

Health and Social Services Committee

HSS-18-02(p.5)

Date: Wednesday 23 October 2002
Venue: Committee Rooms 3 & 4, National Assembly for Wales
Title: Review of Services for Children with Special Health Needs
Draft Report

Purpose

1. The committee is invited to consider:

- the draft report, annexed to this paper, in the light of the members' comments and also the paper on Child Health Surveillance (HSS-18-02(4));
- arrangements for publication of the report.

Publication

2. If the text of report is agreed at the meeting, it should be possible to have it translated and printed by early December. This would enable it to be distributed before the peak pressure on pre-Christmas post. The report could then be launched formally in December, possibly at a venue outside Cardiff.

Committee Secretariat
October 2002

REVIEW OF SERVICES FOR CHILDREN WITH SPECIAL HEALTH NEEDS

A REPORT BY THE HEALTH & SOCIAL SERVICES COMMITTEE

FOREWORD BY THE CHAIR OF THE COMMITTEE

In June 2001, the Health and Social Services Committee looked at policy and practice relating to the health and wellbeing of children. There was particular concern about the services that were available to children with special health needs and their families and carers, and the Committee decided that it should undertake a policy review of certain elements of these services.

The Committee identified eight key aspects of service on which the review focussed. We took evidence from professionals and voluntary organisations working in the field and from parents and carers. Not surprisingly, much of the evidence was anecdotal as it related to people's experience and perception of services they need and receive. In the time available it has not been possible to examine all the evidence received in detail, but the Committee has concentrated on those areas where there has been common concern or conflicting views.

Our overall conclusion is that there are pockets of apparent good practice across Wales, but more needs to be done to ensure that families receive the best services from initial diagnosis through to a smooth transition to adult services. This can only be achieved by the sharing of validated good practice and cohesive working between the various agencies and the families and carers.

On behalf of the Committee I should like to thank everyone who submitted evidence, both written and oral, but especially those parents and carers who took time away from their families to come and talk to the Committee about their experiences, both positive and negative.

Our thanks also go to Professor Jo Sibert and his team for the comprehensive literature review, which I hope will be a useful reference document for all who work with children and their families. The Committee is grateful for the support it has received from the Minister and officials of the Welsh Assembly Government in conducting the review.

We now look forward to receiving the response of the Minister and her cabinet colleagues to our recommendations.

KIRSTY WILLIAMS AM
Chair, Health and Social Services Committee

Members of the Health and Social Services Committee

Kirsty Williams (Chair)	Brecon and Radnorshire
Geraint Davies	Rhondda
Jocelyn Davies	South Wales East (<i>from 21 March 2002</i>)
Brian Gibbons	Aberavon
Brian Hancock	Islwyn (<i>until 21 March 2002</i>)
Jane Hutt (<i>Minister</i>)	Vale of Glamorgan
Ann Jones	Vale of Clwyd
Dai Lloyd	South Wales West
David Melding	South Wales Central
Lynne Neagle	Torfaen
Rod Richards	North Wales (<i>until 10 September 2002</i>)

Gwenda Thomas, Neath, represented the interests of the Local Government and Housing Committee.

Cynog Dafis represented the interests of the Education and Lifelong Learning Committee

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1. SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

The Early Identification and Diagnosis of Special Health Needs

Conclusions:

- the Committee is concerned pregnant women in some areas are only offered screening if they agree to terminate the pregnancy in the event of an abnormality;
- the Committee is concerned that changing the pattern of surveillance of young children from routine health visiting may disadvantage vulnerable families and children. The Committee notes that it is proposed that the National Service Framework for children will provide a vehicle for co-ordinated all-Wales standards.

Recommendations:

R1. Where an early diagnosis cannot be made, access to appropriate services should be made far more flexible for parents and their children, pending diagnosis.

R2. The recommendations of the Chief Medical Officer's working group on child health surveillance should be widely disseminated and taken into account in the development of the National Service Framework.

R3. Local Health Boards should develop strategies to ensure that low birth weight babies and the children of disadvantaged families, travellers and transient families, young lone parents and ethnic and other minority groups have access to diagnostic services.

R4. Where appropriate, pre-conceptual genetic counselling should be offered.

R5. An evidence based antenatal screening should be available unconditionally to all pregnant women.

Provision of Information to Parents and Guardians

Conclusions:

- continuing, comprehensive information should be provided in a variety of settings;
- people giving information should be properly trained

Recommendation

R6. Information at the time of diagnosis should be planned in advance and be sensitive to the parents' needs. Parents should have the opportunity for further discussion with the specialist or other appropriate practitioner after they have had time to reflect upon the diagnosis.

R7. Parents/ guardians should be given comprehensive advice from a designated and trained person at the time of diagnosis, including information on the support and advice available from the voluntary sector.

Co-ordination of Care

Conclusions:

- case conferences should be arranged using technology (but safeguarding confidentiality) to enable as many as possible of the interested parties to be involved;
- a key worker should provide a constant point of reference, advice and advocacy;
- new flexibilities in funding should be utilised to enhance joint working between agencies;
- the transition between children and adult services should be planned in advance;
- the role of the Community Dental Service should be protected.

Recommendations

R8. Good practice should be disseminated to help overcome some of the difficulties in co-ordinating resources and services.

R9. The early appointment of a key worker or care co-ordinator is recommended in all cases where the child needs services or care from one or more specialty or service.]

R10. The potential for extending the use of the existing parent held record and the introduction of electronic records as a means of sharing information between agencies should be explored.

R11. Agencies should be encouraged to make better use of the funding flexibilities and to pool budgets.

Availability of Care and Treatment

Conclusions

- Better ways of co-ordinating and managing speech and language therapy services are needed in the short term;
- The recommendations of the Professor Clark's report on school nursing services should be fully implemented.
- Protocols should be agreed between the local health board and the education authority on the administration of medication for children in school

Recommendations

R12. The Welsh Assembly Government, together with the UK government, should review the speech and language therapy service and draw up strategies for meeting the shortfalls in the short term and in the long term.

R13. The feasibility of the position of speech therapy assistants should be explored to undertake, under supervision, basic therapy services..

R14. The recommendations of Professor Dame June Clark's report on school nursing services should be fully implemented.

Support for Families and Other Carers

Conclusions:

- services should be flexible to meet the differing needs of families;
- a comprehensive respite service should be available for all children from a young age.

Recommendations

R15. Guidance on support for families of young children with special health needs, including examples of good practice, should be issued to all statutory and voluntary agencies in Wales. It is recommended that this be part of the Children's National Service Framework.

R16. The provision of effective and flexible respite services must be seen as a prerequisite for sustainable caring responsibilities within families.

