiotherapist in Duncan felt that as a team manager and clinician working part-time, it was very difficult to find time to do additional things or attend set sessions which were not fully addressing specific learning needs. A public health nurse stated that because of their clinical role, they had to backfill their days, as a small team does not have much flexibility. Nurses mentioned that mandatory in-service training took precedence over CPD, for example, a Chief Nurse in Duncan found that the increasing amounts of in-service training could at times make it difficult to release staff for CPD.

4.42 Comments from a physiotherapist in Duncan referred to caseload constraints, such as size, complexity, and geographical location. The opportunities for protected time to attend in-service and CPD sessions were thought to be less feasible within the community rather than a hospital setting, owing to the complex needs of these children. However, another viewpoint from within the same region was

*“Our manager is very against giving us protected time ... sees we are responsible for our own management, whether admin or CPD ... doesn’t want to impose restriction ... likes to give us that flexibility to fit around our own caseloads” (OT, Duncan).*

4.43 One manager felt that staff needed more time to think, and be allowed more time to become involved in education and research, to help improve their evidence-base. This was echoed by another manager:

*“I have one person on secondment to a research project. I’m pleased about that, but it still feels like a luxury. It would be nice to do more, and to get us out into the real world” (Manager, Duncan).*

### **Staff capacity**

4.44 Sustaining service provision through availability of adequate staffing levels of appropriately trained professionals was, at times, a challenge:

*“I have issues that my staff numbers haven’t increased, and I’m sending out non-qualified members of staff, or relying on the staff within the schools, auxiliaries, to do so much of what previously would have been our job.” (Paediatric Physiotherapist, Banquo).*

4.45 These factors impacted on sustaining service provision, and also inhibited scope for developing capacity within the workforce:

*“Just don’t have the capacity to take on additional work – that’s the bottom line. Some school nurses are paediatric trained, but the majority are not, so don’t have paediatric knowledge to start with. Special needs is such a specialist area, it can’t just be picked up, need to work in that setting” (School Nurse, Duncan).*

*“In OT, we’ve a lot of staff who are quite experienced and quite static, but when one of them leaves, there is no infrastructure of less experienced staff who are in training/learning, so when a vacancy arises, you might take somebody from somewhere, but then you’ve got another vacancy. And you lose time for the person learning to get up to speed, years of time, not just 6 months, because it’s a specialised role they’re in. Then you have a challenge of how does the team support the person? Other members of the team lose time supporting that person.... I question that what we’re doing community-wise is sustainable” (Paediatric OT, Banquo).*

### **Current workforce factors**

4.46 Among frontline NAHP practitioners, the majority of nurses answered that there were plans to develop current staff to meet identified needs whilst the majority of AHPs answered that there were not. Among those who stated that there were no plans, a children’s OT (Banquo) explained that there was no money for development, and that the team had been in place for a long time, indicating that they had managed thus far, and were expected to continue to do so.

4.47 Respondents reported that there were plans to restructure the composition of the workforce, particularly for nurses. Those that provided further information on the plans indicated that services were under review in relation to workforce planning and workload analysis. This was supported by a nurse manager in Macduff who stated that there was discussion through their Workforce Planning and Development Group, and a Chief Nurse in Duncan who stated that planning was in progress for an integrated health and social care workforce.

4.48 Workforce restructuring included increasing the numbers of staff or creating new positions e.g. in Macbeth, a new post to cover a rural area and an additional Band 6 physiotherapist. However, funding seemed to be an issue affecting planning; one therapist noted that restructuring was of *“limited scope due to geography and limited resources”* (Head OT), while another stated planning was *“in response to financial constraints placed on department by Board rather than response to need”* (SLT, Duncan).

### **Education and Training of Carers and Others**

4.49 Most professionals have a specific role for the education and training of others. Carers, family members, patients, clients, and an array of assistants to nurses and allied health professionals, continually require updated knowledge and appropriate skills training. For

example, although parents may feel direct SLT input is required, it is now widely accepted that staff in educational settings can be educated and trained to deliver the programmes planned and developed by the therapy staff. However, this has to be balanced with the quality of care and the struggle to meet increased demand for appropriate service provision.

4.50 SLTs in Macbeth who went into schools hoping to offer education to staff found that:

*“often education doesn’t have the funding to ensure that their support assistants access training to then let them work with that child ... These assistants are vital to our integration ...and to make integration truly work, we’ve got to make sure that [assistants] access the training in the same way that my staff access the training” (Manager, Macbeth).*

Difficulties involving support assistants in training was a point raised within the practitioner focus groups.

4.51 In Banquo, there were a very small number of school nurses for children with special needs, but where previously they used to work in isolation, they were now part of the mainstream school nurse teams. This enabled them to share their extensive knowledge and experience among colleagues. In addition, they received extensive training for CYP with complex needs, and work closely with a team of specialist nurses, for example providing support to children with gastrostomies.

## **Impact of policies**

4.52 The Education (Additional Support for Learning) (Scotland) Act 2004 addresses issues of equity and requires that children with complex needs have support services in place to ensure that their educational requirements are met. This Act (ASL) has been a strong driver for change and working across boundaries. It was felt that it was too soon to gauge the impact that ASL had had from the service users’ perspective, but that it was one way of ensuring that families were getting the services they need. However, as it comes from an educational perspective, it was suggested that occasionally there were difficulties focusing on the health elements, and that teaching staff did not always see, or perhaps fully understand, the impact that complex needs had on a child’s education. A variety of strategies to support the education, knowledge and skills required to implement ASL, have been put in place. For example, in one region, the introduction of the ASL Act afforded the opportunity for managers from health and education to sit down and together work out issues such as roles, responsibilities, access and training. It has been supportive to schools, and promoted appropriate use of school nurses’ skills.

4.53 In response to the ASL Act, Duncan has introduced shared training to address health and social support for children with complex needs. All school nurses in Banquo have undertaken ASL training, which was led by a senior physiotherapist, and disseminated throughout the region.

4.54 The introduction and implementation of the ASL Act generated comment, both positive and negative. In Banquo, participants in general were dissatisfied and frustrated regarding ASL funding. The associated paperwork and bureaucracy, where joint

documentation was submitted for coordinated support plans, was described as just a paper exercise. However, a manager in Duncan pointed out that:

*“It’s spreading a child’s needs out to all mainstream primaries. A child with complex needs can be in any of them, whereas before they were in a special school, it was geographically more convenient - but not so good from the inclusion point of view. As far as an economic way of delivering therapy is concerned, it is good”.*

This manager also acknowledged that it was not without repercussions, as it impacted on the demand for increased staff to be involved in delivering education to teaching colleagues.

4.55 Policies related to child protection were considered the number one priority across all 4 sites, regardless of occupation or setting, *“Child protection guidelines need to be followed – that’s the bottom line.”* Education and training, often multi-disciplinary, was given to ensure staff were up to date with policy and procedure, and all participants saw this as key to their jobs.

4.56 In MacDuff, whilst training was extensive and covered most of the workforce, it was not always necessarily specific to CYP with complex needs. Within Macbeth, all staff working with children have undertaken requisite core training. In Banquo, nursing assistants/carers for children with complex needs underwent a very comprehensive training package, of which a large component related to child protection and child protection awareness.

4.57 In order to respond to the demands of current policies and service provision, the challenges to NAHP practitioners is ensure they provide a reflective, competent, confident and capable service:

*“Practitioners – need to have the confidence to take time to look at what is not working. Have to think about what they will stop doing in order to provide a better service..... Need the opportunity to reflect, need time and resources to do so, in order to develop good practice.” (SLT Manager, Macbeth).*

There is a need for a supportive infrastructure to educate and enable proactive, innovative practitioners to deliver quality service provision.



## Key Points

- There was a tension between the development and retention of specialist skills within professional groups, and the way in which these skills are shared across professional groups. Additionally, there was pressure to share knowledge and specialist skills with generic workers, many of whom were likely to have day to day contact with the children and their families;
- The level of education and skills for nursing staff was clearly an issue with many participants who expressed concern about the lack of basic paediatric training, something they considered a prerequisite for adequate provision of care to children with complex needs.
- There is a clear need for nurses and allied health professionals to strengthen child health and family health knowledge and skills to ensure the best support for opportunistic and direct health and social care, in order to achieve the best outcomes.
- Many services reported the provision of continuing professional development on a “need to know” basis associated with individual patients. This clearly challenges the core competencies model, promoted by NHS Education for Scotland (NES).
- A number of AHPs and a greater number of nurse respondents felt that they did not have adequate knowledge and skills for working with children with complex needs. This is clearly an issue which should be of considerable concern to those providing services.
- Although education and training appeared to be readily available, concern was raised about the location of available programmes and courses, and about the paucity of funds to support staff to attend.
- Skill mix was a major educational and training issue. Time was not always designated for such activities and staff experienced the pressure of having to make decisions between undertaking knowledge and skills education or providing patient care.
- Although the focus of concern related to education of specific skills, there was also a need for input related to implementing specific policy initiatives which affect the delivery of services overall. One example given was the support provided for implementing the Additional Support for Learning legislation.

## CHAPTER 5 EQUITY OF SERVICE PROVISION

### Introduction

5.1 Factors such as geography, demography, workforce, expertise and economics impact on equitable distribution of resources. Working within these constraints, the challenge to service providers is how to deliver a quality service to each individual child requiring it, acknowledging the principles of acceptability, accessibility and affordability.

5.2 The commitment for an integrated equitable and diverse approach, closely linked with Patient Focus and Public Involvement (PFPI) activities, aims to ensure accessible, appropriate, and non-discriminatory services. The White Paper, Partnership for Care (NHS Scotland 2003), emphasises the need to “extend the principles set out in Fair for All” (Scottish Executive 2001, modified 2006). This promotes services that are responsive to individual need; “ensuring that our health services recognise and respond sensitively to the individual needs, background, and circumstances of people’s lives”. This has particular resonance when considering the diversity of children and young people, with differing levels of complex need, and the challenge of service provision within a wide range of community settings.

5.3 In some areas, there was a general increase in the population of children, as more young families moved into particular geographical areas, *“We’re getting a lot of overspill from City A ... I think our paediatric population is one of the fastest growing in Scotland” (SLT, Duncan)*. This also had implications relating to sustainability of service provision, in terms of children’s workforce complement;

*“The population is increasing – the amount of people in our department has increased, but it’s really not changing the numbers of staff working with children” (OT, Duncan)*

and budget allocations;

*“The increase in population in Region B has been a major issue, and I don’t think that’s been reflected in budgets” (SLT, Duncan)*.

5.4 Additionally, it was felt that in general there had been an increase in the numbers of children with complex needs, seen by health professionals, and also in the complexity of some of the children’s care needs.

*“Longer lifespan because of better health care has an impact – children who were not expected to live into adulthood, also the number of children who have a range of significantly more complex needs, not just about having a syndrome, or a diagnosis – the complexity of the issues” (Community Learning Disability Nurse, Duncan)*.

5.5 Specialist roles and services were suggested as a way to optimise quality of care, for example a Community Children’s Nursing Service to provide a generic service for all children in the community.

*“There is no generic CCN service in Banquo. Children who require nasogastric tube change, central lines etc. either have to return to hospital or be seen by District Nurse” (Children’s Community Nurse, Banquo).*

Another professional advocated a “*complex care nurse working across agencies*” to be funded by mainstream funding (Integrated Children’s Service Manager, Duncan).

5.6 The nursing workforce in Banquo was experiencing major problems with recruitment and retention of carers for ventilated children.

*“High turnover of staff as local area has very low unemployment and a large number of carer positions across all sectors, and it was felt that the “local CHPs did not realise the large unmet need to support families” (CCN, Banquo).*

One nurse manager suggested that retention of these particular carers was due to an “*increased level of responsibility*” and she found that there were problems in the “*provision of training for carers - unregistered carers tend to move on regularly and new carers require to be trained.*” (Manager, Macbeth)

5.7 The apparent lack of suitably qualified staff with the right skills, expertise and knowledge was an area of concern in relation to delivering equitable services. One respondent in Banquo stated the lack of suitable and appropriate knowledge and skills had contributed to a chronic working condition. This issue was further emphasised by a physiotherapist who stated there were not enough community paediatric nursing staff skilled to take on new referrals, causing delayed discharge. Suggestions as to how to improve this situation included bank staff with core skills who could be employed if new complex needs children come along, and providing joint training for care staff, health, social work, and education was also presented as a positive step. It was proposed that the appointment of a Nurse Consultant to act as leader for CYP across sectors could champion for the rights of this population.

5.8 Frontline NAHP practitioners were asked to indicate the extent to which they agreed or disagreed with statements relating to service provision, with respect to their own organisation. Results indicated that practitioners were not confident that the needs of children and young people with complex needs in the community were being met, or that the views of this client group were being taken into account, particularly in relation to the planning of services. However, respondents felt positive that service providers within health and other agencies were working jointly.

5.9 Problems of equity specific to individual therapies were apparent. These included podiatry in Macduff where there were long waiting lists, and it was felt that a number of podiatry services could be improved. A paediatric therapist in Town C (Macbeth) felt that there were gaps in augmentative technology which could be addressed by training staff and providing money to buy equipment. Music therapy services were found to be limited:

*“they are provided in time-limited blocks to children within core provision and often unavailable to CYP with complex needs in mainstream provision”*  
(Music Therapist, Duncan).

It was felt that the situation could be improved by recruiting more staff and providing transport for children to attend music sessions.

5.10 Some of the sites still had specialist schools or a centre, but not all. Participants highlighted areas where they felt that parents and children were not receiving an equitable allocation of resources, particularly with regard to provision in schools.

*“ ... there are several children accessing mainstream schools, who have a complex need (e.g. enteral feeding that needs to be done at school, a need to be catheterised) ... And at the moment ... we have inequity, in one child in a ... school, we’ve been able to go in and train staff to do his feeding and his suctioning, but there’s a school not that far down the road, who have agreed to be trained, for a different child, to do the feeding, but yet the education department ... have said, no, they’ve not to do his feeding. And as a nurse, I find it highly frustrating that there can be that inequity, and you’ve got to remember that there is a parent who knows, because they all speak, that child down the road has someone who will feed him at lunchtime, but their child can’t stay over lunchtime because the staff there won’t feed him”*  
(CCN, MacDuff).

*“Very unequal across Banquo because in some areas, a head teacher of a school is quite willing to allow catheterisation, and let the auxiliaries do that, and then the next head teacher say no, that’s health issues, you need to get someone to come in”* (CCN, Banquo).

5.11 There was a feeling that staff, both within education and health, had not been consulted with regard to the implementation of mainstream education, as illustrated by the following comments from participants in Macduff:

*“I just think there was clearly a lack of thought when all this, I can’t speak for education, but when they started to think about mainstreaming and accepting these children, there clearly was no thought about the impact ...”*

*“I don’t think they even spoke to the teachers!”*

5.12 All 4 sites supported families living in remote and rural areas, encompassing large geographical distances, which impacted on equity of service provision. The ASL Act had promoted inclusion for children with complex needs so they could attend their local school, but it also meant that the nurse or allied health professional delivering services had to travel more. This caused difficulties, particularly in rural areas:

*“I always have concern about equity of service, simply because it’s extremely hard for me and my team to support a child – e.g. in village F, which is 40 miles along a very difficult road, especially for 4 months of the year. How are we meant to give equity of service to that child compared to a child that’s maybe in a school in Town G, that’s approximately quarter of a mile from the hospital? ...I find that we have gone along this political agenda, that yes children must be taught in a locality, but there hasn’t ever been any pump priming into services”* (Paediatric Physiotherapist, Banquo).

5.13 This increased travel was felt by some to have impacted negatively on service delivery. However, many participants felt that mainstreaming had promoted improved liaison and working with education colleagues, and had ensured, in the main, that families were receiving appropriate services for their needs.

*“We also prioritise new families coming into the service, because that’s often the time when they’re feeling quite vulnerable, so it’s making sure they’ve got everything in place that they required, and know what their options are.”*  
(Coordinator, Duncan)

### **Gaps in service provision**

5.14 NAHP questionnaire respondents were prompted to list gaps in services for CYP with complex needs. Several key issues emerged concerning a lack of equitable service provision, resources for caring for children with life limiting/life threatening conditions at home, funding for staff and equipment, and recruitment/retention of carers.

*“It would be very nice if there was a pocket of resources, a sort of bridging fund/fast track, so you could get the people that you need, and get the family settled, and then look to the future and then ways forward ... with a little bit of help at that time”*  
(Manager, MacDuff)

5.15 Several participants felt there were certain children and young people for whom access to services might be difficult, or impossible. A learning disabilities nurse in Duncan said:

*“‘Grey area children’ don’t get a very good service. To be able to access our team, they have to have an IQ less than 70. If child has more than that, but clearly has learning difficulties, but doesn’t have diagnosable mental health problem, then they can’t be referred to Child and Adolescent Mental Health Services (CAHMS). We have children who have difficulties whose needs are not being addressed. Political debate going on”.*

5.16 In another region, children who had a physical disability but not a learning disability were felt to be under-served:

*“It’s very much the learning disability label that guides you to the service, and if you don’t have a learning disability, if you have a physical disability, there is no service. That’s a well documented gap in service.”* (Paediatric Nurse Specialist, Banquo).

5.17 A third of questionnaire participants indicated a lack of confidence in service provision, with a number disagreeing with the statement “services for children and young people with complex needs in the community were effective for their needs”. The majority of respondents disagreed that there were sufficient resources to deliver appropriate services. A comment from an SLT in Duncan provided insight into the issue:

*“Whilst there is appropriate service delivery to CYP in community, this can sometimes be very demanding to deliver due to resourcing and manpower*

*issues. Increased demands on services and very little increase in manpower - usually short term project funded. Not targeting ongoing needs."*

These remarks were echoed by another SLT who felt that opportunities did exist, but were not available for all children owing to lack of funding, which raised the reality of equitable service provision.

### **Providing services for minority groups**

5.18 Although the 4 research sites responded to the needs of ethnic and minority groups, such as travelling people, specific services were not generally available. Within Macbeth, the underpinning ethos was to provide an equitable service to all individuals and groups:

*"We don't have a huge travelling group here ... there are some travelling people who would be seen as appropriate and their needs would be factored in." (SLT Manager, Macbeth).*

5.19 Most areas have experienced a large influx of migrants, or immigrants, from Eastern Europe; in Banquo, Polish is the most common language spoken, after English. The majority were young adults who either did not yet have children, or whose children were not yet resident in Scotland, but it was noted that this population could potentially have an increased need for services for children with complex needs in the future.

