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Ms Claire Morris
Deputy Clerk
Health & Social Services Committee
National Assembly for Wales
Cardiff Bay
Cardiff CF99 1NA

Dear Ms Morris

Review of services for children with special health needs

With reference to your letter of the 22nd October, the following is a response to the key issues from Caerphilly Local Health Group.

1. Early Identification and Diagnosis

We recognise that early identification and diagnosis can eliminate or minimise problems not only for children as they develop but also for their families in coping with children with special health needs. There are issues for both primary and secondary care in early identification.

Firstly with regard to primary care, it is recognised that child health surveillance is best undertaken by primary care but it is essential that GP's and primary health care nurses have the up-to-date skills and training to undertake this role. Whilst GP's are initially trained to undertake the Child Health Surveillance programme, there is no regular validation scheme to ensure that their skills and knowledge are current.

Children who are excluded from access to primary care are the target groups for Sure Start initiatives. However, Sure Start is targeted at areas/communities of need rather than "interest groups". This is the role of the core Health Visiting service which is also under pressure to clarify its core role and remit. The Health Assessment of Looked After Children pilot undertaken by Dr Heather Payne in Caerphilly, in partnership with our colleagues from Social Services, is an example of an approach to target children who are potentially excluded from access to primary care.

With regards secondary care, one of the main issues of concern at present is the resources for the therapy services. Therapy resources are required to co-ordinate assessments across therapy services to support the diagnosis being made by the Consultant Paediatrician but there is then a further concern for the need to provide therapy on an on-going basis.

In addition to early identification, we consider that it is important to provide a counselling support services, if required, to parents not only when a diagnosis is made but also when there are concerns raised about the health needs of their child.

Unfortunately, the above issues do not appear to be a priority for the National Assembly in relation to health and health services and therefore, with limited development funds, it is not an issue locally that we are able to adequately address.

2. Provision of Information

It is essential that those who give information about the special health needs and problems of a child are appropriately trained. Mechanisms and services to provide on-going support to the families are essential. One example of this is the role of a specialist Health Visitor within the CDT, with specialist skills and a small caseload, they can act as key worker and also as an advocate to all other professionals and to help interpret information. We also recognise the key role of the Voluntary Sector, not only in the provision of support but also in respect of actual service delivery.

Information for families needs to be co-ordinated and accessible across health services so that there is no need for families to seek information from a range of different health professionals, this only adds to the confusion and frustration. Services also need to be mindful of information not only to parents and guardians, but also to other members of the family, including siblings and grandparents.

The involvement of parents in the development of user-friendly information and the co-ordination and planning of services is the ideal, and should be an essential element of any new developments/business cases. However, effective participation and involvement is time consuming and is often not considered by clinicians as a high priority.

Tape recordings would be one way of helping families receive and understand the information given during a consultation.

3. Co-ordination of Care

Whilst Child Development Teams are a good example of co-ordination, the fact that there is a lack of common priorities across the professions results in fragmentation. Each professional group uses different criteria to

prioritise their cases based on risk, treatment outcomes, etc. In practice this results in members of the CDT undertaking different assessments at different times, adding to the confusion by the family. Consideration also needs to be given to the co-ordination and potential for joint assessments by members of the CDT in order to streamline services for the parents and child. Once assessed, the remaining workload for the individual therapy group then requires identifying and the amount of resource required to meet that need quantified.

Again, there is a clear role for a specialist health visitor within the CDT. In Caerphilly we are fortunate that this role has been recognised as being of value across the agencies and we have secured funding through Children's First from April 2002.

The co-ordination of transition for children and young people into adult services is poorly planned. In addition, the increasing numbers of young people who are surviving into adulthood is creating pressures on adult services who are also not resourced to cope (one particular example is Speech and Language therapy services for adults).

The lack of common definitions across services and agencies also causes problems in the co-ordination of care. Not only do definitions and criteria vary across health professions within the same NHS Trust, but there are also issues across the same health professions operating across other NHS Trusts. Furthermore, definitions between health and education are also unclear.

Information sharing is also an issue which affects the co-ordination of care. Securing informed consent to share information is essential but needs to be handled sensitively and at the right time so that parents understand the reason and benefits of sharing the relevant information.

4. Availability of Care and Treatment

The majority of services who work with children and young people with special health needs (i.e. Speech and Language, Occupational Therapy, Portage, etc) are all facing increasing demands as referrals and caseloads increase. There has been a ten-fold increase in the numbers of children within the autistic spectrum over recent years (Sunderland survey) but resources have not increased to meet the demand. Whilst resources are an issue, the supply and availability of staff is also a major concern at both a post basic and post registration level to address the skill deficiency and lack of trained staff available.

A factual example of the current concerns is in relation to the Speech and Language Therapy. In September 2001 the Special Educational Needs team across Gwent had 8.9 wte funded posts and 2.6 wte vacancies. However, the caseload was 556 children with 53 waiting for up to 8 months. Also at September 2001, the Community Childrens team within SLT had a funded establishment of 22.6 wte with 8.2 wte vacancies, a caseload of 2433 with 1387 children waiting between 14-17 months. These concerns are also being raised at the WAGSEN Therapies sub group.

The service is also under considerable pressure to prioritise the children who have a Statement of Special Educational Need as there is a legal responsibility on the Local Education Authority to ensure a therapy service is delivered. However, the service prioritises on clinical need and, with limited resources and a recruitment and retention problem, this is creating further pressures.

The report from the National Statistics Office on pupils with Statements of Special Educational Needs dated January 2001 taken from the STATS2 survey identifies the number of children who have Statements of Special

Educational Need. Whilst this does not identify the numbers who have health elements to their Statements, this is an indication of the increasing pressure on health services.

As more children with special health needs are placed in mainstream schools these children are further removed from specialist health services working alongside education. As explained earlier, these resources are already limited and therefore focus their support on the special schools where support can be given to a group of children. Children with special health needs who are part of mainstream education are a concern to health in that they may not receive the support and services needed. Teachers are also under increasing pressure in the classroom and do not have sufficient time to support these children. Whilst we recognise that it is not appropriate for all children to be educated in specialist units, there is a concern that inclusion is not always the right approach.

5. Support for Families

Support for families is a concern and needs to be co-ordinated across health and social care. It is also important to recognise the issue of Young Carers and their needs. It is essential that Adult Services undertake a family assessment and recognise the needs of Young Carers. Furthermore it is essential that services for young carers do not further isolate these young people but provide them with support to be part of everyday life and local facilities.

6. Equipment and other Social Services Needs

As equipment is provided by both health and social services there needs to be greater co-ordination of both the assessment and delivery of aids and adaptations. The main problem relates to the decision about if it is a health aid or social aid and also disputes about who should pay for the equipment. There is also no co-ordination across local authorities where policies and procedures vary from borough to borough. This makes it impossible for a health trust to reach a single agreement across all areas it covers.

7. Children with Special Educational needs

As stated in point 4 above this is a major problem. Increasing pressures from LEA's to assess children in mainstream schools is skewing the clinical priorities for the health services and creating tension between health and education authorities.

8. Good Practice

There is an urgent need to identify what is considered "good practice" and also what services should or should not be providing. This needs to be benchmarked across Wales and also England to establish a common definition, common language and to identify gaps in service resource and delivery. There is a clear role for the National Assembly for Wales to identify what is currently good practice across Wales, new and targeted initiatives, resource levels and, most importantly, clear definitions.

I hope that you find these comments helpful, should you require any additional information please contact Jennie Willmott or myself on the above number.

Yours sincerely,

Judith Paget
General Manager