R17. The Welsh Assembly Government should encourage each local authority to support a "Special Needs Support and Advice Centre" to provide services for children and support for carers and families.

Equipment and Other Social Service Needs

Conclusions:

- the supply of equipment and monitoring of its use needs to be co-ordinated ;
- the Committee noted problems experienced by families in having their homes adapted.

Recommendations

R18. The Committee recommends that the supply of equipment should be formally co-ordinated between the statutory agencies with a designated lead agency in every area. The arrangements should include the pooling of equipment budgets, management of stores and monitoring of use.

R19. The Committee's concerns about the terms of the legislation on disabled facilities grants and the process for applying should be brought to the attention of the UK Government with the request that it be reviewed.

R20. Particular care should be taken to ensure that aids, equipment and adaptations are fit for purpose and child centred. This requires regular reappraisal of the suitability of materials as children grow older.

Children with Special Educational Needs

Conclusions

- Parents should be able to choose the type of school best suited to their child.

Recommendations

R21. There is much apparent good practice in special needs education around Wales that should be validated and disseminated.

R22. The move to special needs provision within a mainstream setting should be welcomed, but greater emphasis should be placed on the monitoring of special needs services so that they do not become diluted.

R23. The National Service Framework for children should contain a detailed sub section on special education and health needs.

R24. A member of the board of each local health board in Wales should be designated as responsible for children's services and children's rights.

R25. The situation of children aged under five years with severe health needs requires urgent attention so that they receive appropriate pre-school education.

Good Practice

Conclusion and Recommendation:

R26. Good practice needs to be evaluated and benchmarked. The National Service Framework should provide for systems to be established at strategic and operational level to evaluate and benchmark services and to research and validate good practice. It should also provide the mechanisms for disseminating good practice and for statutory and voluntary organisations to share experience.

2. INTRODUCTION AND APPROACH

2.1. At its meeting on 6 June 2001, the Health and Social Services Committee agreed that it would 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. Cynog Dafis AM and Gwenda Thomas AM respectively represented those committees.

2.2. Informal consultation on the terms of reference and work programme took place during the summer, and at its meeting on 18 October 2001 the Committee agreed the following terms of reference:

- ◆ 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.
- ◆ 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.
- ◆ 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.
- ◆ 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" were 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.

Process

2.3. On 22 October the Clerk to 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 as follows:

"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?"

2.4. The review was advertised in the following publications:

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

2.5. 46 responses were received by the closing date of 19 December 2001 but due to postal delays over Christmas, it was agreed to accept a further 21 responses that were received after that date. The respondents are listed at Annex 2.

2.6. On 9 January 2002, the Committee considered the written responses received and selected 18 organisations to give oral evidence at committee meetings held in Cardiff, Brecon and Rhyl (Annex3) . These organisations represent a wide range of interests, including parents' groups, voluntary organisations, NHS, local authorities and a school.

Literature Review

2.7. In parallel with the Committee's work, the Wales Office of Research and Development 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 was to inform the Health and Social Services Committee's review, but its findings should have value for professionals and other interested organisations beyond the immediate needs of the Committee's review.

2.8. The literature review contains seven components, each of which considers, 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.

2.9. The literature review was completed in March 2002 and the findings presented to the Committee on 25 April.

2.10. The report of the literature review is available on the Internet at www.wales.gov.uk/keypubassemhealth/content/hssreports-e.html

3. THE EVIDENCE AND THE COMMITTEE'S FINDINGS

3.1 THE EARLY IDENTIFICATION AND DIAGNOSIS OF SPECIAL HEALTH NEEDS

3.1.1. Most of those who gave evidence stressed the importance of early diagnosis and intervention. Primary Care services were said by many to be the catalyst for early referral and diagnosis. GPs, health visitors, and specialist community paediatric nurses should receive training and support in these areas. Some parents and their representative organisations spoke of the length of time it took to obtain a diagnosis, because the parent had been unable to convince their GP that there was something the matter with their child.

3.1.2. Some respondents advocated universal neo-natal screening and the Specialised Health Service Commission for Wales said that effective genetic services were crucial to early detection. The literature review does not indicate evidence for screening for all special needs apart from hearing, vision, hypothyroidism and phenylketonuria. Formal screening plays little part in the early diagnosis and intervention in high severity – low prevalence conditions such as cerebral palsy; muscle disease, autistic spectrum disorder and learning difficulties.

3.1.3. Other parents were concerned that the availability and quality of antenatal counselling was patchy. Early scans could indicate that there might be more severe problems than materialised at birth, but some parents had felt that they were being pressurised into termination. It was important that parents were given balanced information. One witness reported that she was aware of an antenatal clinic where scans were refused unless parents indicated a willingness to terminate the pregnancy.

3.1.4. In some places there were still barriers to effective working between health and social services departments which hindered an integrated approach to early diagnosis, counselling and assessment of needs. One witness suggested that the advent of Local Health Boards should improve partnership working.

3.1.5. Many witnesses pointed to inequalities of access to health services experienced by ethnic and other minority groups, especially for families whose first language was not English or Welsh. There are few health advocates for these groups and their needs are often unrecognised. In Newport the number of children registered disabled from minority groups is relatively low, despite evidence of poor health among such children. The authority is developing its strategy for improving their take-up of services.

3.1.6. The Committee received conflicting views from paediatricians on the proposed guidance on child health surveillance in the draft fourth edition of the Royal College of Paediatrics and Child Health (the "Hall Report"). Community paediatricians and school nursing sisters from the NE Wales NHS Trust questioned the assumptions in the report that most children were diagnosed at birth or in hospital. In their experience most were diagnosed through community health services. They did not support the report's recommendation that universal medical examinations on entry to school should cease, or that scheduled health visiting should be replaced by written communication with the parents of two- and three-year olds. Health visitors needed to see children. Professor Jo Sibert considered that the report's findings were well evidenced and that the health visiting service would be more effective if its limited resources were targeted on problem areas rather than on the routine screening of all children.

Conclusions

3.1.7. The Committee notes the difficulties faced by some parents in obtaining a diagnosis for their child. It recognises that while some conditions are difficult to diagnose, early screening and diagnosis are essential because without it families are unable to access therapy, care or other services. The Committee also notes with concern the evidence it has received indicating that pregnant women in some areas are offered screening only if they are agreeable to terminate the pregnancy if any abnormality is indicated.

3.1.8. The Committee is concerned that changing the pattern of surveillance of young children from routine health visiting and placing the onus on parents might disadvantage vulnerable families and children. Midwives and health visitors could provide the first point of contact for marginalised and minority groups. The Committee notes that the report "A Study of Low Birth Weight in Denbighshire: Listening to professional voices, focusing on health needs" (published January 2002)¹ had identified the need for health visitors to make contact during pregnancy, particularly with young women, and to maintain that contact after birth.