*"We know the increase in birth rate in Banquo is almost solely due to immigrant population, Polish particularly" (Paediatric Dietician, Banquo).*

5.20 MacDuff operated a translator service, which was not always easy to organise, but telephone translators were available. Language Line, the national interpreting and translation service, was available in every GP practice in City E. Speech and language therapy used the services of interpreters, where necessary.

*"They're always willing to come and always helpful when they come, but sometimes interpreting services find it quite difficult not to help children if they haven't been trained in delivering assessments. The interpretation and translation of an instruction within a standardised assessment into a different language can change the interpretation, it's quite difficult to do that. It's more likely that you'll be doing the assessment in English, especially if the child is in school, as the language of education is English, and you're making use of the interpretation services to communicate with parents." (SLT Manager, Duncan).*

5.21 In Duncan, quality assurance (QA) personnel working for the City Council liaised with nursing and allied health professionals regarding ethnic minority groups and travelling people, and there were well defined paths to access services. NHS Duncan had strong links with social work and education departments, who linked with travelling families. There were also public health nurses for that client group, working on a link or liaison basis, but one manager felt more support could be offered.

## Discharge planning

5.22 Lack of financial support, appropriate equipment and cohesive funding arrangements had the potential to challenge the efficiency of discharge planning. This could be exacerbated by a lack of understanding on the part of the budget holder,

*“... If you hang on to the end of the financial year, there might be a spare bit of cash, and you think you’ll get a bed... but they’re being discharged now!!” (Service Manager, MacDuff).*

5.23 In one site, a specialist CCN was involved with discharge planning and, whilst this could still pose challenges, her post made the process much more effective.

*“Getting children home from hospital can be an area of difficulty. CCN – specialist post, if children have a few medical requirements, she’ll make sure they have the equipment they need, and the training they require before they then come home. And she’ll support at home until they become more competent in caring for their child, within the environment” (CDC Coordinator, Duncan).*

5.24 It was deemed to be more challenging discharging children with complex needs from hospital to community services in remote and rural areas than those living in urban areas. This was particularly in situations where there may not be people with the relevant skills to provide the required input for the child and family.

*“Some of the challenges to home care packages are where people aren’t ready to accept them until [staff] have relevant skills” (Manager, Duncan).*

5.25 In one site care was provided by a District Nursing service which was mixed adult and children, and was not child specific. This impacted on service provision for children requiring care. Care packages often necessitated the issuing and use of equipment, resulting in difficult dilemmas with regard to funding and staffing. It was felt there was a lack of consistency across Scotland regarding how to manage home packages for children with complex needs, and who provided the funding.

5.26 Given the sometimes unpredictable nature of the health status of CYP with complex needs, and the potential for a child’s condition to change rapidly, it was acknowledged that there was sometimes a necessary degree of reactivity regarding admission to, and discharge, from hospital. This could cause problems for staff trying to locate facilities, funds and access equipment, particularly when a child was discharged suddenly. One manager said she felt that:

*“quite often, discharge from hospital isn’t well coordinated, or suddenly there is a child who is dying, and there’s a huge scrabble around to try and find the equipment [immediately], or there have been changes in the [need for additional] equipment” (Manager, Macbeth).*

5.27 This highlighted the need for proactive, strategic, anticipatory care,

*“If you have everything in place, then the child can come home, and often once they are home, the community paediatric services, DNs, GPs and other people involved in the care, things can be ‘cobbled together’ and make it work, because that’s what nurses do best” (Manager, MacDuff).*

## **Respite Care**

5.28 Across all 4 sites, provision of respite care was felt to be problematic, in that there was never enough. In some cases, although there may have been available facilities, there were sometimes very strict admission criteria, such as a specific medical condition or a certain degree of impairment, which meant certain children and young people were unable to access these facilities. One such example was children who were physically disabled, but cognitively able.

*“I have a 12 year old boy, and a 12 year old girl, not related, who are both at mainstream school. One has a progressive neurological disease, and the other one has spinal injury, physically disabled but at mainstream school, going away to high school next year. We’re at the stage now where **they** both desperately need respite [for their individual personal development], not the parents” (CCN, MacDuff).*

5.29 This same nurse raised the point that respite should be age-appropriate, so that children received support involving peers, rather than adult-only input, and that it should be individualised for the type of care needs the child has. An example of constraining criteria were provided, highlighting inequity in service provision and not in the best interest of the child.

*“An 11 year old girl who has no peer support, she’s been surrounded by adults since she was 3 years old. She doesn’t seem to fit anyone’s respite criteria, so she’s been to School X, they say she doesn’t really fit our criteria, well we don’t really want her going to Rachel House [hospice] because that’s giving all the wrong signals, that’s not how we’re managing her” (CCN, MacDuff).*

5.30 During the course of a focus group, participants discussed the possibility of grouping together the 4 or 5 physically disabled, but cognitively able, young people, such that they could attend for respite together, and provide each other with peer support. However, there were still concerns regarding the often inflexible admission criteria.

5.31 In Banquo, there were no dedicated respite care resources. Hospital beds were utilised for respite care, where possible. One small project in MacDuff was successful in recruiting a small number of Health Care Assistants (HCAs) to set up home-based respite for children within a family setting, for a maximum of four hours per week. The HCAs were trained by paediatric outreach staff, and then matched to specific families. However it proved more difficult to retain these HCAs, as most had other jobs, and their own personal family commitments. This, coupled with a period of major staffing changes, and high levels of staff turn-over, was highly unsatisfactory in terms of the quality, continuity and frequency of service for the families. However, despite the difficulties, the families who took part in an evaluation of the service eighteen months later were, in general, appreciative.



5.32 Within Duncan, children put forward for respite were discussed at the Respite Support Panel, which utilised a multidisciplinary vulnerability scoring system, prioritising children according to the score given by the panel consensus. This then determined where they would go, how soon, and the type of respite they would receive. Prior to being discussed at the Panel meetings, a child should have had an assessment form completed by social services; however, the reality was that a child might have to wait for between 8-9 months in order for the necessary assessment to be carried out. Theoretically, it could be undertaken by any professional working with the family, but families had the right to ask social work to undertake the assessment, which might mean a child was placed on the waiting list immediately, but owing to staffing constraints, there was a delay before the assessment was carried out. The delay could have far-reaching consequences on the health and social wellbeing of individual children, their families and carers.

5.33 Further evidence from participants demonstrated that staff felt that there were gaps in the provision of respite services, as indicated by the comments of a Chief Nurse who pointed out the need for more respite provision which was flexible and could be offered in a range of settings. These points were echoed by an OT who wanted to make respite care and holiday clubs available, reduce waiting times and agree a local protocol. It was felt that the lack of funding for respite could be addressed by a review of provision and prioritisation of access to respite, and by multi-agency provision.

## **Palliative Care**

5.34 Palliative care provision was another area of concern within some areas. Whilst MacDuff had recently conducted a review of palliative services, it focused on adult care. In response, a one day workshop relating to palliative care for children, covering oncology, neuro-disability and other terminal conditions, was organised, with input from consultant paediatricians, a hospice director, and parents. This was also attended by a wide range of professionals. Research participants who had attended felt it had been highly beneficial, and were looking forward to a follow-up workshop. Other participants were extremely disgruntled as they had had no knowledge of the event. Generally, there was a view that there was indeed a gap in staffing provision, whereby the two existing specialist paediatric oncology nurses, employed to provide a service from 9 am until 5 pm, Monday to Friday, were more or less on call, 24 hours a day. There was no palliative care consultant within the region. A mapping exercise was under way, investigating palliative care provision in the region.

5.35 There was a lack of equity across the 4 sites. For example, neither Banquo nor Macduff had a CYP palliative care service, although they had access to 2 children's hospices. In Macbeth, children's nurses responded to need, however, when the demand increased, this was complemented by other staff. Duncan, on the other hand, has palliative care nurses based in one of the national Children's Hospitals, to whom cases can be referred. In addition, they have an Exceptional Needs Group, which covers the whole region, comprising a range of health professionals, who can allocate needs-specific portions of money for services such as home nursing care or palliative care, removing the need to apply to social services for funding. Several participants expressed interest in the recent appointment of 4 palliative nurse specialists to be employed throughout Scotland.

## **Out of hours support**

5.36 None of the four sites participating offered 24 hour support, so no-one was particularly more disadvantaged than any other.

*“In Banquo very little is provided. No joint funding. I support families with very complex ventilation needs, maybe requiring overnight or 24 hour care packages, and although Banquo have said there is a Forum for joint funding, there’s not. There’s meant to be joint funding between Social Work, education and health, and there’s not” (CCN, Banquo).*

5.37 District Nurses were sometimes utilised to avoid hospital admission. Within Macduff, the CCN service provided is from 9-5, Monday to Friday, which leads to gaps in evening and weekend support for families who do not have care packages or support at home. Invariably, if a child was in crisis, they would be attended to within an acute setting, rather than at home.

5.38 There was a view that children’s services required more funding. More and more children with complex needs are living into adulthood, and at home, yet the majority of the funding was being put into adult services. There were poor out of hours facilities in Macbeth, where children and families outwith the major towns had to travel large distances to access particular services. A Charge Nurse in Town C (Macbeth) identified the need for gaps in outreach, respite and palliative care to be filled by increased availability of longer term placements and funding.

5.39 Children and young people need access to appropriate health care. Research involving young people demonstrates that poor attitudes and incorrect assumptions, as well as the way in which we deliver services, often prevent young people accessing the services they need to keep healthy. Health services must meet need appropriately, treat people with dignity and respect, and acknowledge ageism. Ageist practice needs to be challenged, with younger people involved in the design and delivery of services (Fair for All – Age 2008).

## **Transitions**

5.40 The transition to adulthood was repeatedly mentioned as an area needing to be addressed by both nursing staff and AHPs. A Public Health Nurse in Duncan noted that there was a reduction in respite once a family needed adult services, and that increased provision was necessary as there were more children surviving, for longer, with this level of need.

5.41 Children and young people at a transition point in their lives, whether from pre-school to primary, primary to secondary school, or child to adult services, were considered a priority by all participants, particularly with regard to activities of daily living.

5.42 This related to undertaking assessment, obtaining equipment, arranging packages of care, or occasionally an unplanned admission or discharge to a service provider/ facility. Sometimes this worked very well, but it was stated that, on occasion, this had been badly managed. One research participant highlighted a situation emphasising the lack of personal contact and sensitivity from staff involved in service provision. After years of input, a young person had been simply sent a letter informing them of changes to their service provision.

The lack of support for the journey from childhood to adulthood for CYP with complex needs was evident.

5.43 The child to adult transition was further complicated by the lack of a national consensus regarding perspectives on the specific age definitions of a child, young person, or/and adult. Participants were asked to describe the children and young people with complex needs that they currently worked with. The upper age limit of what constituted a child or young person varied, ranged from 16 to 21 years, within and across service providers. Some therapists worked only with preschool children, whilst others worked with children from nursery age through to 18 years old. One paediatric team saw *all* children from 0-16 years, and continued up to 19 years, for those with complex needs. However, in Macduff, for children with complex needs, the transition from children to adult services necessitated transferring to learning disability services as the only service provision.

5.44 Transition of care from acute to community services was also a key area of concern. For SLT in Duncan, where the numbers of children entering acute care were small, the needs of each individual child were addressed, and if a child was going back into school, the SLT would go out to the school and to the home, and make sure that the transition had taken place successfully, before passing the child onto the local therapist. This could be quite a “*well worn path*”.

5.45 However, a manager in a different site highlighted difficulties she was experiencing:

*“I still feel that consultants are not completely signed up for this transition into the community. I have to do a lot of work about getting them really tuned into the service ... I don’t know that they are understanding what is happening in the community” (Manager, Macbeth).*

5.46 A wish for the future was for better and sufficient resources, for staff and parents alike:

*“Tailoring the services to the needs of the child, rather than what can be cobbled together, to ‘make do and mend’” (Manager, Duncan).*

Research participants wished that families had less of a struggle to obtain resources and support. As one manager stated:

*Parents have different views on what they want, and we try to match their expectations, but at the same time, you’re aware that there are some families who really need some resources, but they may be the ones who are least able to fight for them” (Manager, Duncan).*

5.47 The challenges relating to equitable service provision highlighted the influences of policy drivers, the role of advocacy, organisational redesign, additional education and training. Additionally, the need for overall communication systems to be reviewed was emphasised, as illustrated in the following quote:

*“The acute side is now being driven by the Care Closer to Home Agenda, and tied up with GIRFEC – driven by national issues. One of the challenges is making sure that as well as being driven by national issues, you actually*

*respond to the needs of that individual child. It has increased the demand for a changed model of working. It's involved us in more training, it's involved us in changing our paperwork. We've changed our paperwork in our communications with our education colleagues, particularly, so that they understand why we've made the decisions that we've made, and what strengths the child has, and how it can build on those strengths, and the paperwork has changed quite dramatically to share that information with teaching colleagues". (SLT Manager, Duncan)*

### **Key Points**

- Professionals interviewed were aware of inequalities across services for example where specialist support was available in one location but not in another;
- The need for proactive, strategic anticipatory care planning was acknowledged in all four areas, and wherever possible, plans to address issues for those living in remote and rural communities have been developed. However, practitioners suggest that this will always remain an issue in terms of the services that they are able to provide, and specific aspects of service delivery, such as discharge planning;
- A number of gaps in service provision were identified especially for children who had needs which did not meet specific criteria – for example IQ or level of physical incapacity;
- Immigrant groups were often not provided for especially well, although translation services were available in some areas. The higher birth rate associated with some groups was also likely to increase the number of children with complex needs;
- Specific areas of tension regarding equity were identified for children with complex needs, and were very much in line with the areas of concern identified in the literature review, namely transitions between aspects of care and within the school system, and both respite and palliative care.

## CHAPTER 6 COMMUNICATION AND INFORMATION SHARING

### Introduction

6.1 Like all other services, key to the provision of service for children and young people is who has the knowledge about a given condition, about the services on offer and how that information is conveyed within professional groups, across professional groups and to non specialists and, of course, to parents and the children themselves.

6.2 This chapter looks at the many different aspects of communication between organisations, professionals, children, young people, their families, carers and other colleagues. It also explores information provision and sharing, record keeping, and organisational supportive infrastructures.

6.3 NAHPs working with children and young people did so in a variety of contexts, backgrounds and settings. Most NAHPs delivered services at school or at home, with a significant number also providing services in nurseries and Medical/Health Centres. Other settings mentioned included child development centres; childcare centres; community centres; music studios; preschool centres; respite accommodation, and sports centres.

### Information transfer: opportunities and challenges

6.4 The extent to which information and documentation was shared varied among the sites, owing to differing IT systems, record keeping protocols and accessibility related to geographical location and organisational supportive infrastructures. There was little evidence of electronic record keeping. Electronic documentation was considered to be at the very early stages of development, although systems for 'children at risk' were available.

*"No electronic communication – systems don't speak to each other. It's in the pipeline, but has been for some time" (Health Visitor, Duncan).*

6.5 Duncan paediatric physiotherapy services utilised a specialised management information system. This held clinical, managerial and audit information relating to diagnosis, treatment and duration of care. It was hoped that this would be rolled out to other allied health professionals, but to date this had not happened. It was felt that *"if all staff put in stuff about their own patients and we can then produce excellent reports for trends. Again, if we had time, it could be used for clinical audits and systems"* (Manager, Duncan).

6.6 The majority of children being cared for were linked to several different sets of documentation. These tended to be paper records, with differing criteria for shared access by different service providers. The Integrated Shared Assessment tool (GIRFEC, Section 3 – Scottish Executive 2005d), offering a more integrated approach across agencies, was viewed to be in its infancy. The Single Shared Assessment (SSA) tool, which creates a single point of entry to community care services, leading to better use of resources and more effective outcomes, was not generally referred to or in use.

6.7 A large city in Banquo had implemented a shared planning and information record for children with complex needs between 0-3 years old. In partnership with parents, one

individual, with knowledge of all other services, was appointed as key worker. Increasingly, that had tended to be HVs, who have known the family through the antenatal period, emphasising continuity of care. *“Essentially there is one record that everybody can access and see what is going on”* (Manager, MacDuff). This record detailed all involved staff, whether they were in education, health, social work, voluntary sector, along with their role. However, it was not electronic, although there were plans to develop that in the light of GIRFEC, as a template.

6.8 In one city in Macduff, nursing staff were non geographically based and spread across 28 teams throughout the city. This had an impact on communication systems and the sharing of information, as highlighted below:

*“The way we work... at the moment conspires against us in some ways ... if you’ve got two children in the town with similar needs/conditions, but they are with different GP practices, there’s no way of sharing that information”* (Manager, MacDuff).

6.9 Where staff worked in close geographical proximity, such as in Child Development Centres, or were based within a hospital, information sharing was less problematic. Paper copy notes were easily accessible, and increased opportunities to meet and/or speak directly to each other were afforded. But elsewhere, problems could arise, such as duplication of information, for example,

*“If a new family is referred, and [X] comes in, and I come in, and somebody else – family has to go over the same information. They’re telling the same things over and over, and get really distraught about that sometimes. They really don’t like it.”* (Community Learning Disability Nurse, Duncan).

6.10 In a bid to reduce such duplication, Banquo utilised a system whereby if a child with complex needs was required to go into hospital, they brought their ‘passport’ in with them. This was a folder giving detailed information about themselves, such as their food likes and dislikes, their preferred positioning and required exercises with regard to physiotherapy input. This avoided different professionals asking the same questions repetitively, and also made life easier for the child and family members. All health professionals who cared for the child in the community contributed relevant information to the passport. This was generally regarded as an example of good practice.

6.11 It was felt that there needed to be more investment and improvement in equipment, software and training to support access to information such that it can be communicated, shared, maintained and updated electronically. This would help improve the limitations imposed by geographical challenges, such as remoteness, which impact on accessibility of services. This would also lead to an improved and more equitable service for practitioners and service users.

6.12 In one site, a manager indicated that many staff members had community experience, had access to good networks, and knew where to get information regarding unusual or complicated conditions, as the vast majority had access to personal computers and the internet.

