

Date: Wednesday 19 June 2002
Venue: Committee Room 2, National Assembly for Wales
Title: Review of Services for Children with Special Health Needs

Purpose

1. The Committee is to consider the evidence it has received in writing, orally and through the presentation of the literature review. The literature review was commissioned by the Wales Office of Research and Development and undertaken by the Department of Child Health and the University of Wales College of Medicine.

Background

2. 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.

3. The remit of the review is wide ranging and encompasses children with many different special health needs and the services that support and care for them. The Committee has received evidence from health and social care professionals, voluntary organisations and the parents and carers of children with special health needs.

4. The Committee's first step was to undertake written consultation last autumn. The consultation letter invited views on eight key aspects of service and care. These points were also the basis for the oral evidence and for the literature review. The literature review examined the evidence in published literature for seven different client groups. In addition groups of members have made visits to voluntary sector organisations providing services for children with special health needs and their families.

The Evidence

5. A summary of the written evidence was provided for the Committee meeting on 9 January ([HSS-01-02 \(p2\)](#)). A list of individuals and organisations that gave oral evidence is annexed.

6. The evidence from all sources has revealed common areas of concern. These are outlined below as an initial focus for the Committee's discussion, but there may be other issues members also wish to highlight and discuss. The italicised, numbered headings below are those of the eight key aspects of service and care covered in the consultation letter of 22 October.

1. The early identification and diagnosis of special health needs.

7. Parents and practitioners have emphasised the importance of early diagnosis and intervention. The Committee received conflicting views on the recommendations on child surveillance in the draft fourth edition of the report of the joint working party chaired by Professor David Hall, President of the Royal College of Paediatrics and Child Health. The draft report, "Health for All Children" says that there should be a universal programme plus additional services targeted to those who need them. This would mean that after the third dose of vaccine at 4 months the health visitor should negotiate the nature of further reviews with parents/carers according to need, rather than conducting further routine visits at defined intervals.

8. Specific action is needed to reach families in minority groups who may be excluded from primary health care services.

2. The provision of information to parents / guardians.

9. Parents and carers have stressed that information on diagnosis and prognosis needs to be given in the right environment and in a way that is sensitive to the needs and capacity of parents to absorb and cope. The needs of the child and any siblings to understand should also be addressed. Families should have the facility to go away and digest information and to have a follow up session or counselling to talk about their questions and concerns.

10. Those giving information need to be properly trained and systems should ensure that information is kept up to date.

3. The co-ordination of care.

11. Lack of co-ordination between the various agencies was a cause of concern in some areas, although there was evidence that good work was being done in places.

12. The provision of a key worker / care co-ordinator has been demonstrated to be beneficial to the family in accessing and planning care. This was evidenced from the literature review and also from the experiences of the families and voluntary sector.

13. Oral health is often overlooked and the community Dental Service needs to be involved in care planning.

14. Young people often find the transition from children's services to adult services traumatic.

4. Availability of care and treatment.

15. Many of those who gave evidence referred to the shortage of therapy services and training provision, particularly in respect of speech therapy. The literature review indicates that there is little evidence and evaluation of therapy services. There are issues about how children's needs for therapy are assessed and the role that parents and other carers or classroom assistants can play in delivering a programme of therapy.

5. Support for Families and other carers

16. Families receive invaluable support from organisations in the voluntary sector that specialise in specific conditions. The other form of support that is much valued is respite care. This benefits the child, the parents and siblings. However, provision across Wales is patchy and much comes through the voluntary sector. There are difficulties with providing for physically disabled children who may need special equipment / handling arrangements and for others with complex needs.

6. Equipment and other social service needs.

17. Delays in supplying equipment mean the child may have outgrown it before receiving it. Similarly, repairs to equipment take time. Wheelchairs are a particular problem, as they have to be customised. They also need to be lightweight so that children can move quickly in them and to have attractive design features that will improve the child's credibility with his or her peers.