3.1.9. In response to these concerns the Minister announced on 3 July that she had established a working group to consider the recommendations of the draft "Hall Report". The work would be led by the Chief Medical Officer for Wales. The group would be drawn from the health service across Wales and officials of the Welsh Assembly Government. It would develop advice on good practice, drawing on the Royal College's guidance, local experience, information on social factors such as deprivation and would take account of the restructuring of service delivery in Wales.

3.1.10. The group has now met, and the Minister's paper submitted to the Committee on 23 October (HSS-18-02(p4)) records that the group found that current child health surveillance protocols vary around Wales. Many paediatricians expressed a wish for a more co-ordinated all-Wales approach to the implementation of the latest edition of Health for All Children. The Committee notes this and the suggestion in the paper that the development of the National Service Framework for children will provide a vehicle for standards.

Recommendations

R1. Where an early diagnosis cannot be made, access to appropriate services should be made far more flexible for parents and their children, pending diagnosis.

R2. The recommendations of the Chief Medical Officer's working group on child health surveillance should be widely disseminated and taken into account in the development of the National Service Framework.

R3. Local Health Boards should develop strategies to ensure that low birth weight babies and the children of disadvantaged families, travellers and transient families, young lone parents and ethnic and other minority groups, have access to diagnostic services.

R4. Where appropriate pre-conceptual genetic counselling should be offered.

R5. An evidence based antenatal screening should be available unconditionally to all pregnant women.

3.2 PROVISION OF INFORMATION TO PARENTS AND GUARDIANS

¹ Author: Joan Ashdown- Lambert, Project Manager, Senior Researcher, Centre for Health Policy and Practice, Staffordshire University.

3.2.1. Witnesses from all statutory bodies, the voluntary sector, and parents expressed views on the need for comprehensive information services at the time of diagnosis and subsequently as the child develops and his / her needs change.

3.2.2. Several said that in their experience initial information on the diagnosis and prognosis had not been comprehensive. Doctors did not always appreciate the limited ability of parents to absorb information immediately after receiving distressing news. Parents/ guardians needed time to come to terms with the diagnosis and many would welcome a further opportunity for discussion, counselling and more detailed information on the prognosis and treatment. In the most extreme cases parents had been told the diagnosis and then left on their own to seek more information on the condition. Health care staff should be positive about what the child would be able to achieve and not focus only on his or her limitations.

3.2.3. It was also suggested that sufficient time should be allowed in clinical timetables for doctors to prepare for meeting parents /guardians to convey the diagnosis and for the meeting itself. Wherever possible the meeting should involve both parents / guardians and should take place in complete privacy without disturbance.

3.2.4. Witnesses felt that it was important that parents / guardians be made aware of any support groups at an early stage. The voluntary sector played a crucial role in providing ongoing support for parents and families, and contact with other parents and families with similar experiences was invaluable. Generic health care staff, such as health visitors, should be trained to provide ongoing support and information. This could include signposting to support groups. Many witnesses advocated the appointment of a key worker to co-ordinate information as well as securing other services. It was also suggested that there was scope for developing "one stop shop" advice at child assessment centres.

3.2.5. The organisation Contact a Family said that it maintained a directory of Specific Conditions and Rare Disorders, which was widely used by professionals.² It provided basic information on over 800 conditions and disorders affecting children and the relevant support groups.

3.2.6. Several witnesses pointed to the need for the way in which information was conveyed to be tailored to the family's needs and sensitive to their cultural background. It should also be child friendly for the benefit of the child concerned and any siblings. Information should be in a format with which the family is comfortable, such as video.

3.2.7. Many organisations in the voluntary sector were unable to, or struggled with providing and maintaining information in Welsh or minority languages. It was suggested that there should be some central funding for this purpose.

3.2.8. Representatives of the dental profession emphasised that parents should be informed of the importance of oral hygiene and regular dental checks and treatment. This was often overlooked and children with special health needs often had poorer oral health than other children. The Community Dental Service should be involved in the information process, as well as care planning.

² www.cafamily.org.uk/dirworks.html

3.2.9. The Minister advised the Committee that the Children Act called for protocols on information sharing for children in need. Entry on the Disability Register could start the process, but the protocols may need strengthening. Care pathways would be taken forward as part of the National Service Framework for Children.

Conclusion

3.2.10. The Committee accepts the evidence that has been submitted. It endorses the need for continuing, comprehensive information which should be provided in a variety of settings, although specialist centres could be the focus for information. The Committee also feels that people giving information should be properly trained. Information should be available at the hospital from a designated person at the time of diagnosis, if necessary before a key worker is appointed. Parents / guardians should be able to feel assured that the information they receive is reliable.

Recommendations

R6. Information at the time of diagnosis should be planned in advance and be sensitive to the parents' needs. Parents / guardians should have the opportunity for further discussion with the specialist or other appropriate practitioner after they have had time to reflect upon the diagnosis.

R7. Parents/ guardians should be given comprehensive advice from a designated and trained person at the time of diagnosis, including information on the support and advice available from the voluntary sector.

3.3. CO-ORDINATION OF CARE

3.3.1. Sally Rees, a parent of a child with special health needs, who is also a carers' fieldworker and Chair of the Care Co-ordination Network UK, gave evidence of research showing that a co-ordinated multi-agency approach to care reduced stress and empowered families. She said that families were often overwhelmed and confused by the number of professionals taking an interest in, or providing a service to their child. Those families who had a care co-ordinator found that it made a huge difference to their everyday life, reducing isolation, exclusion and anxiety. It was also important that parents were actively involved with the care co-ordination team.

3.3.2. Ms Rees cited Wrexham and Ceredigion as areas where there was good practice in co-ordination and inter-agency working.

3.3.4. The evidence of other witnesses endorsed the key points made by Ms Rees. Many referred to the value of a key worker or care co-ordinator as the focal point for contact with the family. Arrangements should include the provision of advice on issues such as benefit entitlement as well as co-ordinating services.

3.3.4. Both statutory and voluntary agencies acknowledged that the effectiveness of inter-agency working and communication across Wales was patchy. The agencies' different priorities constrained agreement. Poor co-ordination sometimes resulted in duplication of effort. There was also evidence that the statutory agencies were not taking full advantage of flexible budgeting and joint commissioning.

3.3.5. The literature review shows that there are still parts of Wales without disability registers. Other witnesses expressed the view that the registers should facilitate co-ordination of services. The literature review researchers recommend that special funding be given to local authorities and health trusts to complete the work. They also suggest that more research and development should be commissioned to establish the most effective models for joint working between health and local authorities. The researchers recommend setting up child centred multi-disciplinary clinical networks, through Managed Care Networks. These are already proving effective in Audiology.