## Communication

### Referral

6.13 Referral systems differed from region to region. Participants indicated that children and young people with complex needs could be referred to NAHP services by a number of health, social work and education professionals. Most AHPs cited more than one type of professional that could refer directly to their services, such as schools, education psychologists, child community health staff, HVs, and SLTs. A lead SLT (Duncan) stated that SLT had an open referral system, and the most likely referrers were HVs or community paediatricians, while another SLT in the same region stated that it depended on the age of the child, whereby preschool children were referred by HVs, but nursery and school age children were referred by education staff.

6.14 Referrals to nurses were equally varied; a CCN (Banquo) stated *“Usually hospital staff refers initially (consultant/dietician/ ward nurses)”* while a Clinical Nurse Manager explained *“this is a home care package commissioned by social work department in consultation with health board”*. A public health nurse (Duncan) described the situation in special schools whereby all children attending special school are referred to outreach CCN, or occasionally acute services.

6.15 NAHPs tried, wherever possible, to access additional staff with specialist roles for CYP services, such as a community nurse, community children’s nurse, learning disability nurse, looked after children’s nurse, specialist teacher, epilepsy nurse, child protection link health visitor, school nurses and a paediatrician.

### Vertical and Horizontal Communication Systems

6.16 Frontline NAHP practitioners were fairly positive regarding communication issues. Many stated that it was possible to communicate with both higher levels of management and partner agencies in relation to service provision and development. Almost half of the practitioners believed that *“there are opportunities to communicate with committees/managers and directors in relation to service development”*. Similarly, they also agreed that *“there are clear methods of communication between professionals, children, young people their families, carers and other colleagues”*.

One participant spoke very positively about professional support:

*“We’ve got lead support groups for our lead people, and the last peer support group but one, it was wonderful, we just didn’t follow the agenda at all, each lead person said something, and everyone else said, Oh, I could help you with that! And the networking was wonderful, and that was across agencies, and you couldn’t have written it better. That definitely worked, I’m not saying it’ll happen like that every time. But when you’re having teams like this, everybody does learn – it’s definitely coming together, inter-agency working.”*  
(Lead Officer, MacDuff).

6.17 Managers indicated that they sat on various committees, and were members of groups,

*“I’m on the children’s health support group, and currently chair the senior paediatric nurse group as well”* (Manager, Duncan).

Whilst senior management attended strategic meetings concerning policy implementation, some grass roots workers expressed their frustration that communication was not always a two-way process. This raises the issue of vertical and horizontal transmission of communication between the various professions and across multiple service providers. For example, within SLT in Banquo, it was reported that there was little awareness of how best to share information and establish appropriate communication networks. These processes and procedures were felt to be ad hoc.

6.18 Issues related to dissemination of information were raised, *“The information that comes out of that is not even disseminated down, is it? Not in HV.”* (Health Visitor, Duncan). *“At ground level, we don’t get information. We share amongst ourselves”* (Learning Disability Nurse, Duncan) was a view expressed by grassroots practitioners. Participants commented that within the region, there was a consultant paediatrician who had a special interest in complex needs, and who was very good at disseminating information and making contact with staff. This was deemed to be advantageous, and ought to be replicated.

6.19 Some grass roots participants were disgruntled by the lack of representation at meetings which then impacted on their ability to contribute to strategic planning and development of services for CYP. This was particularly relevant when practitioners were requested to deputise for managers, often at short notice. There was a view that to be effective, all communication, in whatever format, should have issues and concerns clearly highlighted, so that practitioners were cognisant and therefore fully able to contribute and deputise at meetings.

6.20 One example of good representation given was of a regional child health strategy group (MacDuff), which had a Complex Needs sub-group. This ‘pulled’ the relevant heads from all agencies to meet together at a strategic level to regularly review services for CYP with complex needs. The meetings were seen as an opportunity for people to bring issues which could then be incorporated into an action plan, thus ensuring professional inter-agency accountability and responsibility. However, one participant stated,

*“If there was a better cross-section of people attending, it would be so much more effective, because it’s the only group that meets to discuss children with complex needs, and there’s a need for that, but unfortunately there isn’t a good representation from all agencies.”* (Lead Officer, MacDuff).

6.21 The issue of communication networks for all stakeholders was raised, with a feeling that there was a lack of robust networks for children’s services. Whilst networks existed within individual sectors, there was little cross-sector communication, so it was not possible to send an email, for example, to contact all key stakeholders.

6.22 Determining the usefulness of information sharing with other professions was at times viewed as challenging;

*“You’re either in the knowledge, or out of the knowledge. And you can’t make a judgement across professions, what the relevance of this bit of information is for other people. Often, you’ve got the bit of knowledge that others would find very useful.”* (Paediatric OT, Banquo).



6.23 One manager commented that a Scottish Executive recommendation (resulting from an earlier review of children's therapy services, (Scottish Executive 2003)), to include managers of children's services in strategic planning, had not been responded to.

*" ... I was involved in the group that put together the blue book ... for the children's services therapists ... one of the recommendations in that was that health boards should involve managers of children's services in strategic planning and that hasn't happened" (Physiotherapy Manager, Duncan)*

6.24 Some doubts were raised concerning the supportive aspect of multiprofessional and interagency partnership meetings. There was a view that at times, the uniprofessional perspective was in danger of being overshadowed

6.25 There was a desire for more opportunities for multi professionals to meet and truly share experience, expertise, knowledge and skills, and managers to promote integrated communities of NAHP practitioners, working with CYP with complex needs. Forums for Heads of Services tended to focus on adult service provision, and participants felt that their remit for working for and championing CYP was overlooked.

*"If we had, for example, a head paediatric dietician for MacDuff, who could actually spend time looking at the service, putting in these bids ...whereas we're trying to do it on quite an adult basis, and having managers who don't really care, or haven't taken the time to find out what is actually going on. That's been a big gap." (Dietician, MacDuff)*

At its simplest, it was felt that communication boils down to *"the right information, given to/by the right people, for the right child, at the right time"* (SLT Manager, Macbeth).

## **Advocacy**

6.26 Involving children and young people is emphasised within 'Delivering a Healthy Future' (Scottish Executive 2007), and highlighted again in the Equality and Diversity Impact Assessment Toolkit (EDIAT) (NHS Scotland 2007). The Patient Focus and Public Involvement (PFPI) Agenda (NHS Scotland 2001) reinforces children's rights to be involved and participate in their care, as supported by The Children (Scotland) Act 1995, and the United Nations Convention for the Rights of the Child Article 12 (UN 1989).

6.27 Advocacy presented itself as an issue during the course of the focus groups. Children's and families' views were not felt by some to be represented at strategic level. In order to address this issue, practitioners felt that opportunities to attend meetings at this level would be beneficial. Knowledge regarding children and young people's voluntary organisations appeared limited. Some acknowledgement of the role of advocacy being provided by organisations such as Children First, the Children's Hearing System, and Special Needs Information Point (SNIP) was apparent. However, some focus group participants indicated that the work of bodies, such as the Young People's Health Advisory Group and the Children's Commissioner, held little relevance with regard to their day-to-day working. One manager acknowledged that the official bodies had made some, albeit limited, impact,

*“I have to say yes, but it has got to a certain level, I don’t know how much has filtered down to the operational managers” (SLT Manager, Macbeth).*

6.28 With regard to advocacy, and its role in influencing service delivery, grass roots workers stated their aim was to ensure optimum service provision for children as best they could, with one focus group participant stating:

*“I think the provision for early years has a well structured pathway ...as soon as children are identified, it doesn’t matter whether they get a label or not, we can get services started. I think we have quite a good working relationship with other services. We work very closely with preschool, home teaching, education and with all the local children’s providers so that we can get them the help that they need when they need it. Some children are more straightforward than others, and things just seem to fall into place; they get a good service package” (CDC Coordinator, Duncan)*

6.29 The advocacy role was taken seriously by all participants, and some expressed concern that children and their families were not fully represented and/or consulted in respect of their needs. It should be noted that seeking the views of children, young people and their carers and families was not the remit for this project.

6.30 A large number of participants felt that services could be tailor-made to the individual needs of the children and young people with complex needs. However a large number were unsure of the extent to which the views of this client group were taken into account when planning services, and many felt that indeed they had not been. In relation to advocacy, it was difficult to conclude that provision was equitable or truly tailor-made to meet individual needs.

6.31 Counterbalancing that view, the underpinning ethos of the educational needs support group (Duncan) appeared empowering both to staff and the recipients of the service. Opportunity for decision making, and autonomy related to allocating funding appeared to provide a forum for emphasising advocacy and staff job satisfaction.

*“It would be nice to think that the budget is following the children out into the community, because parents need that support, they’ve got their children at home. To a certain extent, monies can be applied for if there’s particular needs, there’s a shared budget throughout NHS Duncan – Exceptional Needs Support group, so that children who require nurses etc. to be in the home, then there are special budgets.” (Manager, Duncan)*

6.32 In ‘Delivering a Healthy Future: An Action Framework for Children’s and Young People’s Health in Scotland’ (Scottish Executive, 2007) the emphasis focused on the needs of children who may be vulnerable, or at risk. The need to provide consistent and equitable support to children and their families, based on best available evidence, was highlighted by participants in all regions.

6.33 Getting it Right for Every Child (Scottish Executive, 2006c) set out an approach involving practice change, legislation and removing barriers to ensure that the health, education and social care needs of children were met. Anxieties were expressed in relation to Visible, Accessible, Integrated Care (Scottish Executive, 2006a) which proposed a new

service model, intended to revise nursing services in the light of current policy drivers. Although this document aims to support people to live healthier lives in their homes, and reduce health inequalities, research participants stated concerns regarding their capability in responding to a changing role.

*“the Scottish Executive is constantly introducing ‘new and innovative services’ often on a short term basis which will be initially funded and then ‘mainstreamed’. The strain of this on services is becoming more and more apparent. There is a lack of capacity and lack of resource, financial and otherwise. We don’t need new and innovative services unless we have enough capacity to deliver services in the first place!! New and innovative isn’t always the best - we need to look at what has worked in the past and build on it by investment. For example, the Sure Start project worked because it was invested in!!” (Lead Nurse, School Nursing, Banquo).*

This issue of advocacy in relation to policy implementation, and the need for quality service provision often led to frustration. This will be explored further in Chapter 7.

## **Policies**

6.34 The interpretation of government documents and related policies whereby information could be communicated meaningfully and/or accurately to service providers appeared to be a vital component of quality service provision. The policies most frequently mentioned by participants across the sites were Hall4, Getting it Right for Every Child (GIRFEC), and the Additional Support for Learning Act (ASL).

6.35 In relation to GIRFEC, several sites were carrying out integrated care assessments. However, one participant suggested that it was not being developed particularly swiftly,

*“GIRFEC has sort of fizzled out ... I went to a few meetings in Edinburgh on the consultation group ... when they were developing it, and it sounded very generic, all children, and then it just seemed to go down this lane, and it’s got stuck there” (Lead Officer, MacDuff).*

6.36 Several respondents commented on the challenges of operationalising recommendations within the plethora of policies, one example being Delivering Healthy Futures, particularly with regard to continuing to provide services;

*“It is a challenge to ensure that, as well as being driven by national issues (GIRFEC, Care Close to Home Agenda), you actually respond to the needs of that given child.” (SLT Manager, Duncan)*

6.37 Additionally, concerns were raised relating to the time lapse between implementing a policy, and seeing the ensuing outcomes;

*“ ... not doing routine checks, so that concerns me. How do we pick up? And how early – only now, in the next couple of years will we be able to see the results of Hall 4, and whether interventions could have been done sooner, or children referred earlier” (HV, Duncan).*

6.38 Prioritising work in order to comply with policy was sometimes problematic.

*“We have something called a Core programme – and we’re struggling with it at the moment - HV, school nursing. The Core Programme, and Hall 4 is quite sufficient with all the resource we’ve got at the moment. So we’re talking about additional. So how do you prioritise your priorities? In Banquo have Children’s Services Strategic working groups – partnership, LA, education, health – it’s very difficult to contribute to the prioritisation agenda within that group. That’s the biggest challenge. Every discipline/sector has their own target to meet. Now, joint funding is a joke as a result” (CHP, Banquo)*

6.39 In MacDuff, with regard to Hall4, workload analysis of HV teams has shown that staff were much more active in higher deprivation category areas, and were targeting their activities and time much more towards those who need it. There were a significant number, nearly one third, of under fives who were receiving “additional” and “intensive” services, which included children with complex needs. This raised the need for the workforce to contextualise specific aspects of service delivery. These included location of service provision in relation to remote and rural areas, and level of availability of resources. Accessibility to, and acceptability of specific services, such as those in areas of deprivation, provided an ongoing challenge for practitioners.

6.40 Another issue was the frequency with which the workforce were required to implement policies, with staff having little clarity regarding operationalisation or time for assimilation, before the next change was upon them;

*“Services spread so thinly, trying to accommodate every new Scottish Executive policy ... that actually people recently have been burnt out. No clear guide about what the priorities are – too many” (Lead Nurse, Banquo).*

6.41 Concerns were raised relating to the number of policy documents, the increasing constraints involved in implementing them while at the same time maintaining a service to the children and young people with complex needs. One manager commented;

*“there is a big tension between policy implementation and the operational delivery of services. As with all the big drivers, we’re being asked to do more and more with less and less ... We have savings and efficiency targets, and year on year, most of my resource is tied up in staff, so we’re not filling vacancies, money is going towards savings to meet the higher targets that come in centrally, and increasingly our services have become more and more targeted, particularly around Hall 4”.*

She went on to point out that

*“ ... if a change of practice is being recommended, if no funding comes with that, it can be very challenging because you have to take it from somewhere else” (Manager, MacDuff).*

6.42 Others highlighted competing requirements, and managing priorities;

*“... I find it completely overwhelming, in that there is so much going on against the background of having to achieve efficiency savings, achieve waiting list targets, as well as delivering very high quality care – that would be my main priority – but that is difficult to do with all the other competing priorities. There are so many policy initiatives out just now that it is difficult to decide what you are going to take forward and not take forward. In some ways it’s good, because there there’s much more focus on the children ... but it’s what’s manageable at the coalface” (Chief Nurse, Duncan).*

*“You feel you are drowning beneath all the policy and legislation coming out about children, and it is quite difficult to drip-feed that into the minds of the staff. But we are aware, and we take it on board and are actually quite proactive about trying to respond”. (Physiotherapy Manager, Duncan).*

6.43 This point was echoed by another manager;

*“Well there are so many of them ... We have challenges in extrapolating ... the real relevance is how do we deliver ... we have to keep reminding our staff it’s not anything new, it’s just a different way. ...So I think one of the challenges is the timing of some of these coming out. I think joint overviews are going to be a bit of a help. We’re responsible for extracting from the plethora some of the main themes. Every one I have picked up recently is about how we consult with children.” (SLT Manager, Macbeth)*

6.44 Participants in one site noted 2 measures available in England which they thought could be usefully adopted in Scotland: ring-fenced money for the Every Disabled Child Matters campaign; and central government funding for short-term home based respite care for carers in crisis or emergency situations in every council.

The fact that ASL was law was seen to have advantages;

*“When they move to school age, they’ve got ASL as a framework to move into, and the two [early intervention and ASL] fit into each other. Early days for ASL going in right direction, though ASL Act maybe not as robust as people thought it was going to be” (Paediatric physiotherapist, Banquo),*

and disadvantages;

*“... the introduction of the ASL Act – that’s been a thorn in our side as well because they keep saying to us, well we’ve got the legislation - this, this, and this must be done” (Lead Officer, MacDuff).*

6.45 In this case, the frustration seemed mainly to stem from the fact that the coordinated support plan, required by the ASL Act for children with long-term multiple and complex needs, focused on the child’s educational needs within the school setting, and did not address the family or the environment, which was a major component of the nursing and allied health professionals’ remit.

6.46 At the time of this project, the implementation of the Community Health Nursing Review was underway, and elicited mixed views from participants, ranging from

apprehension, constructive criticism and anticipation. Two sites in this study, Duncan and MacDuff, were development sites for the implementation of the findings from the review. One manager felt that it was a rushed piece of work, but was something they were going to have to live with. With regard to being able to anticipate how it might affect their own service provision, managers were not clear:

*“... the difficulty is none of us can fully understand what the model is going to look like, and what it’s going to look like ... for children with complex needs” (Manager, Duncan).*

6.47 Another commented that there was no mention of either the CCN or public health nurse roles, and expressed concern about who would support families with children with complex needs in the future. Currently, it was often difficult to gain the support of DNs for families as they generally did not have paediatric qualification or experience.

6.48 One participant was concerned that children were not highlighted, and felt that despite her colleagues having contributed to the consultation process, their views had not been taken on board.

*“I’ve seen the job description of the CHN – I think there’s one mention of child in the whole 10 page document. A lot of us in the hospital gave comments back on the review, and when the final thing came out, there wasn’t any change. It seems to be your comments aren’t really listened to” (CCN, Banquo).*

6.49 The current climate was deemed to be challenging for managers as the nursing profession awaited a redesigning or refining of service provision within the community, the Community Health Nursing Review, and the consequential impact it will have on AHPs. There was a degree of uncertainty with regard to what it would actually mean in practice.

*“...I think it’s fair to say, in general, there is an anxiety, and the resistance ... is about anxiety and fear, lack of skills and the implications of all of this ... what support structures are there going to be across the piece? (Service Manager, MacDuff).*

6.50 However, one participant felt that the Review could have benefits, in that it would highlight that there are children in the community (especially those with complex needs) who are part of a family unit who may require care from the ‘cradle to the grave’ (Senior Nurse, Banquo).

### **Adherence to clinical governance**

6.51 Managers within all regions cited several examples of ways in which clinical governance was communicated to staff, and was being upheld. It was felt that clinical governance and standards of care had received a much higher focus over the past 18 months, and this was welcomed. Both MacDuff and Duncan mentioned various audits being conducted, such as observation audits, patient satisfaction audits, audits of clinical care and around record keeping, thus providing them with quality indicators of the service.

