

HEALTH AND SOCIAL SERVICES COMMITTEE

REVIEW OF SERVICES FOR CHILDREN WITH SPECIAL HEALTH NEEDS

Progress to Date

Introduction

1. The Health and Social Services Committee identified children's health as an area they wanted to focus on in more depth, with a view to developing policy in that area. At its meeting on 6 June 2001, it was agreed to carry out a review of services for children with special health needs, focusing on school age children. Given the overlapping interests with the work of the Education and Lifelong Learning and Local Government and Housing Committees, both were invited to nominate a representative to be involved and attend meetings of the Health and Social Services Committee.

Approach

2. Informal consultation on the terms of reference and work programme took place during the summer, and at its meeting on 18 October the Committee agreed the attached terms of reference. On 22 October the Clerk of the Committee wrote to 242 organisations and individuals identified by the Committee as potentially interested in the subject of the review. The consultation letter sought views on eight specific aspects of services for children with special needs:

1. The early identification and diagnosis of special health needs. In many cases early diagnosis and intervention can eliminate or minimise problems, for example with speech, hearing or behavioural disorders. Children who are excluded from access to primary care (eg from groups such as travellers, asylum seekers, some ethnic minorities, homeless or unstable families) may miss the opportunity for early diagnosis. What needs to be done to ensure equality of access?

2. The provision of information to parents / guardians. Following the diagnosis do parents receive the information they need on the prognosis for the illness or disability; the treatment, care and associated special needs; the choices and range of services available; and the implications for other family members? How is this information provided?

3. The co-ordination of care. Is the treatment and overall care planned and co-ordinated effectively between the various agencies and the family to meet the needs of the child?

4. Availability of care and treatment. Are the NHS and other agencies able to respond to the demands for treatment and other care services? (This includes services provided for children in schools such as the administration of medication.) If not what are the shortfalls? How can they be overcome in the short term and in the long term?

5. Support for Families and other carers. Do the families and other carers of children with special health needs receive the support they need in coping with a child with special health needs as well as meeting the needs of other children in the family, and in receiving respite care?

6. Equipment and other social service needs. Are children with special health needs assessed within an acceptable time for aids, adaptations, equipment or other services they need and do they receive the aids, adaptations, equipment or other services that have been identified quickly enough? The definition of an acceptable time will vary according to the individual circumstances of the child.

7. Children with special educational needs. Are the arrangements effective for the delivery of health services, such as speech therapy, to those who are in mainstream schools?

8. Good practice. What arrangements are needed to evaluate services and to promote and identify good practice?

3. The review was also advertised in the following journals:

- Community Care
- Community Practitioner
- Nursing Times
- Western Mail
- Liverpool Daily Post.

4. 46 responses were received by the closing date on 19 December 2001. A further 21 were

received after the close. Following consideration of the responses, 18 organisations were selected to give oral evidence to the Committee at sessions being held in Cardiff, Brecon and Rhyl. These organisations represent a wide range of interests, including parents groups, voluntary organisations, NHS, local authorities and a headmaster.

Emerging Findings

5. The first session was held in Cardiff on 6 February, where a number of core themes were discussed reflecting what had emerged in the responses to the written consultation:

- Provision of speech and language therapy;
- The need for key workers to co-ordinate the work between agencies;
- Provision of respite care.

6. The Committee was concerned that no response had been received from any speech and language therapy organisations and has asked that a slot be made available at a future meeting.

7. The Committee is still on course to report by June.

Literature Review

8. In parallel to the Committee's work, the Wales Office of Research and Development has commissioned a literature review from the Department of Child Health, University of Wales College of Medicine working in conjunction with the Families Study Research Centre of Cardiff University (a joint initiative between Cardiff University and the University of Wales College of Medicine). The primary purpose of this work is to inform the Health and Social Services Committee's review, but the work will have value for professionals and other interested organisations beyond the immediate needs of the Committee's review.

9. The literature review contains seven components, each of which will consider, where appropriate, the eight issues identified by the Committee and included in the public consultation letter. The seven components are:

- mobility;
- sensory impairment;
- emotional / behavioural difficulties / mental health;
- learning disability, autism (and related spectrum disorders);
- long term ventilation;
- life limiting illnesses; and
- children who are looked after in placements.

10. The report of the literature review will be available by the end of March, with an oral presentation on its findings being made to the Committee in April.

Committee Secretariat 12 February 2002

Annex

Terms of Reference

The terms of reference for the review are:

- i. To review the availability of primary care, community and social care services for children with special health needs, including services provided in schools and through the medium of Welsh.
- ii. To make recommendations on how those services might be improved so that children with special health needs have the treatment, care and associated services they need to develop their full potential and live as independently as possible.
- iii. To identify good practice in cross-agency working in meeting special health needs and providing co-ordinated primary care, community and social care services that are

centred on the needs of the individual child.

- iv. To report to the National Assembly for Wales in Plenary on the above by June 2002.

For the purposes of the review "children with special health needs" are defined as those who are physically impaired, or who have complex or chronic medical conditions; or who have emotional, behavioural or learning difficulties associated with a diagnosed medical condition.