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Health & Community Care

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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Researchers at Queen Margaret University, Edinburgh were commissioned by the Health Department in the Scottish Government to provide a picture of the key issues facing 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.

Main Findings

■ Although the number of children and young people (CYP) with complex needs is relatively low, they present challenges to service providers because of the range of services involved and the level of expertise required to meet their needs.

■ Provision for CYP with complex needs is characterised by a multiplicity of practitioners working in a variety of settings including schools, nurseries, health centres and the home.

■ There was a high level of commitment to joint working both within and across service providers however, a number of gaps in service provision were identified namely transitions between health and educational provision, between acute and community, respite, and palliative care and "out of hours" provision.

■ The survey identified a lack of knowledge relating to complex needs. In some cases this related to a lack of specialised knowledge, in others it related to the need for essential training in paediatrics and matters concerning the family.

■ While there was agreement about the development of flexible, family-centred services, concern was expressed about the balance between expert and generalist provision for families and about the way in which practitioners and carers were educated and trained to deliver such services.

■ Concern was expressed about the high level of inequity of service delivery. In part, this was a problem for those with a reduced access to services, such as those in remote and rural areas, and those who were socially disadvantaged, but it was also an issue where the level of services was dictated by proximity to specialist hospital facilities.

■ Although staff were clearly responding to the changing needs of families of CYP with complex needs, concern was expressed about the impact of the changing and sometimes contradictory policy on managers and practitioners, and the implications that this may have for service implementation.

■ Considerable progress has been made towards integration of services for CYP both within and between sectors. Nevertheless, there remain a number of obstacles to further development of integrated working, e.g. funding and communication systems.

■ There was a perceived need for better sharing of information across agencies at a practitioner level to facilitate service integration and to improve the experience of CYP and their families.

■ There was also a need for better use of information systems to support a shared record for CYP with complex needs which is accessible by health, education and social care providers throughout Scotland.

■ Although service changes were being made across Scotland to meet the needs of CYP with complex needs, there was a very limited evidence base to inform such changes. More research is needed on the relative effectiveness of different models of provision.

The Scottish Government

Background

Health services for 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[1] (NAHPs) is seen as crucial in providing services for CYP with complex needs in a variety of settings. The Scottish Government, therefore commissioned research to better understand whether NAHPs 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 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. For example, it will decrease if only the most stringent criteria are applied, on the other hand, it 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.

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 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.

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 and circumstances. 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; knowledge and skills; equity; and communication and information sharing. These themes were incorporated into the research tools used in Phase 2.

Phase 2 involved an exploration of the nature, role and models of NAHPs 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 NAHP exploring issues raised in the survey, supplemented by 4 interviews where focus groups were not possible.

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1 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).

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 to the survey means the findings should be treated with caution.

Findings

These are based on the work carried out in phase 2 and are reported under 4 main headings:

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 were 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. It was felt that there were not enough staff with the appropriate level of expertise to deliver the necessary services. This, it was felt, inhibited 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, who would be able to provide specialist, flexible, services and expert input as and when appropriate.

In one area, speech 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 qualified 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 training to increase knowledge and skills was available, 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 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 remote and rural 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 required. 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 can provide both routine care and the kind of specialist care that such children need in the community.

References

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