6.52 Respondents to the questionnaire mentioned a variety of means that were available to support their adherence to clinical governance. Clinical effectiveness/governance teams were listed most frequently (a Nurse Manager in Macbeth mentioned a child health clinical governance group specifically), followed by Risk Assessment/Risk Management, supervision, CPD/PDP, Policy/procedures/, Protocols/Departmental Guidelines, audits, Patient Group Directions, Quality Improvement team, and a Specialist Nurse Forum. Practitioners referred to various opportunities, and mentioned more than one method of communicating information:

*“ ... follow policy /procedures for clinical practice. Audit of various areas. Specialist nurse forum - peer review. Risk assessment where required i.e. covers working with a ventilated child” (CCN, Banquo).*

6.53 Over half of respondents had encountered barriers to adhering to clinical governance. Finding time was the most frequently mentioned barrier, along with money to develop services in line with evidence based practice. Other barriers mentioned frequently related to staffing numbers and workload. A Lead Nurse School Nursing (Banquo) reported that one problem was the lack of capacity, for example, one city, with a CYP population of 23,000 was supported by 11.23 whole time equivalent school nurses. A clinical nurse manager in Duncan mentioned lone working, recruitment and retention difficulties, and access to IT as factors related to quality assurance standards.

6.54 Staff were not always confident regarding their level of current knowledge in relation to policies and best practice statements. This was thought to impact on and could be a potential barrier in adhering to clinical governance. One physiotherapist in Macbeth felt that there were different policies within health and education, while a Nurse Manager in the same region found that consultants did not always agree with guidelines, best practice statements etc. Both Nurses and AHPs commented on the absence of robust evidence to encourage change of practice and the lack of evidence to support specific interventions.

## Key Points

- Children and young people with complex needs commonly had contact with a very wide range of practitioners of one sort or another. Unless managed carefully, this could lead to a considerable degree of duplication in terms of record keeping. This had the potential to be inefficient and time consuming, and create potential risk in terms of safe case management. One way of addressing this issue was the use of joint record keeping within and across services. Although respondents were aware of this, joint assessment protocols and record sharing was still in its infancy.
- Geographical challenges continued to present themselves in terms of information sharing and joint working. Although these should be relatively easy to overcome using electronic means, the development of trusting relationships between staff were as important as the methods of communications themselves.
- Concern was expressed about communication between management and practitioners delivering services. This was probably inevitable but was exacerbated by the need for open channels of communication across the sector.
- Communication with parents and children and young people was recognised as important in policy documents but proved difficult to implement. Although most respondents expressed an awareness of the benefit of person centred service delivery, there was less clarity as to how this could realistically be achieved.
- One route was advocacy from the voluntary sector such as Children in Scotland but there remained issues around the level of information available for this type of support.
- Policy documents related to service delivery were a key feature of any communication strategies. There was considerable recognition of the value of specific pieces of legislation. The flip side of this was the volume and rapid succession of such initiatives, and the risks these posed in overwhelming those attempting to deliver services.
- The pressure to adapt and remodel services affected the way they were delivered. This in turn put pressure on clinical governance, with practitioners feeling that they had difficulties in meeting targets that were constantly changing.



## **CHAPTER 7      SUMMARY AND MAIN FINDINGS**

### **Introduction**

7.1 This chapter summarises the main findings from the study under the 4 key themes identified above: integration within and between services; service capacity and capability, equity; and communication and information sharing. These themes are all interlinked and inevitably some of the findings overlap. The limitations of the research are examined and, finally, the chapter presents conclusions drawn from the findings.

### **Integration within and between services**

7.2 There was a high level of commitment to joint working both within and across service providers. Professionals felt positive that service providers within health and other agencies were working in partnership. The results suggest that health professionals interacted with a wide range of professionals from other sectors. Numerous voluntary organisations were mentioned as resources for carers of children and young people with complex needs, as well as social work and education services. Typically, the majority of practitioners worked with a variety of client groups and were not working exclusively with children and young people with complex needs. Most delivered services in a variety of community settings such as at home, in schools, nurseries and health centres.

7.3 The issues raised by participants, all of whom worked with children and young people with complex needs, included funding, training, recruitment and retention. Participant raised issues regarding the specialist knowledge and expertise required related to paediatrics, child development, parenting and family health, and children and young people's health care in general. An assigned key worker was identified as the preferred approach to providing a participatory, continuous and consistent quality of care. A key worker need not be a nurse or an AHP and could be selected by the parent and child or young person, based on a set of agreed criteria. The need to acknowledge differing professional ideologies, whilst aiming for clear, shared goals, was paramount, and challenging.

7.4 Although partnership working was endorsed by all staff, there was a need for more leadership in the implementation of joint working practices. The implications of the transfer and allocation of resources from acute to community settings posed a continual challenge. Responses to policy implementation created a cultural shift in the delivery of health care for staff, raising the need to distribute existing resources and funding, ensuring quality services were delivered to the right people, at the right time. To support this, there was evidence that practitioners were already using, or were moving towards, a person centred model of care, with the child and the family at the centre. This raised issues related to organisational infrastructures across health, social care and educational sectors. Support for strategic management to address resource implications, such as funding, improving options for staff cover, and education was required. Partnership working involves shared understanding to ensure true collaboration and the development of an infrastructure to assure a high quality of care to these vulnerable children, young people and their families. There was clear evidence that this was happening at a practice level, despite barriers created by diverse approaches to service provision.

## **Service capacity and capability**

7.5 The perceived lack of capacity generally and of suitably qualified staff in particular was a recurring theme throughout this project. Services faced problems in the recruitment and retention of staff in both community nursing and the allied health professions. Barriers to attending education and training were mentioned and included finance and funding, finding the time to attend, “backfill” support to allow staff to attend, distance and travelling to the location of training.

7.6 Particular concerns were expressed some respondents about the level of paediatric experience available in the workforce and the assumption that skills were transferable across all age ranges and groups of professionals. Some respondents also felt that a highly specialised skill set was necessary to deal with the many and diverse aspects of care required by those with complex needs. This is also potentially at odds with the many differing professional competency frameworks currently in operation. Although continuing professional development was working well in some areas, for example the interagency training for CAMHS staff in Duncan, this was not always the case. Concern was also expressed regarding individual practitioners being responsible for their own professional education and training; which could contribute to a haphazard model of service delivery. One suggestion put forward was for a bank of trained staff, coordinated at health board level, who would be able to provide specialist, flexible, services and expert input as and when appropriate. This could be an alternative, and/or complementary to the current system where it was often assumed that the requisite level of expertise was held locally.

## **Equity of service provision**

7.7 Several recent policy documents have focused on the issue of reducing inequalities, such as Delivering for Health (Scottish Executive 2005b); Visible, Accessible and Integrated Care (Scottish Executive 2006a); GIRFEC (Scottish Executive 2006c); and Delivering a Healthy Future (Scottish Executive 2007). The present research suggests that the delivery of services in the 4 study sites was based on family centred or child centred models of care. A large number of practitioners believed that services could be tailor-made to suit the needs of individual children. However, practitioners were not confident that the needs of children and young people with complex needs in the community were being met, or that the views of this client group were being taken into account, particularly in relation to the planning of service implementation. They also expressed a concern that those parents who had the resources to fight for what was needed could be successful but that this option was not available to all. This may be especially important where there is a series of transitions and negotiations that need to be taken into consideration as the children shift between hospital, home and back again across childhood.

7.8 The health professionals indicated that services were affected by a lack of resources and funding, especially for respite care and for children with life limiting illnesses, and there were gaps in provision during the transitional stage from child to adult services. Similarly, concerns were expressed about inequity of service delivery, discharge planning and the challenges of managing transitions between hospital and community and between schools. A number of specific gaps in service provision have been identified, especially around respite and palliative care, which are both of central importance to a person centred model of provision for those with complex needs. In general, issues relating to age appropriate services were highlighted at particular transition points. The “in-betweenagers”, as a population of

adolescents and young people, were felt in particular to be disadvantaged, therefore care should be provided according to chronological stage, developmental milestones, and complexity of need, acknowledging provision of age-related services.

## **Communication and information**

7.9 Although our respondents were aware of the need for joint assessment, joint assessment protocols and record sharing was still in its infancy. Information technology was not consistently available throughout Scotland to support a shared record for children and young people with complex needs which was also accessible by health, education and social care providers.

7.10 Participants stated clearly that it was critical for them to be able to share information effectively both within and across services, in order to provide a “joined up” approach to service delivery. The research indicated progress in some regions and across some services, but there were inconsistencies. Geographical challenges will continue, although these should not be insurmountable, with increased usage of advanced technology.

7.11 Frontline practitioners were fairly positive about communication issues. Many stated that it was possible to communicate with both higher levels of management and partner agencies, in relation to service provision and development. However, some grass roots practitioners expressed their frustration that communication was not always a two way process. This raised the issue of vertical and horizontal transmission of information within professions, between professional groups, and across multiple service providers.

7.12 Practitioners stated they were not always confident regarding their level of current knowledge in relation to policies and evidence based practice. This was thought to impact on, and could act as a potential barrier to, adhering to clinical governance.

## **Limitations to the interpretation of the report findings**

7.14 The low return rate for the questionnaire means that the findings of this study should be treated with caution. Possible explanations for the low response include the possible overload for staff with other research projects and reviews, staff time constraints, and the fact that the questionnaire was sent out during the summer holiday period. Although it is possible that those who were less motivated to respond would have had a different view point about services, we concluded that that this did not have a major impact on the findings. We did encounter a very wide range of responses amongst those who did respond and these were explored further in the focus groups.

7.15 Underlying the practice of many of the practitioners to whom we spoke was an assumption about the importance of the role played by the families and children. The views of parents and children were not sought in this study and it was not therefore possible to make a judgement about whether parents and young people perceived a given service to be centred around their needs and wishes. Further work would be merited in this area.

## Conclusions

7.16 It should be noted that the fieldwork for this study was conducted between July and September 2007 and services for CAYP with complex needs have moved on since this time. For example, NHS Boards are working towards implementing the recommendations in the Scottish Government guidance *Delivering a Healthy Future – An Action Framework for Children and Young People’s Health in Scotland* which was issued in February 2007. The *Action Framework* recommends that children, young people and their families should receive appropriate information about their care plan and be involved in its development: that a care pathway approach, including discharge and transition should be developed: that systems should be in place to provide each child with a named professional (key worker) and a named consultant paediatrician or equivalent to coordinate all their health care needs: and that children and young people with complex needs must have access to a formal multi-agency annual review with regular assessment and evaluation.

7.17 There has also been considerable work on developing a National Managed Clinical Network (NMCN) for children with exceptional healthcare needs. The aim of the NMCN is to ensure that a package of care, tailored to specific requirements, is designed, and its delivery co-ordinated effectively, to meet the needs of children with exceptional healthcare needs.

7.18 The definition of “complex needs” adopted, whether by policy makers, researchers or practitioners, inevitably makes a difference to the way that services are planned; Definitions of complex needs can be focused on clinical diagnoses (cerebral palsy, muscular dystrophy), medically defined need such as the administration of a specific medication or the introduction of a specific procedure (i.e. intubation or ventilation) or the number of professionals involved. Each approach is likely to lead to the services developing in different ways.

7.19 It is recognised that children and young people in the 21<sup>st</sup> century require more specifically tailor-made provision for their health needs. *Ad hoc* and inconsistent “age banding” (with cut-off ages ranging from 16 to 21 years) can often lead to unsuitable referral to adult services and a reduced degree of choice of services. This inevitably affects transition arrangements across sectors and between different services. Constraints within children’s services, and the inappropriateness of adult services, were perceived to be problematic in responding to the complex needs of this particular group of children and young people.

7.20 Whichever approach is adopted, providing services for children and young people with complex needs demands a high level of interaction between practitioners across different service sectors. Furthermore, a careful balance needs to be struck between general and specific expertise amongst the trained and untrained staff who provide the services. Service providers need to demonstrate that their services are delivered in full consultation with the family and, where appropriate, with the young person.

7.21 Young people, alongside families and carers, must become involved as active participants in the evaluation of relevant policy implementation processes and outcome measures. Within community settings, this encompasses the ethos of “social inclusion” and could be strengthened by adopting a community development approach, i.e. “bottom up”. There is a clear need for the voice of children and young people as service users to be heard, ensuring advocacy by an open, supportive dialogue to develop a needs-led approach to care and service provision.

7.22 The combined demands of equity and specialisation require education and training for all those involved in providing services to the child and young person with complex needs. There should be a requirement that all NAHPs have paediatric knowledge and experience prior to taking up a post. There is a clear need for nurses and allied health professionals to strengthen child health and family health knowledge to ensure the best support for opportunistic and direct health and social care to achieve the best outcomes. These practitioners must also have an underpinning knowledge of community health, in order to cope with the demands of working in a community setting with children with complex needs. In addition, it is critical that health care assistants and support workers, who contribute to service provision, have sufficient skills to take on the roles that are delegated to them. This relates directly to concerns about patient safety and good practice.

7.23 These challenges are shared across the globe and especially where there are socialised models of health care. This project provides a snapshot of different services as increasing numbers of children are managed in the community and routine care is delegated to paraprofessional staff. This is evident where there are a wide range of competing policy initiatives, impacting on transition stages/phases, e.g. acute to community, child to adult services. Children and young people with complex needs make complex demands on services and this, in turn, challenges those services to provide high quality, integrated care. Such services are underpinned by a number of well defined principles, namely protection, participation and provision, as emphasised in the UN Convention on the Rights of the Child (1989), and later reflected in the Children (Scotland) Act 1995. We would conclude that service provision for this specific population of children and young people can reasonably be considered as a test of whether services are truly integrated.

7.24 It is clear that the models of service delivery identified in the literature and the various permutations of them, currently co-exist across Scotland. There has been little comparative evaluative work across the sector or in the international literature. This may be due to the complexity of the issues in terms of the interventions implemented and the outcomes to be measured. There is a need for further research comparing different models of service provision using appropriate outcomes and, where relevant, assessing the cost and value of different models to both service users and providers. Additionally, the NES Corporate Plan 2007-2008, 'Educational Solutions for Workforce Development' (NES 2007a), promotes capacity for research related to children's nursing by compiling a database of past and current research, identifying research themes, and informing an agenda for nursing and allied health professions in this area.. A more cohesive and co-ordinated quality of service provision could be supported by promoting locally based, multidisciplinary development, whereby practitioners increase experience and expertise through research and evidence based learning, sharing examples of best practice.

7.25 Finally, much is already known about what is needed for children and young people with complex needs, and considerable resources are already in place to meet those needs. Nevertheless, that knowledge does not always translate into practice and there is much more that needs to be done to improve services for this population. Participants were overwhelmingly positive about the service that they provided to individuals but felt they could do more if the services were provided in a consistent and comprehensive manner, specifically planned around the children and their families.

## ANNEX 1                      REVIEW OF THE LITERATURE

### 1.            Introduction

This chapter summarises the international literature related to the provision of services for children and young people with complex needs in community settings. The review methodology is presented below, together with summary details of the key literature included in the review (Annex 2). These tables enable the reader to look in more detail at the substance of some of the papers cited in the text. A full list of references is provided in Annex 3.

#### *1.1        Methodology for the review of the literature*

The search strategy incorporated systematic searching of online databases, namely Cinahl, PsycInfo, Medline, BNI, Scopus, and Web of Science. Inclusion criteria were publications from 2000 onwards and in English language. In addition, hand searching of relevant journals, and online searching of professional health and social care websites and organisations was carried out. During preliminary searching, a combination of thesaurus terms and free text terms were entered into the above bibliographic databases. Initial searching identified over 650 publications that were of potential relevance to the literature review. In order to obtain articles of the highest relevance, the following additional exclusion criteria were applied: articles where the sample or intervention was not at service or team level (e.g. individual case study); was hospital based; did not provide model of care; did not provide data or was speculative; and/or where complex or special needs were not described. A total of approximately 90 articles were obtained.

Key search words: Child, infant, adolescen\*, nurs\*, allied health profession\*, high support needs, complex needs, multiple needs, special needs, community, service provision, home.

An example of electronic search strategy in online bibliographic databases is given below, where the following free text (TX) and thesaurus terms (MH) were entered into the CINAHL search engine.

- #1        Child in MH
- #2        Adolescen\* in MH
- #3        Infant in MH
- #4        #1 or #2 or #3
- #5        Nurs\* in MH
- #6        Allied Health Profession\* in MH
- #7        #5 or #6
- #8        complex needs in TX
- #9        multiple needs in TX
- #10      special needs in TX
- #11      high support needs in TX
- #12      service provision in TX
- #13      community in TX
- #14      Home in TX
- #15      #10 or #11 or #12 or #13 or #14 or #15 or #16
- #16      #4 and #7 and #15

Policy and strategy documents were added into Reference Manager, but were not included in the total number of articles utilised in the literature review.

It should be stressed the research team sourced only literature published in English. As far as possible, specific aspects of community services, such as child mental health services or services for children with special educational needs, were covered only when they related specifically to children with complex needs. However, the distinction between relatively simple and complex needs was often difficult to draw and was not always the focus of the reports cited. A number of terms were used in the literature for “complex needs” and, while we have retained the operational definition included in Chapter 1 of the report, it was not always possible to be sure that the terminology mapped onto the studies reviewed. The review identified literature describing specific services rather than the policy underpinning those services.

The review presents relevant information and findings from the academic literature in this area, but does not present a comprehensive international picture of NAHP services for CYP with complex needs in the community. The review begins with an overview of the international literature before examining in more detail the services in the UK in general and in Scotland in particular, and concludes with a summary of the key issues related to provision of services. A number of gaps raised in the evidence base are then identified.

## **2. The international picture**

### *2.1 The United States of America*

The term used in the United States is ‘children with special health care needs’ (CSHCN) (Peters, 2005) and, for planning and policy purposes, the definition adopted by the Maternal and Child Health Bureau (MCHB) is the one used throughout the United States. CSHCN are “*those children who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally*”(McPherson et al, 1998, p. 138).

Within the USA, there are an estimated 9.3 million children under 18 years of age, of whom nearly 13 percent have special health care needs, such that one in five households with children include a child with special health care needs (US Department of Health and Human Services, 2004). A comparison of this figure with that in the introduction to this report suggests that the definition used is much more all-encompassing than the use of the term “complex needs” in the UK. Access to care provision in the US is via health insurance, which might be provided privately, or through public programmes. The Children’s Health Insurance Program (CHIP) has begun to address the issues of children who are uninsured, but the problem of underinsurance remains a major concern for these children and their families (MCHB, 2001). Over the past two decades, a new model of health care for children with special health care needs has emerged, aimed to counteract some of the barriers that exist in the existing medical approach to care. Much of the credit for this model is due to numerous partnerships among federal and state governments, families, health professionals who care for children, communities, and professional and voluntary organizations at the local and national level.