3.3.6. Members of the Family Support Team of the Ceredigion and Mid Wales NHS Trust said that every child in the county who was assessed as having moderate or severe learning, physical or sensory disability, and who required specialist treatment from two or more agencies, was offered a key worker service from the Family Support Team. This was a multi-agency team, with staff from health, social services and education. The main elements of the service were:

- identification of the needs, concerns, resources and strengths of the child and the family;
- co-ordination of services;
- provision of information;
- advocacy if required; and
- provision of specialist services.

The team worked closely with the Community Dental Service to ensure oral health was included in the care review.

3.3.7. Witnesses from the dental profession also emphasised the need to involve the Community Dental Service in care planning as oral health was often overlooked.

3.3.8. Clinicians and nurses from the North East Wales NHS Trust advised the Committee that care co-ordination had been introduced in Wrexham many years ago with support from the Welsh Office and the Joseph Rowntree Foundation. They said that care co-ordination should be available for every family with a child with special health needs, but it needed the commitment of financial investment and human resources. There was concern that the re-organisation of health services could result in the fragmentation of services and the loss of budgets.

3.3.9. Evidence from the British Dietetic Association suggested that a parent held record would be useful for all involved in providing services.

3.3.10. Several people giving evidence referred to the difficulties faced by children in the move to adult services. Children became accustomed to the people who had been treating them and the transition should be planned and prepared over a period of time.

Conclusions

3.3.11. In discussing the evidence members made reference to the need for all parties involved in case conferences to have reasonable opportunity to attend. Telemedicine, telephone and video conferencing could cut down on travelling times and facilitate the involvement of professionals, but confidentiality would need to be safeguarded. Parents and children need to be involved in the discussions, but the conduct of meetings should be sympathetic to the possibility that they would not be comfortable in a formal meeting.

3.3.12. A key worker or care co-ordinator should be appointed at the initial case conference following diagnosis. He or she should provide a constant point of reference, advocacy, and advice on a range of issues including benefit entitlement. Their effectiveness would be enhanced by having access to a budget.

3.3.13. There are good examples of joint working between health, social and education services as a result of the new flexibilities in funding. This good work needs to be developed so that all areas benefit.

3.3.14. The transition between children and adult services needs to be fully recognised, and preparations need to be made well in advance of the move.

3.3.15. The role of the Community Dental Service in providing services for children with special health needs should be protected so that it is not eroded where the service has had to compensate for the shortage of NHS dentists.

Recommendations

R8. Good practice should be disseminated to help overcome some of the difficulties in co-ordinating resources and services.

R9. The early appointment of a key worker or care co-ordinator is recommended in all cases where the child needs services or care from one or more specialty or service. [

R10. The potential for extending the use of the existing parent held record and the potential of electronic records as a means of sharing information between agencies should be explored.

R11. Agencies should be encouraged to make better use of the funding flexibilities and to pool budgets

3.4 . AVAILABILITY OF CARE AND TREATMENT

3.4.1. Of those who submitted evidence about the availability of care and treatment, the majority were concerned about the widespread shortfall in speech and language therapy services, but there were also shortages in occupational therapy and physiotherapy in some areas.

3.4.2. It was pointed out that there were inherent problems with the provision of speech and language therapy by the NHS in schools. There needed to be more cohesion and support for the profession. Several witnesses spoke of difficulty in obtaining speech and language therapy through the medium of Welsh.

3.4.3. The Committee received evidence from representatives of the profession. The witnesses, from the Pembrokeshire and Derwen NHS Trust and the North East Wales NHS Trust, said that the legal requirement to provide services for children with a special educational needs statement and initiatives such as Sure Start had created burdens which exacerbated the shortage of speech and language therapists in the NHS. There was a difficulty in recruiting, with a shortage of training places and the profession did not have a high career profile with undergraduates. It was estimated that there was a shortfall in Wales of 517 therapists. The average caseload was 141, against a recommended figure of 44. The highest had a caseload of 246.

3.4.4. The career structure was not attractive, many therapists working in schools were less well paid, and had fewer holidays, than their teaching colleagues. The establishment of development posts could enhance the career structure and retention of staff but would need funding.

3.4.5. The shortage of qualified staff made it more difficult to train new therapists.

3.4.6. The witnesses from the profession made a number of suggestions for improving services:

- the service should be re-organised to pool and jointly manage the funds of the different agencies to provide children with an inclusive education within a flexible framework;
- the number of training places should be increased at undergraduate and postgraduate levels;
- the development of a two tier structure of speech and language therapy assistants, with nationally recognised qualifications;
- the provision of additional staff to enable research to be undertaken;
- the roll out Sure Start funding to all areas so that early intervention would be available as a matter of course.

3.4.7. Gwynedd Sure Start submitted information on work being done by the Caernarfon Community Group on speech and language development, mainly for children with speech and language delay. Research had shown that primary language disabilities for many children could be prevented or better managed if children received intervention before the age of three. Parental based intervention was an effective means of helping young children. The group ran a training programme for crèche staff to enable them to improve their skills and pass on knowledge and skills to the parents who were accessing the service. The initial training workshops had been the basis for the development of a strategic plan for speech and language training.

3.4.8. The literature review confirms that therapists are a scarce resource, and people wanting to train needed to be well qualified. The pattern of care offered by therapists is changing, with therapists delivering less of the routine treatment themselves, but concentrating on assessment, planning and managing the care programme. Increasingly treatment is given by parents and other carers.

3.4.9. The literature review also indicates a change in emphasis, with therapists concentrating their efforts on high severity - low prevalence conditions. As a result there is a need to develop triage procedures for referral to therapists for low severity - high prevalence conditions. Research is needed to develop safe and effective referral protocols.

3.4.10. The literature review was unable to show evidence of the effectiveness of therapy and the researchers recommends that the Assembly should promote high quality multidisciplinary research as a priority.

3.4.11. Other witnesses gave evidence of their experience of the provision of care services in schools. Integration of children with special health needs into mainstream schools made it difficult for therapists to see and treat as many children in a day as they were able when the children were located together in special schools. There were also problems with the administration of medication in schools, with teachers being unwilling to take on the risks and responsibility. A deputy head teacher told the Committee that teachers were concerned about their lack of knowledge and training and their inability to respond to the children's medical needs. Doctors, and sometimes parents, did not provide the school with the information the teachers needed.

3.4.12. At the Committee's request the Minister provided a paper on the review of school nursing services undertaken by Professor Dame June Clark which had informed the Primary Care Strategy (HSS-15-02(p6)). This found that the school nursing service in Wales was underdeveloped and fragmented. The Minister said that the Welsh Assembly Government would consider the recommendations made by Professor Clark as part of the implementation of the Primary Care Strategy.

