

MINUTES

Date: Wednesday, 6 February 2002

Time: 9.00pm to 12.50pm

Venue: Committee Room 3, National Assembly for Wales

Attendance: **Members of Health & Social Services Committee**

Kirsty Williams (**Chair**) Brecon and Radnorshire

Brian Gibbons Aberavon

Brian Hancock Islwyn

Jane Hutt (Minister) Vale of Glamorgan

Ann Jones Vale of Clwyd

Dai Lloyd South Wales West

David Melding South Wales Central

Lynne Neagle Torfaen

In Attendance

John Cushen Director, Cardiff and the Vale Parents Federation

Teresa Yorke-Wade Parent Representative, Cardiff and the Vale Parents Federation

Jane Bayley Parent Representative, Cardiff and the Vale Parents Federation

Usha Sarangi Parent Representative, Cardiff and the Vale Parents Federation

Julian Hallett Regional Manager Wales, Downs Syndrome Association

Lynne Davies Parent Representative, Downs Syndrome Association

Robert Edge Parent Representative, Downs Syndrome Association

Dr Sean O'Reilly Parent Representative, Downs Syndrome Association

Clive Case Children's Services Manager, Newport County Borough Council

Angela Carpenter Senior Occupational Therapist, Newport County Borough Council

Dr Vicki Jones Senior Community Dentist, Ringland Health Centre

Steve Boyle Clinical Director for Community Dental Services in Gwent

Dr Liz Penny Consultant Community Paediatrician, Cardiff and the Vale NHS Trust

Becky Healy Head of Children's Nursing, Cardiff and the Vale NHS Trust

Judith Paget General Manager, Caerphilly Local Health Group

Geraint Morgan Acting Head of Health Development, Caerphilly Local Health Group

Michael Bray Manager, Caerphilly Children's Centre

Officials

Chris Burdett Children & Families Division

Ann Lloyd Director, NHS in Wales

Dr Ruth Hall Chief Medical Officer

Peter Lawler Primary & Community Health Division

Helen Thomas Social Care Group

Dr Hywel Williams Health Protection & Improvement Directorate

Secretariat:

Jane Westlake Committee Clerk

Claire Morris Deputy Committee Clerk

Item 1: Apologies and Substitutions

1.1 Apologies were received from Rod Richards and Geraint Davies. Helen Mary Jones substituted for Geraint Davies.

1.2 Members were reminded of the requirement, under Standing Order 4.5, to declare any interests before taking part in proceedings. The following declarations were made:

- Dai Lloyd, general practitioner and member of the Council of the City and County of Swansea.

Item 2: Minister's Monthly Report

Paper: HSS-04-02(p.1)

2.1 In response to Members' comments, the Minister made the following points:

- Local Health Boards (LHBs) would operate in shadow form from September. The post of Chairs would be advertised in April, and Executive Directors in May.
- The Workforce Group referred to in the report was looking at the wider working environment within the NHS rather than workforce planning in terms of staffing requirements. The timescale for publishing workforce targets was unchanged.
- Public Health Consultants would be employed within the NHS, which had been one of their main concerns. Host organisations had yet to be decided. The need to develop the role of the public health service in Wales as an independent advocate as well as a source of professional advice and information and raise its profile was recognised. The Wales Centre for Health would also play an important role in the provision of independent advice and information.
- Transfer arrangements for staff employed by health authorities had been agreed with the unions and were currently out for consultation. Key posts would then be advertised in March.
- Paul Williams, Chief Executive of Bro Morgannwg NHS Trust, was carrying out an all Wales review of beds and capacity. Day care facilities also needed to be considered as a number of operations could be carried out through improved access to day care surgeries. This work had not superseded the work of the Emergency Pressures Task Force, whose recommendations were being implemented and had resulted in additional beds.
- Many of the community food initiative projects were being linked to health inequalities schemes particularly those relating to coronary heart disease.
- Many of the high cost clinical negligence claims that would be settled this year were historical, dating back many years. A review of the Welsh Risk Pool was being undertaken and the key issue would be to ensure that the best mechanism was in place to anticipate and deal with claims.
- Hospital activity rates were increasing across the board. The rate of increase would not match the level of additional resources allocated to the NHS, as much of the extra investment was not directed at hospital treatment. A large proportion had been allocated for GP prescribing and new treatments and also to training and education. The benefits of the latter would not be realised in the short term.