18. The process for applying for equipment can be too bureaucratic.

19. In some areas there are problems over which agency is responsible for providing equipment, with both the NHS trust and the local authority having equipment stores. This is confusing for clients and causes delays while funding responsibility is disputed. Many areas do not have joint budgets or shared

arrangements for commissioning and storage.

20. Housing adaptations can take too long and contributions expected from owner-occupier parents can be prohibitive.

7. Children with special educational needs.

21. The underlying philosophy for including children with special health needs in mainstream schools was generally appreciated, but there are still problems in delivering services due to lack of facilities, disruption to the child's lessons for treatment or therapy and stigmatisation. There are also practical problems in therapists and nurses having to travel to more schools to treat fewer children in each. Teachers do not always have enough information about a child's medical condition and treatment. There can be problems over the administration of medicines or invasive treatments.

8. Good practice.

22. Several organisations gave evidence of their practice, particularly in the areas of joint working and planning. However, there was little or no evidence of whether and how good practice is evaluated or benchmarked.

23. The Committee is invited to consider the evidence with a view to reaching conclusions on the adequacy of current service delivery and making recommendations on improvements that should be made.

ANNEX

ORGANISATIONS WHICH GAVE ORAL EVIDENCE

The organisations which gave oral evidence to the Committee are listed below, with hyperlinks to the relevant papers and minutes of the meetings. In addition some supplemented their evidence with material in hard copy. Also shown is which organisations gave evidence on the eight key aspects of care and service identified for the initial consultation.

6 February 2002

Cardiff and the Vale Parents Federation

[HSS-04-02\(p.2a\)](#)

Downs Syndrome Association

[HSS-04-02\(p.2b\)](#)

Newport County Borough Council	<u>HSS-04-02(p.2c)</u>
All Wales Special Interest Group - Oral Health Care	<u>HSS-04-02(p.2d)</u>
Cardiff and the Vale NHS Trust	<u>HSS-04-02(p.2e)</u>
Caerphilly Local Health Group	<u>HSS-04-02(p.2f)</u>
Minutes	<u>HSS-04-02(min)</u>

14 February 2002

Afasic	<u>HSS-05-02(p.1a)</u>
Ceredigion and Mid Wales NHS Trust and Ceredigion Social Services	<u>HSS-05-02(p.1b)</u>
Chartered Society of Physiotherapy	<u>HSS-05-02(p.1c)</u>
All Wales Heads of Occupational Therapy Committee	<u>HSS-05-02(p.1d)</u>
Contact A Family	<u>HSS-05-02(p.1e)</u>
Bridgend County Borough Council	<u>HSS-05-02(p.1f)</u>
Minutes	<u>HSS-05-02(min)</u>

27 February 2002

North East Wales Carer Information Service	<u>HSS-06-02(p.1a)</u>
Association of Spina Bifida and Hydrocephalus	<u>HSS-06-02(p.1b)</u>
Ysgol y Gader	<u>HSS-06-02(p.1c)</u>
North East Wales NHS Trust	<u>HSS-06-02(p.1d)</u>
Gwynedd Sure Start	<u>HSS-06-02(p.1e)</u>
Royal College of Nursing	<u>HSS-06-02(p.1f)</u>

Minutes

[HSS-06-02\(min\)](#)

13 March 2002

Speech and Language Therapists

[HSS-07-02\(p.4\)](#)

Minutes

[HSS-07-02\(min\)](#)

25 April 2002

Professor Jo Sibert and colleagues
University of Wales College of Medicine
(literature review)

[HSS-10-02\(b\)](#)

[HSS-10-02\(c\)](#)

[HSS-10-02\(d\)](#)

[HSS-10-02\(e\)](#)

[HSS-10-02\(f\)](#)

[HSS-10-02\(g\)](#)

[HSS-10-02\(h\)](#)

[HSS-10-02\(i\)](#)

[HSS-10-02\(j\)](#)

The Eight Key Aspects of Service and Care

1. The early identification and diagnosis of special health needs

- Cardiff and Vale Parents Federation
- Newport County Borough Council
- Cardiff and Vale NHS Trust
- All Wales Professional Heads of Occupational Therapy
- Afasic
- Sally Rees, Carer's Fieldworker
- North East Wales NHS Trust
- Royal College of Nursing
- Professor Jo Sibert

