

Date: Thursday 18 October 2001

Venue: Committee Room 1, National Assembly for Wales

Title: Review of Services for Children with Special Health Needs

Purpose

1. The Committee is invited to agree:

- the terms of reference for the review
- the key issues it should address;
- the public consultation letter together with the list of consultees and journals in which to advertise the review;
- draft work programme.

Timing

2. It is important that the Committee agrees these issues so that the public consultation exercise can be completed by the end of the year.

Background

3. When the Committee met on 18 July it agreed that the review should cover health and social care services for all children with special health needs, including the early diagnosis of special health needs and the provision of therapeutic services.

Cross-cutting Issues

4. The Education and Lifelong Learning Committee and the Local Government and Housing Committee have been invited to contribute to the review.

Terms of Reference

5. The draft terms of reference set out below take account of consultation in June with external organisations and further consultation with Assembly policy division and professional staff following the committee meeting on 18 July.

- i. To review the availability of primary care, community and social care services for children with special health needs.
- 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.

The Key Issues

6. The preliminary consultation identified the following as the key issues and it is suggested that they be the basis for wider public consultation.

i. 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?

ii. 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?

iii. 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?

iv. Availability of care and treatment. Are the NHS and other agencies able to respond to the demands for treatment and other care services? If not what are the shortfalls? How can they be overcome in the short term and in the long term?

v. Support for Families. Do the families 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?

vi. 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?

vii. 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?

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

Current Relevant Work

7. The Committee wanted to ensure that their work did not duplicate current or recent work elsewhere. Policy Division officials have advised that the following will be relevant to the Committee's review:

i. the National Assembly has commissioned the National Children's Bureau to undertake a study of resuscitation in schools.

ii. A Therapy working Group is looking at the problems associated with providing appropriate and timely programmes of speech and language, and other therapies to children in Wales. The group comprises officials from the Assembly, LEAs, Health Authority and Trust Managers, therapists, voluntary and other relevant organisations. It is preparing its report which will be submitted to the Minister in the near future.

iii. The Audit Commission is embarking on a study of services for disabled children, young people and their families. This is an England / Wales study.

iv. A stocktake of universal neonatal hearing screening is being undertaken

v. Work on developing a National Service Framework (NSF) for children has just commenced. NSFs set national standards and define service models for a specific service or care group.

vi. The Carlile review is examining child protection in the NHS – the report will be presented to the Minister by the end of 2001

vii. The Children First programme aims to improve services and outcomes for all children in need. This includes Children and families whose main need for services arises out of

the children's disabilities or intrinsic condition. This may include children with physical disabilities, children with sensory disabilities, children with learning disabilities (special educational needs), and children with emotional or behavioural difficulties where those difficulties are attributed to a medically diagnosed condition. Relevant key objectives are:

- To ensure that children in need gain maximum life chance benefits from education opportunities, health care and social care.
- To ensure that children with specific social needs arising out of disability or a health condition are living in families or other appropriate settings in the community where their assessed needs are adequately met and reviewed
- To ensure that referral and assessment processes discriminate between different types and levels of need, produce a timely and effective service response and actively involve users and carers in tailoring individual packages of care.
- To actively involve users and carers in planning services.

viii. **SSIW survey of services for disabled children in Wales.** SSIW recently commissioned a survey of local authorities' arrangements for the planning, management and delivery of services for disabled children and for young carers in Wales. The survey is intended to help identify the areas that might benefit from a Wales-wide approach in terms of strategic planning and consistency of service delivery. The survey results are currently being analysed.

ix. **revised Code of Practice on Children with Special Education Needs.** Subject to necessary changes in SEN Regulations, the Assembly plans to issue a revised SEN Code of Practice in Wales later this year, with relevant bodies having to have regard to it from a date to be determined in 2002.

x. **guidance on Improving the Health of Looked After Children** is in preparation and will be published next year;

xi. **The Framework for the Assessment of Children in Need and their Families** was published in Wales in June. The Framework provides a systematic way of understanding, analysing and recording what is happening to children and young people within their families and the wider context in which they live. Practice Guidance published alongside the Framework deals in detail with the needs of disabled children and their families.