It is recognised that children and young people with special health needs do best if they have access to comprehensive, family-centred, culturally competent, coordinated and fully inclusive services at the community level (Feeg, 2001). In order to achieve this, a new initiative, ‘The 2010 Express’ was launched by the Maternal and Child Health Bureau (2001),

in collaboration with many private and public sector partners, to be implemented in conjunction with 'Healthy People 2010' (US Department of Health and Human Services, 2000). The '2010 Express' presents a blueprint for the organisation, financing and delivery of services for children and young people with special health needs and their families. It sets out a framework for effective partnerships and is designed to provide practical, achievable steps toward meeting the following six core goals by the year 2010:

- Families of children with special health care needs will be partners in decision making at all levels and will be satisfied with the services they receive;
- All children with special health care needs will receive coordinated, ongoing comprehensive care within a medical home;
- All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need;
- All children will be screened early and continuously for special health care needs;
- Community-based service systems will be organized so that families can use them easily; and
- All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

(MCHB, 2001).

The service is delivered by teams of professionals who establish a virtual 'medical home'. This is a broad, inclusive concept, whose goal is to provide a source of ongoing routine health care in the child's community, where providers and families work as partners to meet the needs of the children and families, which are central to the medical home approach. The medical home assists in the early identification of special health care needs; provides ongoing primary care; and coordinates with a broad range of other specialty, ancillary, and related services. Evaluations of medical home projects have shown positive outcomes (e.g. Palfrey et al, 2004; Farmer et al, 2005; Oneufer et al, 2006). However, access to a medical home has been shown to be affected by income, mother's level of education, and the functional status of the child (Nageswaran & Farel, 2007). Many families of children with complex health care needs face financial and employment problems, and are less likely to have a medical home, adequate insurance and access to health care services (Viner-Brown & Kim, 2005).

## 2.2 *Australia*

While not specifically addressing the needs of children and young people with complex needs, recent national child health policy has promoted partnership working at national, state, regional and local levels and between health and other sectors e.g. to develop and promote funding models that recognise and enable integrated, evidence-based, collaborative approaches to children's health, and to engage with children in planning and policy development (National Public Health Strategic Framework for Children 2005–2008). Models of care are rarely described but family centred practice is seen as an increasingly important principle in the provision of services to children and families (e.g. Moore & Larkin, 2005). Family centred care has been picked up by both occupational therapists (Hanna & Rodger, 2002) and physiotherapists (Litchfield & MacDougall, 2002), although concern has been expressed that such models which require time for family consultation and negotiation may decrease the level of "hands on" treatment time. This approach can also challenge professional autonomy because the therapist may no longer be considered the expert who



diagnoses and then provides therapy, but as a resource to a family whose knowledge is to be respected (Litchfield & MacDougall, 2002).

In Australia, a country very much defined by remote populations, another significant development is the role of the multi-disciplinary Therapy Assistant (TA) which was developed in response to the increasing demand for service. This role incorporates a number of disciplines such as physiotherapy, occupational therapy (OT) and speech and language therapy. Therapy assistants provide ongoing management of clients in between allied health professional visits, give continuity of service during AHP staff turnover, and build skills within the community. The typical TA works part time in a community setting delivering speech pathology, physiotherapy, and/or OT programmes to school aged children with disabilities, e.g. in schools or in client homes. Training and standards of practice are important issues and recent literature has discussed ways to improve supervision, particularly in rural contexts (Lin & Goodale, 2006).

Another feature of the provision in Australia is the use of e-health and video conferencing. The latter is used widely in Australia as a medium for health care, particularly for those living in remote areas. One example, in New South Wales, is the Child and Adult Psychiatric Telemedicine Outreach Service (CAPTOS), a tele-nursing project, which links ward nurses to CAPTOS and local community teams, providing clinical consultancy on nursing and interdisciplinary issues, and locally based professional development. Nurses are supported by means of site visits, videoconferencing sessions, an interactive website and sabbatical opportunities (Rosina et al, 2002). Underpinning the Health Service Model for a community, tele-health works with existing services to enhance the nursing care of young people with a complex mix of psychological and physical health problems, regardless of where they live.

### *2.3 Canada*

National policies for children with complex needs in Canada are difficult to access. The Children and Youth Home Care Network has called for "governments at all levels to assign higher priority to developing coherent policies for children with special needs and families, particularly in the home and community". It stressed that service integration and coordination would not improve until there were fundamental changes at the broader system level (CYHN, 2002). Regional policies suggest that authorities are seeking to collaborate with other agencies to plan services for this client group, "an integrated, cross-ministry system of supports and services can assist in optimizing the well-being of children and youth with special and complex needs" (Alberta Children and Youth Initiative Partners, 2003). Target outcomes in Alberta include: the appropriate and effective sharing of information for integrated planning; coordinated long-term service plans; integrated, coordinated and consistent service delivery; families who are well-informed and involved; families who are satisfied with access to required services, and in addition, support the way services are provided, and the quality of services they receive.

An example of improved information sharing was reported by Young et al (2004). As part of the development of a new protocol to address principles of shared accountability within a school setting, a communication log was set up. Prior to the introduction of the communication log, nurses had to phone parents on an as-needed basis to communicate issues, such as the need to replace equipment and requests for more feeding supplies.

However, it was often difficult to contact parents, resulting in messages left on answering machines or no contact at all. It was also problematic for nurses to receive an update about a child's status during the previous night, if they suffered from seizures for example. The communication log was created to address these difficulties. It was clearly labelled, and kept in a large envelope marked confidential, and was sent home daily in the child's backpack. This allowed nursing staff to communicate daily and to address a broad range of issues, from the child's developmental successes to the number and quantity of feeds. Parents were also able to respond, and ask questions about their child's health. This communication allowed the nursing staff to expand their care giving beyond the child to include parents and/or primary caregivers. It also encouraged nursing staff and parents to exchange journals, newspaper articles and photographs, and nursing staff reported an improved therapeutic relationship that included parents.

Within health, national policy in Canada is shaped by growing concerns about access to existing services, particularly in rural and remote areas, limited progress in advancing primary health care reforms and growing waiting lists (Romanow, 2002a). Home care is one of the fastest growing components of the health care system, although it is not currently considered a medically necessary service under the Canada Health Act. There are wide variations across the country in terms of types of home care services covered, because of differences in provincial and territorial budgets, as well as variations in regional priorities and the evolution of local health programmes. Additionally, in some cases, the basic infrastructure (e.g. visiting nurses) to support home care is uneven or non-existent (Romanow, 2002b). The need for greater integration is recognized by provincial and territorial Premiers who are currently considering approaches that will improve the continuity of care for home care clients by enhancing coordination and linkages between home care providers and other health care providers (in acute care, primary care and long-term care sectors) (Romanow, 2002a).

As in Australia, the use of advanced technology is being encouraged as a solution to some healthcare problems. At the meeting of the territorial Premiers in January 2002, it was agreed to identify approaches to facilitate broader adoption of technology including tele-health technologies for use in home and community settings. An example of a tele-health initiative is Tele-HomeCare (THC), a hospital-at-home service in Canada. This used telephone technologies, such as vital signs monitors and two way video equipment, to facilitate the transition stage between discharge from hospital to care at home for children with complex health needs. Interviews with families participating in THC explored the impact of the service on the child and on the family (Young et al, 2006a). The service allowed children to be discharged from the hospital earlier than usual, thus allowing the family to be reunited at home. The use of the technology was repeatedly found to be an important resource to the parent in providing professional support and a sense of security during the transitional phase.

## *2.4 New Zealand*

In New Zealand, the term used is children and young people with 'high and complex' needs, which are defined as:

- behaviours that cause a risk to the child or young person, or others
- needs so complex, or mixed up, that they cannot be met effectively by the usual local services

- ongoing and persistent needs that will take time to address
- intensive interventions are needed to make an improvement
- behaviours that place caregivers under extreme stress so they feel unable to provide care. (<http://www.hcn.govt.nz/factsheets/strategy.htm>)

It is recognised that the needs of some children and young people are so complicated that they cannot be met by just one health, education or social service agency. Thus, the Children and Young People with High and Complex Needs Intersectoral Strategy was developed in New Zealand as a joint initiative of the Ministries of Health, Education and Social Development and the former Department of Child, Youth and Family Services (2001). It describes a way of working together across agencies and professional boundaries to improve outcomes for children and young people by:

- fostering collaboration between agencies
- improving service delivery effectiveness
- building agency capability.

The strategy was developed as a response to the government's recognition that sometimes local agencies lacked the resources and mechanisms to be able to meet the needs of children and young people with high and complex needs. It wanted to meet these needs and provide a coordinated response. The focus of the strategy is on short-term, intensive interventions aimed at making significant improvements. At the heart of the strategy is the belief that effective collaboration makes a positive and essential difference to the lives of children and young people. When needs are high and complex and two or more government agencies are involved, it makes sense to work together. This means that, for every child or young person supported by High and Complex Needs, there will be an interagency team of professionals and family working together on one plan to improve their wellbeing. This plan is supported by at least two local managers, and one agency takes the lead in managing any funding that is approved.

## 2.5 *Eire*

The National Children's Strategy, 'Our children, their lives' was launched by the Department of Health and Children in 2000. The strategy is a ten year plan of action which calls on the statutory agencies, the voluntary sector and local communities to work together to improve the quality of all children's lives. It includes a range of actions across such areas as eliminating child poverty, ensuring children have access to play and recreation facilities and giving children a voice so that their views are considered in decisions that affect them. The Strategy recognises the central role of families in providing for children.

In Eire, children with special or complex needs are perceived as those with a life-limiting condition. This is defined as any condition in a child where there is no reasonable hope of cure and from which the child or young adult will die, thus requiring intermittent involvement before needing active continuous care. There are an estimated 1,369 children living with a life-limiting condition in Ireland (Department of Health and Children, 2005). A recent assessment of palliative care needs for children found that there was a deficit in the existing services available for these children and their families, particularly in terms of supporting families to provide care required at home (Department of Health and Children, 2005). It also recommended that further education was required by healthcare professionals.

An educational framework to support excellence in practice, entitled “Caring for the Child with Life-Limiting Conditions”, has been developed and its implementation is being jointly funded by the Health Service Executive and the Irish Hospice Foundation. As part of this initiative, 400 nurses and midwives were invited to take part in extensive programme in 2007 to raise their awareness and understanding of children with life limiting conditions and their families.

One study in Eire explored the views of mothers caring for young children with life-limiting conditions, regarding the usefulness of the financial, practical, and emotional supports being offered to them, and their suggestions for service improvements (Redmond & Richardson, 2003). Much of the stress experienced was related to the service response offered, which related to inadequate, uncoordinated and hard-to access services. The findings of the study indicated that the administrative and bureaucratic regulations underpinning eligibility for service provision causes frustration and resentment. Perspectives from the findings also give valuable insights into how parents who are functioning well in difficult caring roles need services that understand and fully appreciate them, in the broadest dimensions of their parenting. Unless this is acknowledged, those who design and deliver services will underestimate a potent source of knowledge and expertise. Research has noted that where families are more in control of the management of their support services, there is an association with increased service satisfaction, increased community involvement of individuals with intellectual disability, and increased employment of mothers (Caldwell and Heller, 2003 cited in Redmond & Richardson, 2003).

### **3. The UK Context**

Issues pertaining to children and young people with complex needs are visible in many of the recent policy documents related to the overall care of children throughout the UK. Underpinning service delivery are broad, widely held assumptions about social inclusion, such as “The Salamanca Statement and Framework for Action on Special Needs Education” UNESCO (1994) and the “UN Convention on the Rights of The Child” (UN, 1989). At a generic level we see this in documents such as the “National Services Framework for Children” (DoH, 2004a) and “Every Child Matters” (Department for Education and Skills, 2003) in England, and in Northern Ireland, in “A Healthier Future, a 20 year strategy” (DHSSPS 2004). More specific requirements have been laid down in the Additional Support for Learning Legislation (2004), and in documents related to the development of the children’s workforce - “Framework for Developing Nursing Roles” (Scottish Executive, 2005a) and “Nursing: Towards 2015” (Longley et al, 2007).

For the child with complex needs, there are a number of documents which recommend specific aspects of service delivery to support the child and family in school and the home, whilst ensuring links are developed into secondary and tertiary care when required (Education (Additional Support for Learning) (Scotland) Act (Scottish Parliament 2004). For example, the Primary Care Strategy Framework in “Caring for People beyond Tomorrow” (DHSSPS 2005); “Partnerships in Caring ... Standards for Service (DHSSPS, 2000); and “Standards and Guidance for Promoting Collaborative Working to Support Children with Special Needs” (Department of Education, ETI & DHSSPS, 2006), contain recommendations to this effect.

#### **4. The Scottish context**

In Scotland, themes of partnership and collaboration are reflected in a series of documents, such as “Delivering for Health” (Scottish Executive, 2005b); “Visible, Accessible and Integrated Care” (Scottish Executive, 2006a); “Delivering Care, Enabling Health” (Scottish Executive, 2006b) and “Getting it Right for Every Child” (Scottish Executive, 2006c). The appointment of a Scottish Commissioner for Children and Young People in 2004, and the subsequent establishment, in conjunction with NHS Health Scotland, of a Young People’s Health Advisory Group, has provided an opportunity for the views of children and young people to be listened to more closely. The need to engage children and young people, encourage involvement and participation in seeking perceptions of service provision and service providers is a fundamental requirement of the workforce. Empowering and enabling children and young people in self-care and responsibility requires recognition of advocacy roles and authentic and genuine strategies to seek the views and expectations of children and young people.

Recent extensive changes within the NHS, such as Agenda for Change (DoH, 2004b), have had a major impact on all staff. Specifically, in Scotland, other changes such as imminent restructuring of community health nursing (Scottish Executive, 2006a), the new joint strategy for nursing and AHPs (Scottish Executive, 2006b), and recent reform of children’s services (Scottish Executive, 2006c), will have an impact on the work practices of all those in the nursing and allied health workforce working with children and young people in the community. Although these policies will have a direct impact on children’s services there is little which specifically addresses the needs of children and young people with complex needs (NES, 2007a).

Cross-boundary working between health, education and social services, is a priority policy objective, providing the foundation for high quality service provision across child health services, and is essential for an effective system to protect and support children and young people with health needs. The Scottish Executive (2007a) has emphasised the importance of providing care locally, and has required that services be provided in a more integrated way. This was reinforced by the launch of “Integrated Children’s Services Planning Guidance” (Scottish Executive, 2005d). To support implementation of these plans (Scottish Executive 2006e), the Scottish Executive has recently published an Action Framework, within which it outlines three key milestones for improvements in health outcomes and health services for children and young people with complex needs (Scottish Executive, 2007b). These are that CYP with complex needs, as identified by the integrated shared assessment process, have a named ‘key worker’; receive an effective multi-disciplinary assessment within 10 weeks; and have an annual multi-agency review of their care needs . These milestones are to be in place by 2008.

The emphasis on local care provision had previously been highlighted in the “Additional Support for Learning Act (Scotland) 2004”, the development and implementation guidance in “Getting it Right for Every Child” (Scottish Executive, 2006c), and six months later, in another document “Getting it Right for Every Child: Draft Children’s Services (Scotland) Bill Consultation” (Scottish Executive, 2006d). All of the above were intended to impact directly on the provision of primary care and community based services, with the expectation that statutory duties would be placed on all agencies that plan, commission, and provide services to meet identified need. The planned implementation programme emphasises issues requiring action, such as resources (human and financial), data protection, confidentiality, governance,

accountability and contractual issues. Additionally, findings from the National Delivery Plan for Children and Young People's Specialist Services in Scotland Consultation (Scottish Government, 2008) will similarly be acted upon.

High quality provision for children and young people with complex needs in remote and rural areas such as the Western Isles, Orkney, Shetland and rural Highland inevitably represent a challenge for those developing services. There are currently a number of different methods of providing paediatric services, and gaps exist particularly in community provision (Oates, 2005). The systems in place in the three Island Health Boards in Scotland are as follows.

In Shetland, community child health services consist of a community children's nurse, a learning disabilities nurse (who also provides adult coverage), two physiotherapists, an occupational therapist, and three speech and language therapists (also covering adults). In addition, there are 13 health visitors, a school nurse, a Registered Sick Children's Nurse (available during working hours only) and a CAHMS paediatric nurse. Prior to the provision of a community children's nurse in Shetland, children with complex health needs had to travel to Aberdeen for hospital treatment (Crouch, 2005). The CCN can now provide care for chronically ill children, with conditions such as diabetes, and post operative children in their own homes. The CCN provides training and support for DNs and HVs, as well as other professionals in education and social care. Training for parents and carers is also provided, for example, through demonstrating care techniques on a lifelike training mannequin.

Orkney currently has 5 SLTs, 2 physiotherapists, one OT, 3 school nurses, a team of community nurses and 5 HVs. There is also a community psychiatric nurse for children, funded for 2 years by the Changing Children's Services Fund. Community health staff feel that coordination of child health care is poor (Oates 2005). There are no children's trained nurses or a resident paediatrician. A need has also been identified for a named professional whom staff can approach for a medical opinion or for parents to consult about their concerns.

The Western Isles has a Consultant Paediatrician post, which is filled by a locum and based in Lewis. There is a paediatric physiotherapist, 2 OTs (with a caseload of 40 children and a waiting list), 4.2 wte paediatric SLTs, 9 HVs and 2 school nurses. The Western Isles children's services are being redesigned, with 3 models under consideration. The first model allows for a Consultant-led Community Child Health service with unscheduled care provided by a non-training grade paediatrician. This individual would require clinical supervision from the mainland. In the second model, the paediatrician is supplemented by the provision of unscheduled care of children and neonates by GPs, with intermittent support from the mainland. It is likely that more children would be flown to the mainland for in-patient care. The third and preferred model is for a Consultant Paediatrician to provide a clinical lead to an integrated Child Health Service (i.e. integration of hospital and community services as a single service). The paediatrician would be supported by a multidisciplinary team in the community, consisting of public health nurses, family health nurses, a specialist nurse for child protection, specialist practice nurses, staff from National Children's Homes and GPs. Allied health professionals would work both within the hospital and community setting. (Oates, 2005, Appendix 5).