Supplementary evidence

- Gwynedd Sure Start on Caernarfon Community Group

2. The provision of information to parents/guardians

- Cardiff and Vale Parents Federation
- Downs Syndrome Association
- Cardiff and Vale NHS Trust
- Caerphilly Local Health Group
- Afasic
- Contact a Family
- Sally Rees, Carer's Fieldworker
- Association of Spina Bifida and Hydrocephalus
- Ysygol y Gader
- Professor Jo Sibert

Supplementary evidence

- Chartered Society of Physiotherapists

3. The co-ordination of care

- Cardiff and Vale Parents Federation
- Downs Syndrome Association
- Newport County Borough Council
- All Wales Special Interest Group – Oral Health
- Cardiff and Vale NHS Trust
- Afasic
- Contact a Family
- Sally Rees, Carer's Fieldworker
- Association of Spina Bifida and Hydrocephalus
- Ysygol y Gader
- Royal College of Nursing
- Professor Jo Sibert

Supplementary evidence

- Contact a Family (Wrexham)

4. Availability of care and treatment

- Cardiff and Vale Parents Federation
- Downs Syndrome Association
- Newport County Borough Council
- Cardiff and Vale NHS Trust

- Caerphilly Local Health Group
- Afasic
- Ceredigion and Mid Wales NHS Trust
- Chartered Society of Physiotherapists
- All Wales Professional heads of Occupational Therapy
- Contact a Family
- Bridgend County Borough Council
- Sally Rees, Carer's Fieldworker
- Association of Spina Bifida and Hydrocephalus
- Ysygl y Gader
- North East Wales NHS Trust
- Gwynedd Sure Start
- Royal College of Nursing
- Professor Jo Sibert

Supplementary evidence

- Caerphilly Local Health Group
- Ceredigion and Mid Wales NHS Trust
- Gwynedd Sure Start on Caernarfon Community Group

5. Support for families and other carers

- Cardiff and Vale Parents Federation
- Downs Syndrome Association
- Cardiff and Vale NHS Trust
- Newport County Borough Council
- Afasic
- Ceredigion and Mid Wales NHS Trust
- Contact a Family
- Sally Rees, Carer's Fieldworker
- Association of Spina Bifida and Hydrocephalus
- Ysygol y Gader
- Gwynedd Sure Start
- Professor Jo Sibert

Supplementary evidence

- Contact a Family (Wrexham)

6. Equipment and other social service needs

- Cardiff and Vale Parents Federation
- Downs Syndrome Association
- Newport County Borough Council
- Caerphilly Local Health Group
- Afasic
- Chartered Society of Physiotherapists
- Sally Rees, Carer's Fieldworker
- Association of Spina Bifida and Hydrocephalus
- North East Wales NHS Trust
- Royal College of Nursing
- Professor Jo Sibert

Supplementary evidence

- Caerphilly Local Health Group
- Contact a Family (Wrexham)

7. Children with special educational needs

- Cardiff and Vale Parents Federation
- Downs Syndrome Association
- Caerphilly Local Health Group
- Afasic
- Chartered Society of Physiotherapists
- All Wales Professional Heads of Occupational Therapy
- Contact a Family
- Bridgend County Borough Council
- Ysygol y Gader
- Royal College of Nursing
- Professor Jo Sibert

Supplementary evidence

- Gwynedd Sure Start on Caernarfon Community Group

8. Good practice

- Cardiff and Vale Parents Federation
- Downs Syndrome Association
- Newport County Borough Council
- Caerphilly Local Health Group
- Ceredigion and Mid Wales NHS Trust

- Contact a Family
- Bridgend County Borough Council
- Sally Rees, Carer's Fieldworker
- Association of Spina Bifida and Hydrocephalus
- North East Wales NHS Trust
- Gwynedd Sure Start
- Royal College of Nursing

Supplementary evidence

- Gwynedd Sure Start on Caernarfon Community Group
- Contact a Family (Wrexham)