Draft Work Programme

8. If the Committee agrees the draft consultation letter at annex 1 it will be issued by the end of the

week. The Committee's programme could then be:

5 December 2001	Results of Literature Review to Committee
19 December	Closing date for responses to public consultation
9 January 2002	Committee to consider responses to consultation, evidence from the literature review and to decide whom to invite to give oral evidence to the Committee
February / March	Taking oral evidence and members undertaking visits. (possibility of a committee meeting in N Wales)
April / May	Discussion of evidence and conclusions
June	Report approved by Committee and laid.

**Committee Secretariat
October 2001**

Annex 1

DRAFT CONSULTATION LETTER

REVIEW OF SERVICES FOR CHILDREN WITH SPECIAL HEALTH NEEDS

The Health and Social Services Committee of the National Assembly is undertaking a review of health and social care services for children with special health needs.

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.

- 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.

The Committee has identified the following key issues and I am writing to invite you to submit written evidence on them:

- 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?
- 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? If not what are the shortfalls? How can they be overcome in the short term and in the long term?
- 5. Support for Families.** Do the families 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?

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?

If you wish to submit evidence please send it, preferably by e-mail or on disk, but otherwise in hard copy to Claire Morris, Deputy Clerk, Health and Social Services Committee, National Assembly for Wales, Cardiff Bay CF99 1NA.

E-mail address: health-soc-serv.comm@wales.gsi.gov.uk. **Submissions should arrive no later than Wednesday 19 December 2001.**

When putting together your submission would you please keep the following on mind:

- Evidence should be factual rather than anecdotal.
- Your response should be as succinct as possible.
- Please make it clear which of the key issues you are addressing by referring to the number.
- It would also be helpful if you would indicate whether your response relates to a specific type or types of special health needs.
- The National Assembly normally publishes responses to public consultation. **If you do not want your response or name published it is important that you specify this at the end of your submission.**
- Please indicate whether you are responding on behalf of an organization, or as an individual.
- Please indicate whether or not you would be prepared to give oral evidence to the Committee.

The Committee will consider responses to the written consultation early in the New Year before taking oral evidence in February and March.

If you have any queries please contact me (on the number at the foot of the page) or Claire Morris, the Deputy Clerk (tel 029-2089 8148).

Jane Westlake
Clerk to the Committee

Proposed Consultation List

All Wales Chief Pharmacists NHS Trusts Committee
All Wales Committee for Healthcare Professions
All Wales Special Interest Group in Special Dental Needs
Association of Optometrists
Association of Welsh Community Health Councils
British Association of Community and Child Health
British College of Optometrists
British Society for Disability and Oral Health
British Society of Paediatric Dentistry
British Dental Association (Wales)
British Diabetic Association
British Dietetic Association
British Orthoptic Society
Chartered Society of Physiotherapy
Clinical Effectiveness Support Unit
Commission for Racial Equality - Policy Development Officer
Community Dental Services Clinical Directors
Community Practitioners and Health Visitors Association
Dean of the Dental School
Director of Dental Postgraduate Education
Directors of Pharmaceutical Public Health Group
Guild of Healthcare Pharmacists
Health Authorities - Chairs
Health Authorities Chief Executives
Health Authorities - Directors of Dental Public Health
Institute of Health Services Management - Welsh Division
Local Authorities - Directors of Education
Local Authorities - Directors of Social Services
Local Authorities Chief Executives
Local Health Groups - Chairs
Medical Physics Sub-Committee of the National Assembly Welsh Scientific Advisory Committee
Medical Practice Committee
National Association of Principal Educational Psychologists
National Family and Parenting Institute
NHS Confederation in Wales
NHS Staff College
NHS Trusts - Chairs