Oates' (2005) report recommended that discharge planning for children with complex needs who are being discharged back to remote and rural areas requires improved and careful planning as there are no community children's nurses (with the exception of Shetland) and

sourcing equipment or unusual drugs or feeds can take time. Training for the community nurses in, for example, tube feeding, is likely to be required.

## **5. Models of service delivery**

A number of different models for the provision of services to children with complex needs are described in the international literature. Many of these have common features but vary according to the context or to the types of professionals that are available in a given service. Rather than list them all, we have opted to describe the 3 most common types of service delivery, and then provide a set of key factors which are often included in the description of the services concerned, and some of which overlap across models.

The 3 types of models are as follows :

- The Acute Care Model
- The Community Care Model
- The Child / Family Centred Care Model

The first two are reflected in the two dominant models of paediatric home care identified in a survey of Children's Nursing Services in England conducted by While & Dyson (2000): the hospital outreach model with strong links to the hospital service and the community care model has strong links to primary health care and other local provisions.. The third model represents a development of the other two, as parents become increasingly prominent in the decision making process, and the "care" needed draws as much on educational and social services as it does on health.

### **5.1 Acute Care Model**

The acute services model is based within a local hospital and can contribute to the scope of ambulatory care provision for children and their families. Although care may be provided in the home, the management of the service comes from within a hospital setting. This model may include outreach services, but again the assumption is that the direction of the service comes from the hospital not from the community. Of course, this may be appropriate for children with complex needs when they are initially discharged from their local hospital into the community. Such models rely on generalist nursing staff while others include specialist nurses with expert knowledge of a particular condition such as diabetes, cystic fibrosis, or HIV/AIDS, or who can provide palliative/symptom care, neonatal care, and disability care (Eaton, 2000 & 2001). In some cases they include ambulatory or assessment units, usually hospital based, which allow children to be assessed, treated and observed for a limited period of time with the aim of avoiding admission to hospital. Children who receive this service are often sent home in the evening and may be telephoned or visited the next day by an outreach nurse attached to the unit (Eaton, 2000 & 2001). One example of this type of service is described in the box below:

### Hospital based outreach services

The provision of a community children's nursing service based within a children's ward at a district general hospital in North East Lincolnshire has been described by Coley & Partridge (2002). The service developed in response to changes in the service profile, from a mainly acute but generic caseload, to an increasing number of children with chronic illnesses requiring more specialist input. The skills mix included both generalist and specialist nursing staff, and the team comprised a team leader, F grade nurses, a children's diabetes specialist nurse and a play specialist. Apart from the diabetes nurse, all of the team had a generic caseload, but additionally had an interest in a particular area, e.g. respiratory conditions, special/complex needs. All the nurses in the team were qualified children's nurses and were required to hold or be working towards the BSc Community Nursing (Community Children's Nursing). One gap in the provision of the North East Lincolnshire service was that referrals were only accepted by the team if the child could be safely managed between 9 am and 9 pm as there was no local out of hours service provision. However, the team had the flexibility to provide a 24 hour service for short periods of time in individual cases.

In the UK, there is an increasing interest in the Hospital at Home approach to provision (e.g. Cummings, 2002; Maunder, 2006; Sexton et al, 2005; Hewitt-Taylor, 2004; Glendinning & Kirk, 2000; Noyes et al, 2006). Hospital at home is defined as a service that provides active treatment by health care professionals, in the patient's home, of a condition that otherwise would require acute hospital in-patient care, always for a limited period (Shepperd & Iliffe, 2005). Such a model is often favoured because it is more acceptable to families than those where children are admitted to hospital, and results in considerably less social and family disruption (Davies & Dale, 2003a, b). Davies and Dale (2003a, b) have evaluated a regional hospital at home service, as described in the box below.

### Hospital at Home Service

An acute paediatric hospital-at-home service in Rugby (servicing 14 GP practices covering 21,500 0-16 year olds) was established in 2000 with the aim of preventing the admission to hospital of acutely unwell children. The service is staffed by 4.4 WTE nurses, 7 days per week, 8am-10pm with telephone on-call cover at night. The impact of the Rugby Children's Hospital at Home Nursing service on acute paediatric resource use, and the effect on families and primary care services, was evaluated in a series of papers by Davies & Dale (2003a & 2003b). A study of the staff nurses and managers suggested that the Rugby home care service integrated more closely with the children's community care team, especially for cross-cover, joint training and documentation. Nurses reviewed the service as successful but requested the need for "protected time" for team meetings and communication. Overall, GPs' responses to the service were positive: they found it easy to access, and thought the nurse role was important in relieving parental stress. Some GPs expressed concern over who was clinically responsible for the patient and others recognised the need for improving communication and continuity of care between services.

Another example of an acute services model in the UK is the Ambulatory/Assessment approach. An exemplar is provided by James Cook University Hospital in Middlesbrough. The assessment unit is a designated area adjacent to children's wards and is staffed by nurses



who have no inpatient responsibility. Subsequent to referral, the assessment unit determines whether a child requires admission to hospital, or can be discharged home without further input; see a family doctor; see a specialist nurse; or be given an outpatient appointment. The hospital may provide outreach generalist or specialist services. Specialist nurses within the team include diabetes, asthma, CF, epilepsy and critical care. It was found that community nurses reduced admission to the wards by working with other members in the assessment unit, providing a single point of entry, and bridging the gap between primary and secondary care. The unit appeared to be cost effective and there was evidence of parental satisfaction with the service (Kibirige et al, 2003).

### 5.2 *The Community Care Model*

The community care service model provides a service which is based in the community provided by nursing and other practitioners. Primary care led services within the community may offer ambulatory care for children who are ill and may require hospital care. However, the presumption is that the greater part of the child's management will take place within their community and be carried out by those employed in the community. Again there are a number of examples of different approaches within the model. For example, the Community based approach includes generalist or specialist nurses who are based in a community setting, often a health centre or GP surgery. A modification of this is the District Nursing Service approach, in which children are visited at home by district nurses who do not have a specific children's qualification (Eaton, 2000 & 2001). There is a lack of literature describing the provision for children and young people's care by district nurses. Eaton states that ideally all nurses working with sick children in the community should have both paediatric and community nurse qualifications (2000). One identified weakness is that district nurses are required to treat and support all ages of the population (Eaton, 2001), thus may lack the experience, training and confidence required to treat children with complex health needs (Glendinning & Kirk, 2000).

### 5.3 *The Child/Family Centred Care Model*

The child/family centred care model shifts the emphasis from a service driven by the priorities of those providing the service to the priorities of those receiving it. This principal can be applied to those providing both acute and community services but may be more readily applied to community services which may be less subject to medical priorities. The emphasis here moves beyond the control of specific professional groups or those with a responsibility for delivering individual services to children and to families, and to children and families' own perception of their needs at a given time point. In the Family Care Model, care is provided by the family, in partnership with health professionals. Another approach is the "Team Around the Child" (TAC) (Limbrick, 2001; 2005; 2007). The TAC is a model of service provision in which a range of different practitioners (ideally no more than four or five), who are already working closely with the child and family, agree to meet regularly to share observations, to agree to a joined-up service plan and to review progress. It is a 'virtual' team, and membership and working relationships will vary as the needs of the child and family change. TAC represents a model of collective care, and no one practitioner group is responsible for the care. A key worker, who can be from any of the collaborating services, facilitates each individual team. Another important principle is that parents are equal members of the team. The model is designed to be flexible in order that children's services are able to meet the diverse needs of each and every child in their own individual context, and

has the child's needs very much as its focus. Runciman & McIntosh (2003) evaluated an initiative in Scotland, shown in the box below:

#### The Team around the Child

An intersectoral initiative between health, social and education services in Lanarkshire provided support at home from two experienced children's nurses for parents of children with complex disability (the PATCH project). An independent evaluation of parents and agency members' perceptions of the PATCH service (Runciman & McIntosh, 2003) found that training and partnership elements addressed practical, emotional and social difficulties experienced by families. The freedom to work flexibly (Olsen & Maslin-Prothero, 2001) and to approach agencies directly, and the ability to cut across established organisational structures were significant factors in improving support for families. Key aspects of nursing expertise rested on a range of abilities that would be expected of an experience nurse with specialist knowledge and skills. Appropriate use of knowledge in exercising clinical judgement and decision making, rapid assessment and ability to offer care in crisis, and a range of direct care-giving skills, including technical skills, were highlighted. Effective communication, interpersonal skills, teaching skills, liaison and referral skills were evident. Additional contributions included the ability to work effectively across care settings and agency boundaries, to act as an advocate for parents, and to offer emotional support. Possible outcome indicators for such a service emphasised action that was reactive, proactive, and creative. Knowledge of acute children's health services and of the workings of community agencies allowed the PATCH nurses to work across boundaries, which was contributory to improving the support for families of children with complex needs.

Quilter (2006) gives an example of a Team around the Child service and her experience of a secondment working as a service coordinator. The purpose of the secondment was to set up a pilot project to bring together multiagency working for children with complex needs in South West Surrey, aiming towards the development of a 'seamless service', and developing a single assessment process. Although a trained HV, her role, based in Social Care, was to bring together all the agencies working with the child and family, and to train and support Primary Workers. This was a non-designated keyworker role, taken on by one of the professionals working actively with the child, who could come from any discipline. Working in this role demonstrated the very difficult task that Social Workers face in assessing the needs of the child and looking to provide services to support them in the face of limited resources. Gaining an understanding of the processes involved in supporting young children in either mainstream or special school highlights the difficulties these services face with limited resources and the drive for inclusion.

It is important to note that, on occasion, one model appears to merge into another. This may be due to the way that practice has developed and the way in which staff have chosen to work. For example, hospital based community neonatal nursing outreach services aim to help families to cope with the early transfer of small, vulnerable infants to the home. One such service in northern England is provided by a team of four experienced senior neonatal nurses and midwives who provide an outreach service in family homes, children's wards, outpatient clinics and family centres. A recent evaluation of the service found that the team do not use a formal framework to guide practice and interventions, and the staff found it difficult to articulate how they worked; the author commented that nurses can easily ignore nursing models, focusing instead on the current context of care and immediate needs of patients in an

individualised flexible response (Cappleman 2004). This “hospital at home” concept or “team around the child” is in keeping with the ethos of a child centred approach; the child as focus with the family as context. The putative hospital model effectively becomes a Child/Family Centred Care Model.

## **6. Significant factors contributing to the service models**

Significant factors that vary across service models include the following:-

- Integration within and between services
- Knowledge and Skills
- Equity
- Communication and Information Sharing

### *Integration within and between services*

#### **6.1.1 Collaboration**

For many years now there has been recognition that the key to services for children with complex needs is interagency collaboration. In the main these agencies have developed separately and have distinct cultures with different patterns of training, expertise and, of course funding. The single most substantial objective for any service development in this area must be the effective interaction between agencies. A number of policy documents were identified with statements to this effect. It was much less easy to identify evidence that such collaboration had specific benefits to the child and to the family.

Describing services for these children is particularly taxing as neither the needs of users nor the related activities and competencies of staff have been characterised (Caan et al, 2000). Children and young people with complex health needs may receive support from a number of agencies. On average, disabled children with complex health care needs will have contact with ten different professionals and several agencies (Abbott et al, 2005). Issues related to user satisfaction support the drive for a named/link professional to coordinate care. A lack of continuity and coordination can arise due to the nature of the complexity of cases often involving multiple clinical conditions (Robson & Beattie, 2004). Evidence suggests that there are limited community resources to meet these needs (Caan et al, 2000), particularly age appropriate and developmental stage responses.

Greater collaboration between agencies and the need to improve inter-agency working is a key policy priority for the UK and Scottish governments (National Service Frameworks (DoH, 2004a), GIRFEC (Scottish Executive, 2006c), and “Delivering a Healthy Future” (Scottish Executive, 2007b). Sloper (2004) emphasised the need for methodologically sound research, which investigates the outcomes of different models of multi-agency working in services for children, including assessment of cost-effectiveness, and an exploration of the ways in which factors identified as facilitators of multi-agency working relate to outcomes. There is some evidence that key workers or identified/named contact person(s) produce more positive outcomes for families (Sloper, 2004, Carter et al, 2007, Beecham et al, 2007), as well as for other health and social care providers (Halliday & Asthana, 2004). Provision of key workers for children and their families, working across health, education, and social services, has been recommended in the “Children’s National Services Framework” (DoH, 2004a). Results from Greco et al’s (2006) study showed that although the basic aims of the key

worker services were the same, there was wide variation in the key workers' understanding of their role, the amount of training and support available, management and multi-agency involvement.

Watson et al (2002) explored multi-agency working in services to disabled children with complex healthcare needs, and their families. They found that partnership with families was key, commitment from services crucial and that success relied on a single pathway for families, through the key worker or service coordinator. Key workers need support in order to coordinate, facilitate and deliver services both across statutory and voluntary agencies, and between primary, secondary and tertiary care providers. This is paramount, in order to identify flexible and adaptable care pathways for children and young people with complex needs in community settings (Leadbetter & Lownsbrough, 2005). Service providers must work in partnership at both strategic and operational levels to develop integrated and coordinated services that can meet the needs of this group and their families (Kirk & Glendinning, 2004). Provision of a clear, written job description for key workers will help to clarify the key worker role, for themselves, other professionals and parents, and better manage expectations of the service (Halliday & Asthana, 2004; Greco et al, 2006).

### 6.1.2 Costs

An evaluation of the costs of key worker support for disabled children and their families was conducted by Beecham et al (2007). Key workers provide a single point of contact for disabled children and their families, supporting them and facilitating access to other services, and recent increases in key worker provision have been accompanied by a proliferation of delivery models, yet there is very little information on their costs. The study found that, on average, key worker contact with disabled children and their families cost £151 over a 3-month period. Contact costs were found to vary with the level of the child's disability and the number of roles that key workers performed. This latter variable was associated with improved outcomes. Such findings can help inform managers and planners about allocation of their scarce resources. Good-quality services appear to cost more, but the relationship between cost, quality and outcomes is not a simple one. Cross-boundary working provides the foundation for high-quality provision across child health services and is imperative for an effective system and the support of children and young people with complex health needs. In their study, While et al (2006) found evidence of considerable cross-boundary working, but trans-disciplinary working was not well established across all areas of child health provision.

Recent research on best practice in multi-agency working and the experiences of families of children with complex health needs suggests parents need the opportunity to share and receive support from other parents who understand the lived reality of caring for the child with complex needs (Carter et al, 2007). This study supports the notion that having a coordinator to help the family plan the journey ahead is fundamental in ensuring that things worked well. Collaboration and cooperation is essential between all parties to ensure that the most appropriate person is appointed as coordinator.

The literature provides useful guidance on evaluating multi-agency services, such as the use of different models of working related to outcomes for users, parents and children (Cameron & Lart, 2003). Glendinning (2002) suggests a number of criteria for evaluating effectiveness of partnerships. Areas to be evaluated include the extent to which partnerships meet their stated objective; the ratio of benefits to costs; the impact of a new partnership development on other client groups or the wider locality; the acceptability of service to users and other

stakeholders, as well as accessibility, appropriateness, accountability, responsiveness, and finally, implementation and rollout. However, few such evaluative studies were found for inclusion in the review.

### 6.1.3 Joint Assessment

Joint Assessment is clearly key to collaboration across and between services. The single integrated assessment plan and record process, coupled with clearer and stronger accountability, currently under development as part of the implementation of “Getting It Right for Every Child” (Scottish Executive, 2006c), is intended to benefit children and young people with complex needs in community settings in Scotland. The introduction of an integrated assessment process, “For Scotland’s Children” (Scottish Executive, 2001), should foster inter-agency working and be explicitly incorporated in Integrated Children’s Service Plans. There is a constant requirement to ensure that the health services and facilities provided for children, and the knowledge and skills of the staff of all disciplines contributing to their care are specifically tailored to the needs of children and young people at the various stages of their development. The need for age-appropriate care, awareness of parental expectations, and recognition of the wider needs of the family must play an integral role in service provision. These issues are particularly relevant for staff working with families whose circumstances have a significant impact on their role as parents/caregivers, and have implications for care, both individually and collectively (Scottish Executive, 2007a).

Integrated working also requires good channels of communication between professionals and across sectors. Corlett & Twycross (2006) have suggested that parental participation and role negotiation are central elements in family-centred care, but research suggests that such negotiation tends to be ad hoc, depending on the relationships developing between the family and health professionals. Lack of effective communication, professional expectations and issues of power and control often prevent open and mutual negotiation between families and health professionals, especially nurses. The article summarises key lessons from a critical review of relevant research literature, which suggests that nursing staff often control parental participation leaving parents feeling disempowered and deskilled. Poor communication and lack of information sharing exacerbate the situation. Where parents do not comply with nurses’ expectations, conflict can arise, resulting in more anxiety for already stressed parents. Current health policy requires that health workers listen to children and their families, to actively involve them in the decision-making process and to plan care around their needs and wishes. Nurses need to be aware of the way they interact with parents and the control they may unwittingly exert. A greater emphasis on communication, interpersonal and negotiation skills within nurse education is also needed.

## 6.2 *Knowledge and Skills*

Skill mix is the key to the delivery of equitable services to children with complex needs, much as it is in other areas. Increasing specialisation in the provision of services has highlighted the distinction between generalist and specialist service providers. Although community children’s nurses (CCNs), who are responsible for much of the care to children with complex needs, have been increasing in recently years, it is widely accepted that their services are inequitably distributed. The past three decades has witnessed a dramatic growth in the UK from only 25 Community Children’s Nursing teams in 1987 to over 250 (RCN, 2000 & RCN, 2002). A children’s community nursing service may consist of up to 15 nurses in the team, or only one or two nurses who are working in isolation (RCN 2000). They may

include nurses with advanced specialist roles, but the skill mix will depend on a number of factors such as client need in the local area, the size of the team and the model of service provision as discussed below. This increase in CCNs was a result of the Platt Report (1959), which established the fundamental policies for the welfare of sick children (Robertson, 2002).