2.3 The Chief Medical Officer confirmed that the outbreak of gastroenteritis that had resulted in ward closures over the last few weeks had been short-lived, in most cases lasting no more than 48 hours.

2.4 There was disappointment that the excellent CHI report on Bro Morgannwg NHS Trust had not received any media coverage. Bad news stories in the NHS received frequent coverage but examples of good practice and quality care

were ignored, and this was very demoralising for staff working in the NHS. The Chair congratulated the Trust on behalf of the Committee.

Action

- The Minister would report to the Committee on the findings of the bed and capacity review.

Item 3: Review of Services for Children with Special Health Needs

Papers: HSS-04-02(p.2a - p.2f)

3.1 Following consideration of the written evidence submitted in response to the Committee's consultation letter of 22 October 2001, a number of voluntary and statutory bodies had been invited to give oral evidence to the Committee.

Cardiff and the Vale Parents Federation

- In the Vale of Glamorgan, some respite care was available, but not for children with physical disabilities. In Cardiff, four beds were available through an NCH scheme but there was no nursing support so there was no respite provision for children who required tube feeding. An ideal solution would be something that incorporated the social care provided by NCH and the nursing care of Ty Hafan.
- Parents were very concerned about the future of Barry Hostel, which provided respite care for children with learning disabilities.
- Barnardos Family Link provided an excellent service but there were not enough families in the Vale for the number of children who wished to use it.
- Crossroads was receiving additional funding but was only accessible if the child was registered with a social worker.
- Every child had different needs and no one solution would suit everyone.
- If children did not have a social worker, the family was not aware of the services available to them.
- The availability of respite care should be included in the social care assessment.
- A one-stop shop would not necessarily mean a single physical location. A mechanism was needed for centrally collating information. Parents needed access to a single point of contact, whether a key worker or specialist social worker, to advise them on what services were available to them.
- Because services were limited there had to be prioritisation, which meant a lot of children missed out. Others were not covered because of their specialist need.
- School was believed to be the most appropriate setting for assessment and provision of services. For pre-school age children, children's centres attached to hospitals could provide opportunities for group therapy and for parents to meet as well as assessment.
- Under 5's operated a scheme which enabled attendance at a mainstream pre-school by providing the child with an assistant. However, this scheme was now under threat and they were not been able to fund as many places.

Downs Syndrome Association

- The Association had no direct way of making contact with families; they relied upon hospitals, particularly maternity units, to pass on information. Problems often occurred with frequent changes of staff in maternity units and ensuring the most up-to-date information was being given out.
- The Association ran training courses for people working with Downs Syndrome and it was suggested this could be incorporated into the NHS training programme.
- Latest research suggested that all children with Downs Syndrome should be treated as visually impaired, although this had not yet received wide publicity. One of the biggest problems was getting glasses that fitted

because the nasal bridge did not fit Downs Syndrome children.

- The involvement of paediatricians in the co-ordination of care varied from area to area. In Conwy and Denbighshire NHS Trust, the Consultant Community Paediatrician had been an invaluable source of support and guidance to services. In other areas, paediatricians did not feel this was their role.
- Obtaining speech and language therapy was extremely difficult. One nine-year-old boy had received only one term of speech therapy and this had been paid for privately. In another case, the NHS speech therapist had refused to work with a private therapist so the therapy had been discontinued.
- Parents were extremely concerned that lack of speech therapy would lead to their children becoming excluded from everyday life because of their difficulties in communicating with other children.
- Speech and language therapy was provided through the NHS in schools, which created complications. There was no Welsh language training for speech and language therapists and no special education provision through the medium of Welsh.
- Provision of respite care varied throughout Wales and demand was exceeding supply. If the child had not been assessed and had no care plan, parents were not offered respite services. In Rhondda Cynon Taff funding was only available to provide respite care at weekend and outside school term time.
- Parents were very conscious of the effects on siblings but there were no services provided for them. A forum where siblings of Downs Syndrome children could meet others would be helpful.
- A lot of pressure was placed on support assistants to follow through the programmes initiated by speech therapists. A support assistant had not been able to help with physiotherapy programmes because they were not allowed to touch a child's knee or ankle.
- There was a shortage of male support assistants. Sometimes an assistant of the same sex as the child was necessary, for example to go swimming, and it was suggested that operating a pooled resource rather than designating an assistant to a child would be helpful.
- The suggestion that retired teachers could be trained to assist with speech and language therapy was welcomed.