Conclusions

3.4.13. The Committee recognises that the shortage of speech and language therapists is UK-wide and cannot be remedied quickly. In the long term a strategy was needed for the development of the profession and the way therapy is delivered. In the short term, better ways of co-ordinating the service and managing and supporting therapists are needed. The Committee notes that there are few Welsh medium speech and language therapists.

3.4.14. The Committee notes that there are plans in the Primary Care Strategy in response to the recommendations of Professor Clark's report on school nursing services. Members take the view that the recommendations should be fully implemented. The school nursing service should reflect pupil numbers and there should be a development programme leading to specific qualification. An effective school nursing service could be the keystone supporting the links between families and the statutory health, education and social services.

3.4.15. The local health board should agree a protocol with the local education authority to specify who should be responsible for the administration of medication for children while at school, especially where a school either does not have its own nurse, or where one is not available

Recommendation

R12. The Welsh Assembly Government, together with the UK government, should review the speech and language therapy service and draw up strategies for meeting the shortfalls in the short term and in the long term.

R13. The feasibility of the position of speech therapy assistants should be explored to undertake, under supervision, basic therapy services.

R14. The recommendations of Professor Dame June Clark's report on school nursing services should be fully implemented.

3.5. SUPPORT FOR FAMILIES AND OTHER CARERS

3.5.1. The evidence submitted to the committee showed that the voluntary sector were key players in providing support and respite care. Although the main concerns of those giving evidence were about the availability of respite services, there were other issues.

3.5.2. It was suggested that health professionals could do more to advise parents on the support that was available at the time of diagnosis. In Denbighshire, the Disability Register was used as a database for providing information to parents and this practice could be adopted elsewhere.

3.5.3. Several witnesses raised the need for the siblings of children with special health needs to have some support. There were good examples of sibling support groups where children could make friends with others with similar family problems. The Special Needs Activity Centre in Margam holds weekly workshops for siblings to help them understand and cope with their problems and gives them the opportunity to enjoy the play facilities at the centre.

3.5.4. There were limited opportunities for children with special health needs to access local leisure facilities. It was particularly important for older teenagers to be able to do so independently of their family.

3.5.6. In Wrexham the Diana Nurses are providing comprehensive support to families. Sargent Cancer Care had provided family support workers in Northern Ireland and would like to be able to do the same in Wales.

3.5.7. Gwynedd Sure Start has piloted the "Incredible Parenting Programme", based on an American concept to help parents improve their relationship with their children. As a result of the programme a support group had been established. Sure Start was also trying to engage with hard to reach families and were developing relationships with Citizens' Advice Bureaux and the Benefits Agency to secure better advice and support for families.

3.5.8. Access to respite services varied from area to area. In Ceredigion families were generally able to have a weekend a month, but where there were extreme difficulties more could be given. A respite care social worker worked with the family to establish the need. It was more difficult to provide respite for children with complex health needs, where respite could not be given by another family.

3.5.9. Cardiff and the Vale Parents Federation reported that there was no respite care available in the Vale for children with physical disabilities and only four beds available in Cardiff. The Federation recommended that respite care should be covered in the social care assessment plan.

3.5.10. The voluntary sector provided much respite care, but had to compete for funding. There was evidence from several sources that those people who were less able to articulate their need missed out.

3.5.11. Members of the Committee visited two projects which provide support for families. TOGs on Torfaen and the Special Needs Activity Centre, Margam. The reports of their visits are at Annex 4.

Conclusions

3.5.12. Members consider that services should be flexible to meet the differing needs of families. The needs of the whole family should be taken into account in developing services. It is particularly important that siblings receive support and that services are available to help them.

3.5.13. The Committee notes that there are good examples of providing respite care, but that access often depends on where people live or how well they know the system. A comprehensive respite service should be available to all from a young age. The crucial need for respite care to be available to families at times of crisis at home should be recognised.

3.5.14. Members were concerned that delays in obtaining clearance from the Criminal Records Bureau may deter people from taking up work in the care sector.

Recommendations

R15. Guidance on support for families of young children with special health needs, including examples of good practice, should be issued to all statutory and voluntary agencies in Wales. It is recommended that this be part of the Children's National Service Framework.

R16. The provision of effective and flexible respite services must be seen as a prerequisite for sustainable caring responsibilities within families.

R17. The Welsh Assembly Government should encourage each local authority in Wales to support a "Special Needs Support and Advice Centre" to provide services for children and support for carers and families.

SPECIAL NEEDS ACTIVITY CLUB

The Special Needs Activity Club (SNAC) in Margam was set up in 1993 by parents of children with disabilities who had encountered a lack of provision for social activities for children with special needs between the ages of three and sixteen. Since then, membership has increased and SNAC has become a registered charity in its own right. It is also affiliated to SCOPE, who are on hand to offer help and advice.

Activities offered by SNAC:

- Social activities for children with special needs
- Integration with other siblings and sibling support
- Parent support groups
- Soft Play Room
- Multi-sensory Room
- Pottery, Art & Craft
- Short breaks holidays for all the family

TORFAEN OPPORTUNITY GROUP

The aim of Torfaen Opportunity Group's (TOG) family centre is to work in partnership with the statutory bodies and other agencies to provide a centre of excellence offering a quality service to support the families of children with special needs enabling them to have a much better quality of life.

Activities offered by TOG:

- ◆ Volunteers and Work Experience
- ◆ Professional Advice Services
- ◆ Parenting Skills Workshops
- ◆ Drama/ Art/ Music Therapy
- ◆ Crèche
- ◆ Support Group Workshops
- ◆ Parent and Toddler Group
- ◆ TOGS Home- Start Scheme
- ◆ Children's Youth Club
- ◆ Parent Support Group

3.6. EQUIPMENT AND OTHER SOCIAL SERVICES NEEDS

3.6.1. Many parents, health workers and social care professionals and voluntary organisations submitted evidence on the problems associated with obtaining equipment and housing adaptations.

3.6.2. Although joint funding and other flexibilities were now possible under the Health Act, it was not yet proving effective in practice. Health, Education and Social Services needed to work more closely on the assessment and provision of equipment. One witness referred to the number of care plans that existed for a disabled child, with separate care plans for health, social services and education, and further plans for family support. A single plan would help to clarify the roles of the different agencies.

3.6.3. Most of the witnesses took the view that there was a need for budgets to be pooled, with clarification of responsibility for equipment. In some instances equipment that was no longer required was not collected by the issuing agency for recycling and re-issue.

3.6.4. Delays between assessment and delivery of equipment may mean that the child would outgrow the equipment before he or she received it. There were particular problems with delays in the delivery of wheelchairs. Wheelchairs should be specially designed for children to meet their needs for mobility and play and to give them credibility with their peers. In England people were given vouchers which gave them more choice in choosing their wheelchair.