This view was reiterated in 1997 by the House of Commons Select Committee which recommended that such services should be staffed by qualified children's nurses. However, these services have been slow to develop (Coley & Partridge, 2002) with professionals conveying disappointment with the small size of the community nursing workforce (Hickey, 2000, While & Dyson, 2000; Maunder, 2006). Often a service has been set up because an innovator or local team has identified a local need and acted accordingly, rather than being part of a larger organised development (Whiting, 2004; Eaton, 2000; Coley & Partridge, 2002).

Paediatric Physiotherapists and Occupational Therapists often work in multi-disciplinary teams to provide services for children and young people who have complex needs. The teams may be based in community child development units, schools or hospital departments and can also include professionals from nursing, education, social work and SLT. In mainstream schools, the role of paediatric therapist will often involve explaining the child's condition to teachers and special needs assistants, recommending strategies to help the child cope at school, planning necessary adaptations to the environment, training special needs assistants to work with the child, and reviewing & monitoring the child's progress (Hong & Palmer 2003). An example of multidisciplinary collaboration in the provision of joint treatment for infants and children with feeding difficulties is described in the box below.

#### Within Sector Skill Mix

The Taunton and Somerset Feeding Clinic. The clinic treats children with conditions such as cerebral palsy, autism, learned aversion and delayed oral development who have feeding difficulties. The therapists, consisting of a paediatric dietician, specialist OT and specialist SLT, have a coordinated approach to care and delivery of joint treatment plans at one combined appointment. The service provides support, advice and intervention plans for each child. Each therapist has a particular role in treating the patient, for example the OT may work with parents to evaluate what the child can do and solve the problems causing feeding difficulties. The dietician works to promote optimal nutrition and the SLT would investigate the child's oro-motor skills and swallowing sequence. One benefit to the families includes avoiding the disruption and inconvenience of several different appointments (Seabert et al. 2005).

Approaches to decision making by community based physiotherapists caring for children with cerebral palsy were explored by Young et al. (2006b). Physiotherapy practitioners focused on their responsibility for making decisions about resource allocation, and thereby, about the usefulness and intensity of interventions. Parents indicated that these practitioner-led decisions were sometimes in conflict with their aspirations for their child. Parents and children appeared to have most involvement in decisions about the acceptability and implementation of interventions. Children's involvement was more limited than parents who could legitimately curtail unacceptable interventions, whilst children were restricted to negotiating about how interventions were implemented. Young et al. (2006b) found that advocating shared decision making required greater understanding of its weaknesses, as well

as its strengths, and greater clarity about the domains that are suitable for a shared decision making approach.

An example of a service redesign of school and nursing services to develop community based skill mix teams is described below by Richardson-Todd (2005):

#### Palliative Care – The Jigsaw Service

The Jigsaw service, as described by Richardson-Todd (2005), is another example of a community based service redesign initiative. It involves the redesign of school and nursing services, working together with relevant agencies to provide Children and Family Service in community clusters based on geographical boundaries around school pyramids. Each community cluster will have a skill mix team of several Health Visitors, school nurse, staff nurses and health support workers (usually nursery nurses), and maintain strong links with GPs and primary care health team. The teams' service will include early years' provision and youth services. The author anticipates that teams will be part of an integrated locality team comprising other health professionals (e.g. paediatricians, CAMHS mental health workers, practice nurses, GPs, AHPs) as well as partner organisations, and also work with multi-agency team of social care, educational staff and community based staff.

Training represents a key element in the development of effective skill mix. As responsibilities are handed down to less qualified staff it is critical that effective standards of care are maintained. Although skill mix is welcomed by many staff as a way of increasing the equity of service provision there is a concern that the delegation of skill may result in a reduction in the standards of care. In such cases it is common for qualified practitioners to retain control of detailed case management thereby reducing the effectiveness of the process of delegation. The issues are the same across all staff groups, although some have a more developed process of training up less experienced members of a team. Replacing more experienced staff with less qualified staff remains an issue for most staff groups.

The literature identifies specific needs in nurse training e.g. providing care for technology dependent children and those with complex needs at home (e.g. Hewitt-Taylor 2004, 2005) and training in child protection (Long et al. 2006). There is also concern regarding the lack of confidence of newly qualified Community Children's Nurses, and whether they are adequately prepared to work in the community. It is often challenging to educate CCN students, as they are required to work in very different community teams, carry differing caseloads, and have a wide range of practice experience and needs (MacGregor & Gray 2005). A number of educational establishments have reported difficulties in finding suitable community placements for students (Hickey, 2000). Farasat & Hewitt-Taylor (2007) evaluated a pilot programme whereby two third-year child health nursing students attended a five week placement to provide support for children with complex and continuing health needs and their families in the home environment. The students were accompanied by a trained mentor, a registered nurse employed by a private provider of home care services, and worked with other RNs and healthcare support workers. The placement was described by students and their mentors as a positive experience, which allowed the students not only to gain important clinical skills and experience, but also to appreciate the social, emotional, developmental and educational aspects of supporting these children and their families in their homes.

### 6.3 *Equity of service provision*

One of the characteristics of the literature is that services are commonly described by those who provide them or those who receive them. Needs are identified and addressed in specific populations but there is often little sense of whether these services are being provided equitably. For this reason, we have identified a number of areas which the literature tells us may be particularly problematic. These include transitional arrangements when the child moves from the acute to the community sector, and both respite and palliative care.

### 6.4 *Transitional Arrangements*

Consistency in discharge planning, and in the information, advice and support given to parents is clearly needed. Parents' need for information about a child's illness and treatment during a hospital admission and for a more consistent and coordinated approach to discharge planning was highlighted by Smith & Daughtrey (2000). It was also evident that there are families who would benefit from various forms of support once children are discharged home from hospital, following an acute medical episode. The authors recommended that there should be a coordinated and reliable approach to discharge in preparing and setting up complex care packages for children and young people requiring technological and clinical care at home. Stephens (2005) subsequently developed a framework to smooth the transition from hospital to home for children with complex care needs, and recommended that adequate funding should be allocated for all such children who require continuing care at home.

### 6.5 *Respite care*

Respite is key to the service delivery for children with the most complex needs. This can be provided by professionals, paid carers or lay/unpaid carers (McConkey et al. 2007, p.79). Beale (2002) describes a service set up in the Midlands:

#### Respite care

A CCN team in Wolverhampton set up a respite care service after a survey of parents of technology dependent children indicated a gap in service provision. This service has yet to be evaluated but has been described by Beale (2002), who promotes the provision of respite care by CCNs as beneficial. Initially staff were recruited from bank staff but after the heavy demand for service became apparent, children's nurses were recruited from acute hospital settings. Staff received training on working autonomously in the community; meeting the specific needs of each child and family; and underwent a competency training assessment of their skills. To alleviate the cost of using E grade children's nurses, support workers were also used and were taught clinical skills such as tube feeding and drug administration; however, children who had particularly complex needs or were fragile continued to be cared for by Children's Nurses.

The team provides respite care at home, in social services residential settings (the nurses worked collaboratively with social services staff), and in a Child Development Centre. To determine how much respite a family should receive, a dependency rating scale was created to indicate their levels of stress. Families were also assessed using a detailed model called the 'Lifebook' which records all aspects of nursing care, lists all professionals that were involved with the child, as well as noting the needs of siblings. This book was kept by parents and children who were encouraged to use it.



The evaluation of a nurse-led, home based respite service for the families and children under the age of five, with complex health care needs, revealed the mixed reactions of parents to this innovative service contributing to family wellbeing (Olsen & Maslin-Prothero 2001). Parents highlighted their need for a much more responsive and immediate type of support, in relation to the fluctuating nature of their child's health care problems. For parents, the system of pre-booked respite set up to maximise contact hours between nurses and families, but with less staff available for immediate crisis responses, was a major problem. Any service seeking to provide support to parents of children with complex care needs will need to confront the balance between maximising the number of families on the caseload, on the one hand, and being able to offer more responsive support, possibly to a smaller number of families, on the other.

Olsen & Maslin-Prothero (2001) also pointed to the danger of alienating families at times of greatest need if the support is not offered in a more responsive way. Efforts should be made therefore to offer respite support in a more flexible and diverse set of ways to ensure that a broad range of families can make use of the service. This emphasises the importance of a regular assessment of each family's need for respite, so that support can be offered when most needed or, at other times, redirected to other families.

## 6.6 *Palliative Care*

Equity is key to the delivery of palliative care. Currently there is no comprehensive palliative care provision for children in the community in the UK; services are fragmented, dependent on condition and geography, and are difficult to obtain (Maunder 2006, Davies 2006). In the Western Health and Social Services Board in Northern Ireland, the most developed model of service currently in use is for children with cancer. This is based on paediatric nurse 'outreach' service from the Regional Children's Cancer Centre at the Royal Belfast Hospital for Sick Children. Locally this is supported by GPs and a small number of Community Children's Nurses, the Children's Palliative Care Nurse, social work, other health care input and voluntary services (WHSSB 2003). A Framework for the Development of Integrated Multi-agency Care Pathways for Children with Life-Threatening and Life-Limiting Conditions was developed by a working party (ACT 2003, 2004). Davies (2006) highlighted the need for this framework and its potential to transform the delivery of palliative care services to overcome present inequalities. He described how the three stages of the pathway (diagnosis or recognition, living with a condition, and end of life and bereavement) follow the patient's journey and complement guidance set out in the Children's National Services Framework (DoH 2004a) for multi-agency assessments, protocols and standards to ensure high-quality coordinated care and services. He stressed the need to evaluate the effectiveness of pathways through audit and research.

Diana Children's Community Teams (DCCT) are an example of Nurse-led palliative care in England. In 1998 the Department of Health provided £4 million to fund 10 teams of Diana Nurses over three years to provide specialist support for very sick children and their families. A DCCT in Leicestershire and Rutland aimed to: provide an alternative to hospital admission; provide 24 hour terminal care support and bereavement support in the community; be a source of specialist advice and information for parents, carers and other professionals; and have an identified key worker for families (Robson & Beattie 2004). It replaced three independently managed community nursing services (paediatric Macmillan service, Children's Community Nursing Service and a children's home based respite service). The Diana Service sought to integrate and build on these existing services; this was a move away

from the traditional uni-professional service, incorporating a wider range of multi-professionals working in partnership through joint visiting and collaborating on palliative care pathways (Danvers et al. 2003). The multidisciplinary teams consisted of respite nurses, support staff, children's community nurses, occupational therapists and physical therapists, play specialist and oncology nurses. The introduction of new therapy, play and cultural link worker roles was identified as a great resource for the team (Danvers et al. 2003). A single manager was appointed to facilitate integration of the service elements and decisions affecting the future care and service provision were made in a forum for each individual family. Partnership working with the families was encouraged, for example, parents could choose to act as the official service coordinator. In cases where English was not the first language, nurses worked with cultural link workers when visiting the home; this, combined with the provision of family service meetings, created a feeling of greater control and empowerment for parents (Robson & Beattie 2004).

Evaluations of some of the Diana teams can be viewed in the box below:

#### Palliative Care – The Diana Service

Evaluations of the Leicestershire service (Danvers et al. 2003; Robson & Beattie 2004) suggest that the Diana service is beneficial to children with complex and life limiting conditions. Both parents and professionals reported satisfaction with service and improved family support. The majority of multi-agency professionals felt that interagency working had partially or greatly improved. It was found that there was a reduction in service gaps and duplication by agencies because of the increased understanding of interprofessional & interagency roles achieved by e.g. greater clarity through meetings (Robson & Beattie 2004). In addition, this service was identified as an example of good practice by the Royal College of Nursing (2002).

Another Diana team in Salford worked collaboratively using a family centred approach to meet the specific needs of individuals, providing services such as nursing, home help, counselling, respite, activity days and sibling support. Significantly, the Salford team and the qualities of children's nurses were evaluated through the eyes of children and their siblings (Carter 2005), encompassing an inclusive and participative approach. The sick child's siblings highlighted that attention to their needs was important. Carter also found that children use parents as their gold standard for care and they are clear about the skills and attributes they value relating to 'outsiders' who provide care to their family. A third Diana team, based in Cornwall, involved two children's nurses who developed a team of eight trained support workers, a clinical psychologist, part-time art therapist and part-time shared occupational therapist/physiotherapist post. The team was set up to provide and coordinate a service for children with life-limiting or life-threatening illnesses, and provide respite for their families (Oliver 2000/2001). This service acted in addition to two specialist nurses addressing the needs of children with cancer and their families. Issues in developing the service included the design of appropriate documentation such as recording care input by the team, and the creation of suitable policies and procedures.

The regional Paediatric Palliative Care Networks, which were launched by the Department of Health in 2006, have excellent potential for bringing all the key players together, including children's nurses, paediatricians, therapists, child mental health professionals, support groups

and spiritual leaders. The network aims to provide a key worker to each family and liaison with regional centres and primary health care teams. Respite care is available to families, on a flexible basis, in the child's home or at a children's hospice or suitably staffed children's respite unit. Nursing care is available twenty-four hours a day to children during the terminal phase of their illness. However, their development has been patchy and there is a danger that they will founder without greater support. Craft & Killen (2007) found huge variation in the availability of services across England. There were examples of excellent practice but there was too little sharing of good practice and no apparent system for holding commissioners to account for the quality of services delivered to these families. There were many areas where services were inadequate; there was little strategic planning or evidence of using commissioning to develop a sustainable service.

Maguire & Price (2007) used a model of structured reflection for paediatric palliative care to assess the signs of stress in parents and the wider family of a child with complex needs. This reflection reinforces the multi-faceted role of the children's nurse, who, in addition to delivering physical care, acts as a teacher, supporter and facilitator to the child and the family (Graham & Price 2005 cited in Maguire & Price). The authors suggested that this model, using a paediatric/children's nurse, was advantageous in developing and advancing professional judgement and practice in providing quality care in any area of children's health. In addition to its value in the educational arena, it could also have benefits for staff debriefing, clinical supervision and appraisal.

A recent study (Beringer et al. 2007) explored factors which affected palliative care service delivery for children with life-limiting conditions, both at home and in hospices, from the perspective of a sample of children's community nursing teams. The nurses in this study either provided general CCN services in addition to palliative care, or provided palliative care exclusively. There was uncertainty regarding the specialist palliative CCN, as it was a new role and some participants were not clear at what stage they should offer 'palliative' care, and were wary of being seen to 'take over' caseloads from their general CCN colleagues. The general CCNs held a 'mixed' case load, and cared for a child (and family) throughout their disease, offering continuity and less chance of blurring of role boundaries, in addition to promoting the retention of a wider range of clinical skills. The physical location of services was found to be crucial in facilitating communication and multidisciplinary working. The fixed-term nature of funding was felt by some to inhibit referrals to the service from other health professionals, cause difficulties in recruitment and retention, and exert pressure on staff to try to secure ongoing funding, sometimes at the expense of providing care.

## *6.7 Communication and Information*

Equity also relates to access to information but because this is so pervasive an issue we have picked it out for special consideration. Limited access to and availability of clinical and/or service information for children, young people, parents and carers is an issue. The US 2001 National Survey of Children with Special Health Care Needs (US Department of Health & Human Services 2004) found the most commonly reported missing component of family centred care was provision of information. Transmission of information from professionals to families was deemed to be more problematic when, compared to information given by families to the professionals, and in some cases in children with rare disorders, the professionals had little or no knowledge, and the parents then had to become experts on their child's condition (NHS QIS 2004).

McConkey et al. (2007) recommended the creation of a service map for each individual child and family, to be shared with all service providers, providing names and contact details of all those included. They went on to suggest the development of an individual family-centred service plan, within an overall service framework, which would identify those people who have greatest involvement with the child and family at present. The accompanying plan would describe how they coordinated their support and those personnel who may have more peripheral but significant contact with the family. The plan would also identify how they were kept informed and identify those professionals and services that were absent for the child and family. This will inevitably raise questions about equity and need (McConkey et al. 2007, p.19). Of course, information needs are central to the development of person centred care models of service provision because it is the parents who make the decisions and they are only able to do so if they have the relevant information.

The Scottish Community Children's Nursing Network, with input from speech and language therapists, identified nasogastric and gastrostomy tube feeding in children as an area in which there were shared concerns over inconsistencies in practice. Identified problems included families lacking information about the effect of tube feeding on their child and the rest of the family, a lack of support for families to cope with problems in child care, difficulties in the supply of feeds and equipment after discharge from hospital and poorly coordinated support services. As a result a best practice statement was developed by the Nursing & Midwifery Development Unit (NHS QIS 2003) to offer guidance to nurses, midwives and health visitors working with children in the community, as highlighted by Bond & Moss (2003). This statement has since been reviewed and updated (NHS QIS 2007).

Children and young people with complex needs are a diverse population, varying widely in the types and numbers of technologies involved in their care, the intensity and timing of the support required, and additional disabilities and long-term prognoses (Glendinning et al. 2001). Randall (2003) developed a care pathway for oxygen dependent children with chronic lung disease, detailing the specific ways in which health visitors can work with specialist nurses in the Community Children's Nursing Team (CCNT) to support parents to provide home care for their children. Technological issues have been a focus of discussions in the UK as they have been world wide. Service provision for children and young people dependent on technology is uneven in distribution. It is difficult to establish how many as their needs are so diverse, but it is estimated that there are 6,000 such children in the UK (Glendinning et al. 2001). These children, with a continuing need for the support of medical technology, have emerged in community settings as a result of medical advances and government policies, and are increasingly being care for at home (Noyes et al. 2006). Caring for these children has a significant social and emotional impact on parents, because of their specialized and intensive care needs. Obtaining appropriate and coordinated home support services is problematic, and will be explored further in the following section looking at the workforce.

Later research carried out by Kirk et al. (2005) stated that looking after a technology-dependent child altered the meaning of parenting. Professionals need to recognize that providing care has a substantial emotional dimension for parents, who need opportunities to discuss their feelings about care giving, and what it means for their identity as parents and their relationship with their child. Challenges to carers and parental demands contribute to family stress and the resulting negative health consequences.

Tele-medicine has proved valuable in speech and language therapy. In a study by McCullough (2001), parents reported increased knowledge and confidence in developing

their child's communication skills, and tele-therapy was demonstrated to be an effective and reliable addition to a new era of therapy provision. Recognition in this context, that parent training is a vital component of successful treatment programmes, makes the use of tele-therapy from clinic to home an ideal medium of sharing skills with carers (McCullough 2001).