Newport County Borough Council

- An integrated approach to early diagnosis, counselling and assessments was needed but there were major structural barriers between health and social services which seemed to have increased as a result of local government organisation. The creation of Local Health Boards should assist this, as would the Framework for the Assessment of Children in Need and their Families, providing true partnership between social services, education and health could be achieved.
- The number of children registered as disabled from ethnic minority groups was relatively low, given other evidence of poor health among children in these and other minority groups. The Authority was developing its strategy for giving them access to services.
- Protocols for occupational therapy had been developed with the NHS, creating professional networks, which made the most effective use of therapy time.
- A significant development in Newport was the creation of an assessment framework, but there was still a danger that children would receive separate plans from each agency.
- As part of the Children First programme, consideration was being given to creating a case co-ordinator along the lines of the child protection model. This would mean that the key worker could work for health, social services or education, but would ensure that assessment, planning and intervention were co-ordinated.
- Co-ordinated care planning was a problem for the whole of Wales, not just in Newport.
- In the current climate of risk assessments and the constraints of the Moving and Handling regulations, it was becoming increasingly more difficult to recruit carers to offer family based respite care. Also, funding to provide respite carers with the equipment and adaptations they needed to fulfil their role was limited.
- The establishment of the Care Standards Inspectorate for Wales, whilst welcome, was creating difficulties in the provision of respite care for children with physical disabilities.
- Enabling children with special needs to access the same facilities as other children would reduce problems with

social exclusion. Work was planned with the Leisure Services Department to develop a joint post whose role would be to ensure that children with special complex needs could access leisure facilities.

- For ten occupational therapists working in Newport there were only two surveyors to deal with their referrals for housing adaptations. A priority system was in operation but inevitably there were delays. Some properties were unsuitable for adaptation so families needed to be re-housed. In some cases, it could take about four years for a family to be re-housed and receive the necessary adaptations because of the criteria and guidelines that were in place.
- Obtaining a grant for adaptations was a complicated process. Families needed access to more information on how long the process could take and who could help them with their application. Often families who had to make a financial contribution could not afford to do so, so many did not bother with the grant process.
- Sharing information at a more strategic level was problematic, partly due to the lack of integration of computer systems.
- In theory delegating budgets to key workers was thought to be a good idea, but realistically the same structural barriers that were obstructing joint working would be in place.
- Pooled budgets and joint stores for equipment would be a step forward but a lot more work was needed.
- The multi-agency review of services to children with disabilities was due to be completed in June and the results would be provided to the Committee.

All Wales Special Interest Group - Oral Health Care

- Oral health should be included in health and social care assessments and care plans for children with special needs.
- Members of the oral health team should be part of the multi-disciplinary team co-ordinating the care of a child with special needs.
- A significant number of children were not registered with any regular form of dental care and children with behavioural difficulties found it particularly difficult to gain access.
- The number of children registered with a dental practitioner was available but there was no effective means of identifying which of those children needed extra help so referral to the community dental service by the multi-disciplinary team was necessary.
- Children on higher levels of medication were at greater risk from oral ill health.
- Oral health could be a lower priority for parents of a child with special needs. Children had to attend a family dentist regularly to maintain registration.