3.6.5. Committee members who visited the TOGs Family Centre in Torfaen, also heard from parents and carers about the anomalies and inflexibilities of rules :

- the refusal to supply appropriate nappies for a six-year old learning to use the toilet;
- refusal to fund a special car seat (£1,000) to enable a child to use a car that had been funded ;
- services being dependant on a child's actual age rather than their mental age.

3.6.6. Concerns about housing adaptations related mainly to the bureaucracy and delay in having grant applications processed, and the system of means testing. Many parents needed help in completing the application forms due to their complexity, and advice on the availability of grant. Delays were often due to shortage of staff in local authorities to process applications and assess the works needed. The level of the parental contribution sometimes put the cost of the work out of the reach of the family and the adaptations were not made.

3.6.7. One voluntary organisation said that local housing departments did not have enough understanding of the needs of some disabled people and should have better guidance on building and adapting housing for special needs. There was also concern about the quality of the work with instances where simple mistakes had significant impact.

Conclusions

3.6.8. The Committee agrees that the supply of equipment needs to be co-ordinated between the statutory agencies and the authorities should use the funding flexibilities available to them to the best effect. The arrangements for co-ordination and pooling of funds should include the designation of a lead agency to take overall responsibility for the ordering, managing and storing of equipment. The use of equipment supplied should be monitored and once it is no longer required it should be re-cycled wherever possible.

3.6.9. The Committee notes that the Specialised Health Services Commission for Wales is currently reviewing the wheelchair service in consultation with users, carers and others with a view to publishing a new strategy in the autumn.

3.6.10. Although the Committee had not received any specific evidence, it was suggested by one member that toy libraries could play a useful role in the development of children's co-ordination and manipulation skills. The Committee agrees that they are worthy of support.

3.6.11. The Committee notes the problems faced by some families in obtaining adaptations to their homes. Members are concerned about the requirement for some parents to contribute to the cost and that some families are unable to afford the work. Members also note that the work often reduced, rather than enhanced, the value of the house, thus having a double impact on the family's resources. Members feel that the process for applying for grants should be simplified.

Recommendations

R18. The Committee recommends that the supply of equipment should be formally co-ordinated between the statutory agencies with a designated lead agency in every area. The arrangements should include the pooling of equipment budgets, management of stores and monitoring of use.

R19. The Committee's concerns about the terms of the legislation on disabled facilities grants and the process for applying should be brought to the attention of the UK Government with the request that it be reviewed.

R20. Particular care should be taken to ensure that aids, equipment and adaptations are fit for purpose and child centred. This requires regular reappraisal of the suitability of materials as children grow older.

3.7. CHILDREN WITH SPECIAL EDUCATION NEEDS

3.7.1. Most of the issues relating to special educational needs are covered under the heading of Availability of Care and Treatment. Respondents under this section also referred to the difficulties in providing therapy services in schools, especially in mainstream schools. Caerphilly County Council pointed to the need for the statutory responsibilities of the respective agencies to be clarified. There were other reports of conflict between health and education authorities in assessing and meeting need. Some parents spoke of the difficulty in securing and maintaining a place in a special needs school.

3.7.2. In North Wales there are some initiatives for training teachers and support staff to help children with special needs such as dyspraxia. However, it was reported that there was a shortage of dietetic services to schools in North Wales.

3.7.3. The Swansea NHS Trust reported that there were good examples of where an holistic child-centred approach to complex health needs could assist a child in attending a mainstream school. The approach could also be applied successfully to children with less complex needs. The Royal College of Nursing also advocated an holistic approach to meeting a child's needs in school.

3.7.4. The Royal College of Physiotherapists said that many schools had inadequate and / or inappropriate facilities for therapy. Physiotherapists could give useful advice and guidance to parents to help them choose a suitable school.

3.7.5. Afasic, Gwent suggested that children who have communication difficulties need an alternative curriculum focussing on the main areas of need, ie communication skills, living skills, coping strategies and home / school support.

3.7.6. A response from Bro Taf Health Authority referred to the problems children with special needs might experience with school transport, if they were not escorted.

Conclusions

3.7.7. The Committee accepts that the majority of children do not need to attend a special school and benefit from integration into mainstream education. However, some children will need special schooling, at least for some of the time. There should be a balance in provision, with parents being able to choose the type of school that best suits their child.

3.7.8. Overall the integration of children with special needs into mainstream schools is developing well and the quality of the education they receive is improving. The SEN Code of Practice for Wales, which came into effect on 1 April 2002, and Shaping the Future for Special Education – An Action Programme for Wales provides the framework for improving the services further.

Recommendations

R21. There is much apparent good practice in special needs education around Wales that should be validated and disseminated.

R22. The move to special needs provision within a mainstream setting should be welcomed, but greater emphasis should be placed on the monitoring of special needs services so that they do not become diluted.

R23. The National Service Framework for children should contain a detailed sub section on special education and health needs.

R24. A member of the board of each local health board in Wales should be designated as responsible for children's services and children's rights.

R25. The situation of children aged under five years with severe health needs requires urgent attention so that they receive appropriate pre-school education.

3.8. GOOD PRACTICE

3.8.1. The Committee's consultation letter of 22 October 2001 asked what arrangements were needed to evaluate services and to promote and identify good practice.

3.8.2. During the course of the inquiry the Committee heard from many sources about initiatives and innovative ways of providing services that were considered to be working well. Reference is made to some of these in the course of this report.

3.8.3. There was some evidence that services were being evaluated, for example the All Wales Professional Heads of Occupational Therapy reported that they were developing benchmarking of their services across Wales to address inconsistencies in quality and differences in standards. The Gwynedd Sure Start "Incredible Parenting Programme" was based on an American programme which had been tested and evaluated in the States. There was research that evidenced the value of key workers.

3.8.4. However, most of those who commented on this particular aspect of the consultation letter said that more needed to be done to evaluate and disseminate good practice. The comments included:

- A national strategy or service framework for disabled children would be a way of disseminating good practice and addressing the inequities in service between geographical areas.
- Practitioners needed access to evidence based information on good operational practices, rather than practice being based on personal views and ideology.
- Quality audits of good practice were needed, with a suitable forum to promote change.
- Local disability organisations and user groups should be included in the identification and evaluation of good practice.
- Research and evaluation was required to measure more effectively outcomes of intervention and to investigate evidence based practices and clinical governance. Innovation should be evaluated and there should be comparison with what was happening elsewhere in the UK. The development of the National Service Framework should encourage this. The use of outcome measures and assessment tools such as client questionnaires could assist evaluation.
- Services should be benchmarked with an exchange of information between agencies and areas.
- Benchmarking should include consideration of outcomes in all aspects of a child's growth and development, and the extent to which services meet parents' and siblings' needs should be covered.
- There should be standards against which multi-agency services could be judged as a totality.
- The Welsh Assembly Government might have a role in identifying and disseminating good practice, possibly through a web site.
- The development of good practice was dependent on effective multi-disciplinary communication.
- Evaluation had to be clear in its objectives and how it would inform service change.
- A national, multi-agency conference should be held to disseminate good practice.
- The Downs Syndrome Association had a team of specialist advisers that could contribute to dissemination. They already provided web based training for health professionals.