## **7. Issues related to the organisation of the workforce**

For children and young people with complex needs, physical, psychological, social and environmental wellbeing are fundamental issues to be addressed by the workforce. There is therefore a need for practitioners from peri-natal care, childhood development, adolescent and teenage years, in fields such as public health, health promotion, speech and language therapy, occupational therapy, physiotherapy, radiography, nutrition, dietetics, art therapies, psychology and sociology. This necessarily involves agencies and organisations within statutory and non-statutory services including healthcare, housing, education, and environmental organisations and the voluntary sector where appropriate. Facilitation of service delivery requires interagency collaboration and partnership working across all sectors within health and social care services. The healthcare workforce addressing health initiatives for children and young people must include the prevention of ill health, health protection, promotion of healthy lifestyles, and the maintenance of health status of individual children, groups and population based approaches. The workforce needs to change and respond to the current user expectations around community and individual rights.

Models of service delivery within nursing teams for children in the community vary considerably (Eaton 2000, While & Dyson 2000, Davies & Harding 2002). The balance of acute nursing and community nursing knowledge and skills needs to be carefully considered, if the needs of children with complex needs and their families are to be met effectively (Runciman & McIntosh 2003). Challenges therefore include workload and workforce considerations as the service expands, and ability to continue to provide three key features: 1) rapid response; 2) support in crisis whenever needed by families, including “out of hours work times” and 3) top up training for families over time, and for agencies when staff leave and are replaced. At a time of change for community nursing roles, dialogue between educators, managers and practitioners is essential to clarify how best to support such a service through both pre- and post- registration education provision. Parents’ voices need to be heard in this professional debate.

The implementation of the European Working Time Directive (Council of Europe 1993) has highlighted educational and operational needs for the nursing and allied health professional workforce. Support necessary to meet service needs and targets within “Agenda for Change” (DoH 2004b), and the need to address the “Knowledge and Skills Framework” (DoH 2004c) has impacted upon the workforce. “Shaping the Future, the Primary Care Modernisation Strategy for NHS Lothian 2007-2012” (NHS Lothian 2006) provides a public consultation document, which is a proactive initiative responding to the growing concerns about the planning of a complex workforce.

Issues such as an ageing workforce population, gender issues, appropriate knowledge and skills, infrastructure and mechanisms which are supportive to the primary care workforce will influence the redesign of primary care services. The increase and effective use of information technology and its impact on the healthcare workforce needs to be appraised. There is a growing pressure for agencies working with children to be more publicly accessible, in

has been little attempt to date to say whether these changes make a real difference to the children concerned in terms of specific outcomes for themselves or their families. On a wider scale we found little that could be called an impact assessment.

### *8.2 Skill mix*

Equity also requires a sophisticated assessment of skill mix, planning services and who will provide them, rather than adding numbers here and there to existing services. It is necessary to carry out coherent modelling of what it is that these children need. This goes back to the assessment of impact; how many staff and in what combination will sustain/enhance the quality of life of the family?

### *8.3 Education and training*

Education and training underpin the effectiveness of the delivery of services but was rarely considered in the papers that we reviewed. There was little acceptance that the basic skills of the workforce are an issue for central government. Often these specialist skills are the focus of master's programmes but, by definition, this mitigates against equity because only those who already have a level of professional specialisation will be able to access such programmes. These programmes tend to emphasise the specialist nature of the tasks concerned and add to the "medicalisation" of the individuals concerned. More is needed at the level of basic training on the provision of services to families and how to work within the complex ecological context which is the essence of work in the community.

In addition to the nature of the training of health professionals, gaps in service provision are likely to occur as a direct consequence of the ageing workforce, something which affects both nurses and AHPs, potentially creating challenges in terms of succession and development. Although the health boards feed into the planning of recruitment in nursing, the same is not the case for AHPs. On top of this, despite an increasing demand for AHPs, many health boards express difficulties in their recruitment and retention. Finally, more information is needed about the roles that practitioners are to play in the community. The review of community nursing which is currently underway is raising interesting questions about the levels of specialisation held by those working in the community. In many ways, children and young people, many of whom have highly specialised needs, provide a useful test of the level of specialisation needed to manage a relatively low incidence population.

### *8.4 The role of person centred care*

The Scottish Executive has identified the first priority in their vision for children's services: they should be "accessible, locally based, address locally identified needs and risks and ... designed along with parents and children" (Scottish Executive 2005e). This ethos of placing patients at the centre of any service provision has been reiterated in the recent Action Plan (Scottish Government 2007a). While there may be obstacles in practical terms for those wishing to provide services for low incidence conditions such as complex needs, we were struck by how little emphasis was placed on the role of the young people and their families in the planning of service. Given how intrinsic their role is in the success of any provision, this is a major weakness in much of the published literature. This is not to say that such work is not being carried out, simply that it is not making its way into the literature.

## **9 Summary of main findings**

It is clear that children with complex needs are of concern to those developing public services across the world. Indeed the transition of paediatric care provision from the acute to the community setting is part of a global trend (Wang & Barnard 2004). The definition of complex needs that is adopted inevitably makes a difference to the way that services are planned. The wider the net cast, the less likely it is that the children will have complex medical needs, and the more likely it will be that they have social and learning difficulties as their primary need. It can reasonably be argued that children and young people with complex needs represent a test of whether those services are truly functional because, as we have seen, these children are readily identifiable, require collaboration across services and are dependent on a number of well recognised features. In this section we pull out and discuss further some of these key features.

Although a number of different approaches to the provision of services for these children and young people are described in the literature, they often overlap or are not comparable because they do not use the same criteria. For this reason, we have proposed a simple three way distinction between models of services which focus on Acute Service Model, the Community Service Model and those which focus on Child/Family Centred Care Model. It has not proved possible to compare these models empirically and it is not, therefore, possible to say that one is necessarily better than another. In part, this is a function of the complexity of the task, but it is also unclear to what extent these models represent stages in the care pathway. Children move out of acute care into a closely managed community provision, which in turn gives way to self management, and with this comes a shift away from medically dominated care to integrated care. However, models do vary in a number of interesting ways and this probably reflects historical and geographical factors as much as it does explicit policy decisions to develop services in one direction or another. Similarly the model adopted probably reflects the level of medical need of the children concerned. Thus those with more severe medical needs are likely to remain within a more Acute Service Model, while those with long term social or educational needs may best be appropriately dealt with in a Child/Family Centred Care Model.

response to recommendations that the public plays a greater role in policy making, with an evidence-based focus. Consultation processes are in place to support the full participation of children and young people in designing, planning and delivery of appropriate services for this particular group, such as the Young People's Health Advisory Group (Scotland).

There is emerging evidence for the effectiveness of multi-disciplinary initiatives (Stevenson et al. 2007). A comprehensive educational framework will ensure rigorous scrutiny of quality and governance arrangements across all educational activities. This will support a range of educational research and development projects. An evidence base will be defined, along with key research priorities for patient safety, team-based education, assessment/clinical skills and CPD/life-long learning (NES 2007a).

Occupational therapists working with children and young people with complex needs, from a variety of diagnostic groups, require knowledge and skills related to specific interventions. The content of professional entry level occupational therapy university curriculum focused on activities of daily living/self care, motor skills, perceptual and visual motor integration, and infant and child development (Rodger et al. 2006). Client and caregiver teaching as an intervention appears to be taught more often, and therefore appears to be more highly valued in the Australia/New Zealand programmes, compared to those in Canada.

Workforce planning requires closer links between service, financial resources and workforce, to enable more of the right people in the right jobs, in order to provide an effective, efficient, quality service. The development of an organisational structure is an important aspect of forward planning, to ensure ways of working that respond to the Knowledge and Skills Framework, in order to support service integration. Any organisation must take account of partnership working, their remit as a learning organisation and their responsibility to manage equality and diversity, which will also include patient focus and public involvement work. The workforce must respond to the four key objectives that reflect Ministers' priorities for the health portfolio: health improvement, efficiency and governance, access to and accessibility of services; and care and treatment appropriate to individuals (NES 2007a).

Cognisance of the RCN and Allied Health Professionals Working Group - Protected Time for Continuous Professional Development (CPD) agreement - also needs to be taken. Factors related to sustainability and capacity building within the workforce and service providers should be incorporated. Nurses and allied health professionals caring for children and young people with complex needs in a community setting, need to recognise the importance of information sharing. However, it needs to be appreciated that this can only be achieved and sustained in a climate of inter-professional trust and mutual respect. This requires arrangements such as interprofessional education (IPE), and co-location of health and social care professionals. Policy implementation has to be considered as a bottom-up rather than a top-down process (Hudson 2005).

## **8 Gaps in the evidence base**

### *8.1 Evaluation*

The majority of the papers outlined in this review are descriptions of services. There has been little attempt to indicate how and why services have reached the state that they have or how we would know whether the proposed change was of much value. It is true that the papers commonly report process outcomes, waiting lists, adherence to care pathways etc. but there



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## **ANNEX 2 INTERVIEW SCHEDULE FOR TELEPHONE INTERVIEWS WITH MANAGERS**



**Queen Margaret University**  
EDINBURGH

### **Telephone Interview – Topic Schedule**

#### **Who is caring for CYP with complex needs?**

- Characteristics of core teams delivering CYP services (roles, skills/competencies, levels of responsibilities – delegation/leadership)
- Sustainability of services – recruitment, retention, workforce demographics
- Priorities re staff/service development (CPD) – education/skills
- Specialist services, e.g. travelling people, special needs, ethnicity
- Contact with other CYP service providers – nursing, AHP, other agencies

#### **What services are provided for CYP with complex needs?**

- Current CYP services provided – models of service
- Opportunities and challenges for service provision – geographical, specialisms, equity
- Facilitators/barriers to service provision (e.g. managed clinical networks) – actions required/planned/undertaken to address above (e.g. integrated/ partnership working)
- Examples of good practice – information sharing/documentation; children and young people/carers/parents participation, representation.

#### **How are services implemented?**

- Operationalisation – implications regarding policy implementation
- Transition – seamless/acute to community
- Funding – resources/staffing
- Clinical governance/standards of care
- Future/the way forward

Thank you for agreeing to participate.

## ANNEX 3 QUESTIONNAIRE SENT TO PRACTITIONERS

### SECTION 1 YOU AND YOUR JOB

Please answer all questions (where relevant) as fully as possible, and with regard to your current job role and provision of services to Children and Young People [CYP] with complex needs

1. Job title: .....

2. Sex: Male ☐ Female ☐

3. Age (please tick one): 20-24 ☐ 25-29 ☐ 30-34 ☐  
35-39 ☐ 40-44 ☐ 45-49 ☐ 50-54 ☐ 55-59 ☐ 60+ ☐

4. What category is your employer? e.g. Health Board, Social Services, non statutory/voluntary organisation, other?

.....

5. What category reflects your work base, where you work from? e.g. medical and/or health centre, community centre, hospital, other?

.....

6. Length of time in current post:

.....

7. Qualifications:

Academic:	Year of completion
Professional:	

8. Nature of your primary role: Line Management ☐  
Direct clinical service provision ☐  
Both ☐

Please indicate the nature of clinical service provision; if both how is it divided/shared

.....

.....

**9. Please indicate staff you manage, and staff you work with: [please tick all that are applicable]**

Occupation	Manage	Work with
Health Visitor		
District Nurse		
Community Children's Nurse		
Community Mental Health Nurse		
School Nurse		
Registered General Nurse		
Registered Children's Nurse		
Public Health Nurse		
Public Health Practitioner		
Specialist Children's Nurse		
Midwife		
Play Leader		
Nursing support staff		
Speech and Language Therapist		
Occupational Therapist		
Physiotherapist		
Art Therapist		
Music Therapist		
Orthoptist		
Dietician		
Radiographer (diagnostic)		
Radiographer (therapeutic)		
AHP support staff		
Other (give details)		
.....		

**Please feel free to add any relevant information or comments in relation to this question**

.....

.....

**10. Please indicate the children and young people (CYP) client group(s) you currently work with:**

.....

.....

**11. Do you work with CYP with complex needs and other client groups?**

Yes ☐ No ☐

**12. Has your role been changed or extended in the past year?** Yes ☐ ☐  
No

If so, how?.....

**13. Are there plans to change or extend your role in future?** Yes ☐ ☐  
No

If so, in what way?

.....

**SECTION 2 CARING FOR CYP WITH COMPLEX NEEDS** *This section focuses on work in connection with CYP with complex needs and should be answered in that context*

**14. Please indicate all workplace settings where you deliver services to CYP with complex needs: [tick all that apply]**

School	<input type="checkbox"/>	Home	<input type="checkbox"/>	GP/Health Centre	<input type="checkbox"/>	Hospice	<input type="checkbox"/>
Residential setting	<input type="checkbox"/>	Community Project	<input type="checkbox"/>	Community Hospital	<input type="checkbox"/>	Nursery	<input type="checkbox"/>
Rehabilitation hospital	<input type="checkbox"/>	Day centre	<input type="checkbox"/>	Other – give detail(s) below	<input type="checkbox"/>		<input type="checkbox"/>

**15. How is contact normally initiated (who refers)?**

.....  
.....

**16. Do you provide education/training for carers/parents/families?** Yes ☐ ☐ No

**17. What other organisations/service providers are you in contact with that are available to support parents and carers of CYP with complex needs in the community?**

.....  
.....

**18. Please list additional staff with specialist roles for CYP services you have access to**

(e.g. children and families, cystic fibrosis, epilepsy, child protection, looked after and accommodated children, learning disability)

.....

.....

**19. Please indicate colleagues you work with from any of the following sectors, for the provision of services for CYP with complex needs:**

Employer/sector	Job title(s) and what type of CYP service(s) they provide
Social care	
Education	
Social Justice	
Non-statutory/Voluntary	
Other	


**20. Do you/your team use any particular models of care? (e.g. child-centred, family centred-care)**

.....

.....

### SECTION 3 VIEWS ON SERVICES FOR CYP WITH COMPLEX NEEDS

**21. Please indicate the extent to which you agree or disagree with each of the following statements, with respect to your organisation:**

				
1	2	3	4	5
strongly agree	Agree	not sure	Disagree	Strongly disagree
Statement				Rating
There is evidence of joint working between hospital and community care for CYP with complex needs				
Statutory and non-statutory/voluntary organisations collaborate and work in partnership to deliver services to children and young people with complex needs				
Services for children and young people with complex needs in the community are effective for their needs				
There are sufficient resources to deliver appropriate services for children and young people with complex needs in the community				
There are appropriately educated and trained staff to deliver effective services for children and young people with complex needs in the community				
The existing education and training programmes are sufficient for community staff requirements				
Services can be tailor made to individual need of children and young people with complex needs in the community				
The views of children and young people with complex needs are recognised in planning, providing for and auditing services				
24hour support and advice is available for children and young people with complex needs in the community				
There are clear methods of communication between professionals, children, young people their families, carers and other colleagues				
Opportunities exist to communicate with Directors/Managers/Committees in relation to service development				
Opportunities exist to communicate with Directors/Managers/Committees in relation to service provision				
Opportunities exist with partner agencies to communicate with Directors/Managers/Committees in relation to service development				
Opportunities exist with partner agencies to communicate with Directors/Managers/Committees in relation to service				
All service providers for children with complex needs work together toward shared and agreed goals, while maintaining their independence				
All service providers for children with complex needs address issues of overlap, duplication of services and gaps in service provision				

**22. If you wish, please comment on any issues related to the above statements:**

.....

.....



**23. Can you give one example of a service that in your view is particularly effective and please indicate why you feel this to be the case:**

Service	Reasons for service success

**24. Are you aware of any gaps in the services to CYP with complex needs you would like to see addressed? What would be the most effective way of responding to these gaps?**

Gaps in service	Most effective way of responding to these gaps?

**25. Are there any new and innovative services which you would like to see introduced that would respond to the needs of children and young people with complex needs?**

New and innovative services	Most effective way of introducing these new and innovative services?

#### **SECTION 4 WORKFORCE AND SERVICE DEVELOPMENT ISSUES**

**26. Are there plans to develop current staff to meet identified needs?**

Yes ☐ No ☐

Please specify:

.....

**27. Are there plans to restructure the composition of the workforce?**

Yes ☐ No ☐

Please specify:

.....  
.....

**28. How do you sustain and develop clinical practice?**

.....  
.....

**29. Which of the following might better facilitate you/your team delivering services to CYP with complex needs? [please tick all that apply]**

More Education / Training – parents/families		More Education / Training – CYP NAHP staff	
Increased staffing levels		More skill mix	
Better referral systems		Improved administration	
More Specialist workers		Better Communication systems	
Better information/documentation		Other – please give details	

Other: .....

**30. What is available to support your adherence to clinical governance?**

.....  
.....

**31. Have you encountered any barriers to adhering to clinical governance? (e.g. risk management, accountability, evidence based practice)**

.....  
.....

**32. What Continuous Professional Development (CPD) / education / in-service training relating to CYP with complex needs have you attended within the last two years? (e.g. diabetes, cystic fibrosis, special needs)**

.....

.....

**33. Please list any CPD / education / in-service training you would like to enable you to work more effectively with CYP with complex needs:**

.....

.....

**34. Are there any barriers to attending the CPD / education / in-service training offered? (if so, please expand on your answer)**

.....

.....

.....

**35 Please highlight the most important workforce issues currently influencing service provision to CYP with complex needs (e.g. recruitment, retention, experience, expertise etc.).**

.....

.....

.....

**Thank you for completing the questionnaire. Please return in the envelope provided.**

**Please feel free to add any additional comments.**

## ANNEX 4 TOPIC GUIDE FOR FOCUS GROUPS



Queen Margaret University  
EDINBURGH

### FOCUS GROUPS

Thank you for agreeing to participate in the focus group. It is intended the session will last no longer than an hour. The purpose of the session is to explore in more detail research data obtained from telephone interviews with managers and directors of services, and completed questionnaires. The data relate to the following themes:

- Sustainability of the workforce – e.g. recruitment and retention of staff, suitability of existing staff,
- Integrated working – how supported/facilitated; what does or doesn't work well; any improvements?
- Education and development of staff – opportunities; barriers; how undertaken
- Models of care
- Impact of current policies/strategies on current service provision
- Any other comments/feedback

We look forward to a constructive and interesting discussion.

Dolly McCann  
Fiona O'May

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