Cardiff and the Vale NHS Trust

- A key issue in the early identification and diagnosis was training across the disciplines and agencies and this required a strong, supportive framework.
- Information needed to be provided in a multi-lingual, multi-media way. Timeliness of information was crucial.
- Speech therapy needed to be set within the context of the multi-disciplinary team because there were continual overlaps with the work of all agencies.
- It did not matter whether health authorities or education authorities employed speech therapists as long as there was cohesion and support for the profession.
- Speech therapy was much broader than just the linguistic elements, for example feeding difficulties.
- The training of helpers in school to assist speech therapists would be very welcome.
- There was a severe lack of respite care for children with physical disabilities. Learning disabilities were taking preference and the focus needed to be widened to include physical disabilities and hearing impairment but additional resources would be needed before this could happen.
- Provision of key workers varied throughout Wales.
- The key worker role was one of co-ordination, liaison and support for families. A report from York University

suggested it should be independent, not tied to any particular agency. In that event inter-agency funding should be provided but managed independently.

Caerphilly Local Health Group (LHG)

- Development of services for children had been a priority for the LHG.
- Services were being developed based on dialogue with parents.
- A multi-disciplinary team met on a weekly basis and all referrals to the Caerphilly Children's Centre came through that team. There was a very strong commitment from all the partner agencies involved in the process.
- Referrals mainly came from the health service but could also come from education, social services and the voluntary sector.
- Following referral, the family would be visited and a care plan developed.
- Where a child had a statement of need for speech therapy that the NHS was unable to fulfil then the education authority was required to. This could be very confusing for parents.
- The LHG had taken their commissioning role very seriously and Gwent Health Authority had adopted a fairly devolved approach in this area so the changes proposed under the NHS restructuring were seen as an extension of their current role.
- Joint flexibilities would provide opportunities to work with local authorities and education authorities in a more integrated way, although there were some practical difficulties particularly with budgets.

3.2 The Chair thanked everyone who had submitted evidence to the Committee. Members were particularly concerned by the evidence regarding provision of speech and language therapy. It was therefore agreed that representatives of the profession would be invited to give evidence to the Committee at its meeting on 27 February in Rhyl.

3.3 The Chair also asked that information be provided to Members on the provision across Wales of:

- speech and language therapy
- specialist health visitors
- key workers
- school nurses.

Action

- The results of the multi-agency review of services to children with disabilities being carried out by Newport County Borough Council would be provided to the Committee.
- Caerphilly Local Health Group would provide a written response to Brian Hancock on the continuation of care plans between primary and secondary schools.
- Members to be provided with information on the provision across Wales of speech and language therapy, specialist health visitors, key workers and school nurses.

Item 4: Minutes

Paper: HSS-03-02(min)

4.1 The minutes of the meeting held on 23 January 2002 were deferred to the next meeting.

Item 5 : Any Other Business

5.1 Dr Ruth Hall, Chief Medical Officer, made a statement on the MMR vaccine. A copy is attached at Annex A.

Annex A

Advice on MMR Vaccine: Key Points

1. MMR remains the safest way to protect children.
2. All authoritative bodies support this, from the World Health Organisation to our own Welsh National Communicable Disease Advisory Group, which met yesterday.
3. It is critical to keep up coverage to avoid disease breakthrough. It only needs to drop slightly for the disease to reappear. Measles in particular can kill and the others can have very serious long-term consequences.
4. Understandably, people are anxious and lack confidence. People's feelings are very important. They rightly need support in coming to decisions. They must talk their concerns through with the doctors or nurses they trust locally - GPs, practice nurses, health visitors.
5. We are making sure that professionals in Wales involved in immunisation have all the facts at their fingertips so they can be as helpful as possible.
6. Use of single antigen measles vaccine would not achieve equivalent coverage. It is not currently manufactured under licence in this country. Additional professional time would need to be diverted.
7. We do need to understand the causes of autism better. The Department of Health has research in hand and we are keeping closely in touch with this work.
8. Despite understandable concern, MMR vaccine remains the safest way to protect our children.

Dr
Ruth
Hall

CMO