3.8.5. Many of those who submitted evidence said that there were inadequate resources to carry out evaluation and disseminate good practice. Additional, discrete funding was needed to resource research and evaluation.

3.8.6. The literature review concludes:

“Throughout our work we have found that the literature on children with special health needs is very sparse and very patchy. There are very few randomised, controlled trials outside specific drug treatment such as methylphenidate for attention deficit disorder or botulinum toxin in cerebral palsy. The other exception is Child and Adolescent Mental Health.”

Conclusion

3.8.7. There is much apparent good work going on in Wales, but it needs to be properly evaluated and benchmarked in a structured way to assess outcomes and the extent to which services are meeting families’ needs. Effective joint planning and working between statutory and voluntary agencies is the key to success. Channels for communication and dissemination of validated good practice are needed. The Committee notes that the development of the National Service Framework for Children will provide the means for achieving this.

Recommendation

R27. The National Service Framework should provide for systems to be established at strategic and operational level to evaluate and benchmark services and to research and validate good practice. It should also provide the mechanisms for disseminating good practice and for statutory and voluntary organisations to share experience.

4. THE WAY FORWARD

4.1. The Committee's report is referred to Jane Hutt AM, the Minister for Health and Social Services, for the consideration of the Welsh Assembly Government. The Committee considers that many of its recommendation can be taken forward through the National Service Framework for Children's Services which the Assembly Government is now drafting.

4.2. The Committee requests that the Minister responds to the recommendations by February 2003. Finally, the Committee recommends that the appropriate subject committee should review the findings of this report and the implementation of its recommendations early in 2005 with a view to evaluating its impact on services for children with special health needs.

Annex 1
Consultation letter of 22 October 2001



Cynulliad Cenedlaethol Cymru
The National Assembly for Wales

Pwyllgor Iechyd a Gwasanaethau
Cymdeithasol
Health and Social Services
Committee

Bae Caerdydd / Cardiff Bay
Caerdydd / Cardiff
CF99 1NA

Eich cyf / Your ref
Ein cyf / Our ref

Dyddiad / Date 22 October 2001

Dear Sir / Madam

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, 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.

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? 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?

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 in 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 and they may also be seen and discussed by Assembly Members at Committee meetings. **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 organisation, 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).

Yours Faithfully

Jane Westlake
Clerk to the Committee

Annex 2.
Individuals and Organisations who Responded to the Consultation Letter

Afasic	
All Wales Dental Public Health Group	✓
All Wales Heads of Occupational Therapy Committee	✓
All Wales Special Interest Group/Special Oral Health Care	✓
Association for Spina Bifida and Hydrocephalus (ASBAH)	✓
Bridgend Community Health Council	
Bridgend County Borough Council	✓
British Dental Association	✓
British Dietetic Association	✓
Bro Taf Health Authority	
◆ Children's Health Team	
◆ Directorate of Public Health & Policy	✓
Bro Taf Local Medical Committee	✓
Caerphilly County Borough Council	
Caerphilly Local Health Group	
Cardiff and the Vale NHS Trust	
◆ Child Health Directorate	✓
◆ Dental Department	
◆ Women, Children and Community Service Group	
Cardiff and the Vale Parents Federation	
Cardiff Community Health Council	
Cardiff Local Education Authority	✓
Cardiff Local Health Group	✓
Care Co-ordination Network UK	✓
Ceredigion & Mid Wales NHS Trust and Ceredigion Social Services	✓
Chartered Society of Physiotherapy	✓
Clinical Psychology Advisory Sub-Committee of the Welsh Assembly Medical Committee	✓
College of Optometrists	✓
Contact a Family	✓
Conwy and Denbighshire NHS Trust	✓
Disability Rights Commission	✓
Disabled Children Count	
Down's Syndrome Association	
Dyfed Powys Health Authority	✓
Dyfed Powys Paediatric Network	
Epilepsy Wales	
Family Fund Trust	
Freedom to Care	✓
Gwent Health Authority	✓
Gwent Healthcare NHS Trust	
◆ Community Dental Service	✓
◆ Corporate Services	
Gwynedd Sure Start	✓
Morgannwg Local Medical Committee	

Mr H, Parent	✓
NCH Cymru	
Newport County Borough Council	✓
North Glamorgan NHS Trust	✓
North East Wales NHS Trust	
◆ Audiology Department	✓
◆ Children's Community Physiotherapy Service	✓
◆ Community Child Health Services	✓
North Wales Community Dental Services	✓
North Wales Local Medical Committee	
North West Wales NHS Trust	✓
Philip Minchom, Consultant Paediatrician	✓
Pontypridd and Rhondda NHS Trust	
Powys County Council	✓
Rhondda Cynon Taff County Borough Council	
Royal College of Nursing Wales	✓
Sally Rees, Parent Carer; North East Wales Carer Information Service; Chair of Care Co-ordination Network UK	✓
Sargent Cancer Care for Children	✓
Sense Cymru	✓
Specialised Health Services Commission for Wales	✓
Swansea Community Health Council	
Swansea NHS Trust	
◆ Community and Local Hospitals Operational Unit	✓
◆ Department of Child Health	✓
◆ Department of Medical Physics and Clinical Engineering	✓
Torfaen Opportunity Group and Family Centre	✓
Vale Adults' and Children's Network	
Velindre NHS Trust	
Welsh Nursing and Midwifery Committee - Children's Committee	✓
Ysgol y Gader	✓

Annex 3.
Individuals and Organisations Who Gave Oral Evidence to the Committee

The first oral evidence session was held in Cardiff on 6 February (HSS-04-02) and the Committee heard from:

- ◆ Cardiff and the Vale Parents' Federation
- ◆ Downs Syndrome Association
- ◆ Newport County Borough Council (Children's Services)
- ◆ All Wales Special Interest Group - Oral Health Care
- ◆ Cardiff and the Vale NHS Trust
- ◆ Caerphilly Local Health Group

The next session was held in Brecon on 14 February (HSS-05-02), and evidence was received from:

- ◆ Afasic, Gwent
- ◆ Ceredigion and Mid Wales NHS Trust and Ceredigion Social Services
- ◆ Chartered Society of Physiotherapy
- ◆ All Wales Heads of Occupational Therapy Committee
- ◆ Contact a Family
- ◆ Bridgend County Borough Council (Education, Leisure and Community Services)

The Committee heard evidence in Rhyl on 27 February (HSS-06-02), and the following organisations submitted evidence to the Committee:

- ◆ Sally Rees, a Carer's Fieldworker in Flintshire
- ◆ Association of Spina Bifida and Hydrocephalus (ASBAH)
- ◆ Ysgol y Gader, Dolgellau
- ◆ North East Wales NHS Trust
- ◆ Gwynedd Sure Start
- ◆ Royal College of Nursing

The Committee became increasingly concerned by the evidence regarding provision of speech and language therapy, and invited representatives of the profession to give evidence to the Committee at its meeting in Cardiff on 13 March (HSS-07-02).