NHS Trusts Chief Executives
Royal College of General Practitioners
Royal College of Nursing
Royal College of Paediatrics and Child Health
Society of Chiropodists & Podiatrists
Society of Radiographers - Regional Officer for Wales
UNISON Health Group - Regional Head of Health
University of Wales Bangor - Dean of Faculty
University of Wales College of Medicine - Department of Community Child Health
Wales TUC - General Secretary
Welsh Central Pharmaceutical Committee
Welsh Dental Committee
Welsh Executive, Royal Pharmaceutical Society
Welsh Federation of Housing Associations
Welsh Local Government Association
Welsh National Board for Nursing, Midwifery & Health Visiting
Welsh Nursing & Midwifery Advisory Committee
Welsh Pharmaceutical Committee
Welsh Secretary, British Medical Association
WNMC Children's Services Sub-committee
United Kingdom Central Council for Nursing, Midwifery and Health Visiting
Dr Hywel Williams, Bro Taf
Dr Chris Vulliamy, Dyfed Powys
Dr Aideen Naughton, Gwent
Dr Alison Maddocks, Morgannwg
Dr Carys Graham, North Wales
Ms Sue Pearson, Bro Taf
Ms Rae Pearsall, Dyfed Powys
Ms Lin Slater, Gwent
Ms Dilys Calder, Morgannwg
Mrs Joyce Hughes, North Wales

Access for Black Children with Disabilities Project Cardiff
Advisory Centre for the Visibly Impaired
All Wales Forum of Parents and Carers
All Wales People First
Association for All Speech Impaired Children
Association for the Welfare of Children in Hospital
Association of Crossroads Care Attendant Schemes

Association of Directors of Social Services
Association of Educational Psychologists
Association of Voluntary Organisations in Wrexham
Association of Workers for Children
Barnardo's
Bobath Children's Therapy Centre
Bridgend Association of Voluntary Organisations
British Agencies for Adoption & Fostering
British Association of Teachers of the Deaf
British Deaf Association
Carers National Association
Carmarthenshire Association of Voluntary Services
Catholic Children & Family Care Society (Wales)
Ceredigion Association of Voluntary Services
Child & Family Centre
Childline Cymru
Children's Cancer Support Service
The Children's Disability Forum
Children in Wales
The Children's Society
Christian Lewis Trust
Churches Counselling Service in Wales
Chwarae Teg
Circles Network
Contact a Family
Conwy Council for Voluntary Services
Community Service Volunteers
Council for Wales of Voluntary Youth Services
County Mental Health Development
Cynnydd - Wales Youth Justice Forum
Denbighshire Voluntary Services Council
Depression Alliance
Disability Wales
Disability Rights Commission
Down's Syndrome Association
Drugaid
Dyslexia Association of South and Mid Glamorgan
Early Childhood Development Centre
Epilepsy Wales
Equal Opportunities Commission
Flintshire Local Voluntary Council
Glamorgan Dyslexia Association
Gwent Association of Voluntary Organisations

Gwent Dyslexia Association
Gwynedd Dyslexia Association
Gwynedd Voluntary Services
Home Start
Homes Fit for Children
Llais Ifanc
Manic Depression Fellowship
MENCAP in Wales
Merthyr Tydfil Voluntary Action
MIND Cymru
Mudiad Ysgolion Meithrin
National Association for Sick Children / Action for Sick Children
National Autistic Society
National Deaf Children's Society
National Schizophrenia Fellowship
NCH Action for Children
Neath Port Talbot Council for Voluntary Services
North East Wales Dyslexia Association
NSPCC Cymru
Pembrokeshire Association of Voluntary Organisations
PHAB Wales
Play Wales
Powys Association of Voluntary Organisations
Powys Dyslexia Association
Rescue Foundation for the Brain Injured Infant
RNIB
RNID
Save the Children
Scope
SCOVO
SENSE Cymru
Special Needs Advisory Project - Cymru
Swansea Council for Voluntary Service
Torfaen Voluntary Alliance
Ty Hafan Children's Hospice
US Network
Vale of Glamorgan Council of Voluntary Services
Voices from Care
Voluntary Action Cardiff
Wales Association of Youth Clubs
Wales Council for the Blind
Wales Council for the Deaf
Wales Council for the Disabled

Wales Council for Voluntary Action
Wales Pre-School Playgroups Association
Wales Senior Children's Nursing Forum
Wales Youth Agency
Wales Youth Work Partnership
Welsh Women's Aid
West Wales Dyslexia Association
Workers
Youthlink Wales
Ynys Môn Voluntary Services
Colin Hughes

Journals

British Dental Journal
Community Care
Community Practitioner
Community Dental Health
Special Children

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