Annex 4

Reports of visits by Committee Members

Annex 4a

Evidence given to David Melding AM and Dai Lloyd AM during a visit to Special Needs Activity Centre, Margam, Port Talbot

1. Our visit was facilitated by Carole Wellington and Cllr. John Rogers who both described the range of work undertaken in the Centre.
2. The Centre presently helps 70 families and 1,142 children attended during Jan - March 2002. Most families are in the Neath Port Talbot area, but the Centre is open to others from outside the county.
3. Activities are available on weekday evenings, Saturdays and during the school holidays. As well as helping children with special needs, the Centre is open to siblings of special needs children.
4. The Centre has been established and developed by parents. A high quality, purpose built Centre has been built. Funding has come from the Lottery, commercial sources and charitable trusts. No funding is received from either the Local Authority or the Health Authority (but none has been requested).
5. The Centre does not employ full time administrative staff, although part time care assistants are employed. Parents serve on the management board and cover the managerial and administrative duties. As the Centre has grown, the structure is under more strain as more is expected from parents. Revenue funding is now a worry.
6. Links with the Local Authority are described as good and Social Services refer families on a regular basis to the Centre. Some referrals come via the Health SECTOR, but in general, links with health organisations are weaker.
7. This point refers to the health sector and ways in which services might be improved.
 - Links with health organisations need to be improved
 - Centres like SNAC could be used as outreach health clinics. It is often difficult e.g. to get an autistic child to sit patiently in a GP surgery
 - Therapy sessions could also be offered at the Centre
 - Information is often sparse or poor in the health sector
 - Hospitals do not cater very well for children with special needs. Parents often have to stay with special needs children but few facilities are offered; "You have to sleep in the chair" we were told by one parent.
 - Hospitals can be intimidating places at the best of times, but much more so for children with special needs.
 - Early diagnosis is often not secured, health staff are too reluctant to commit themselves.
8. This point refers to Local Authorities and the ways in which services might be improved.

- When services are commissioned the importance of parent/carer support and sibling support must be considered.
 - Information is vital especially in the early days when parents are likely to feel overwhelmed. Special schools must be seen as key for accurate, ongoing information and advice.
 - The importance of "social" activities should not be overlooked
 - Key workers are important, especially in the early days when "you are raw".
9. Comments on respite care have been separated out;
- Generally, respite care services are in short supply
 - Some children settle into residential respite, others do not but would be OK in family based respite
 - Continuity of services is vital, same surroundings and same staff give confidence to children with special needs.
 - No respite is effective unless parents are confident about the quality of care
 - The 24 hour curriculum (i.e. school based respite) is important for some special needs children such as those with autism
 - Most respite care is structured and needs to be booked well in advance. Little is available when parents are "just at the end of their tether".
10. We are very grateful to the management board, parents, carers and children at the Special Needs Activity Centre for their warm welcome and valuable evidence which will help the Committee's inquiry considerably.

Note of meeting with parents and others at TOGS Family Centre, Torfaen on 26th April 2002

Committee members in attendance:-

Dai Lloyd
David Melding
Jocelyn Davies

Parents and carers raised many points of interest but there was a general feeling that health-care for their children lacked co-ordination and is inefficient :-

- e.g. often the transport sent to take a severely disabled young man to hospital for out-patient appointments did not have the facilities he required for the journey.
- e.g. children wait a very long time for specialist equipment, like chairs etc, so they've outgrown them by the time they arrive and the child has to begin the assessment again and again without getting the full benefit of the item being supplied.
- e.g. expensive equipment no longer being used isn't routinely collected back and re-circulated.

Parents also expressed concern about the inflexibility of certain rules:-

- e.g. the refusal to supply pull-down nappies for a six year-old who was learning to use the toilet at night.
- e.g. the refusal to fund a car seat for a six year lad which will cost in the range of £1,000 for his parents to purchase even though the car itself is fully funded.
- e.g. services provision often depends on actual age of the child rather than the mental age.

There was also a general feeling that parents were getting ripped off when they purchased disabled equipment from recommended specialist suppliers. Many agreed that the same items were cheaper elsewhere.

The issue of early diagnosis provoked much discussion and anger. Parents found the quest for a diagnosis frustrating and often not resulting in the provision they assumed would follow:-

- e.g. a father telling of constantly being "on a waiting list somewhere" and being referred from one professional to another
- e.g. a mother describing how her concerns were ignored for years but shown to have been well founded when her child was eventually diagnosed as autistic.
- e.g. many parents felt they were "hitting my head against a brick wall" even though their children had severe and complex disabilities/difficulties.

Everyone agreed that early identification was vital but there was a feeling that the assessment process was being used as a distraction from the fact that the child wasn't getting the provision needed. Parents complained that their children were constantly being assessed without positive outcomes and if key professionals left their posts the children would often start the whole assessment process again with newly appointed people. Some parents said the assessment/ diagnosis process lasted several years and during that time their children did not receive the necessary provision. Speech and language therapy was lacking and the delay in getting therapy for their children made their problems worse. Parents also complained that even after they'd secured services for their children they were constantly battling to retain them.

Other points raised included:-

the need for more key workers to help families access everything they needed;
the need for more resource units within local schools instead of units attached to schools further away;
the provision identified on Statements of Special Educational Needs wasn't always forthcoming; provision is withdrawn due to funding difficulties; and unless actual service providers are named on Statements that service will not become a reality;
the problems associated with the transition to adulthood where hospital admittance will be onto wards where the patient's difficulties may not be fully appreciated.

There was a great deal of praise for the support and service provided to the families from the TOGS Centre, which demonstrated good practice. The centre is excellent but relies for funding on ESF, lottery and their own fundraising efforts. There can be no certainty that those sources of funding will continue in the future and there is a great deal of effort devoted to chasing after funding streams.