

Date: 6 February 2002

Venue: Committee Room 3, National Assembly for Wales

Title: Response from Cardiff and the Vale NHS Trust

1. Early identification and diagnosis

To ensure equality of access the following are required:

- Develop more of a skill mix within professional groups (especially speech therapy, clinical psychology, school nursing service) by appointing more clinical assistants who will then be supervised by fully trained professionals.
- More psychology support to primary care teams – through existing structures (Children's Centres, Health Centres to Health Visitors and GP's).
- More joint training initiatives between primary care teams, community child health staff, child and adolescent mental health staff (CAMHS) and social services staff on emotional and behavioural disturbance. These are best organised on a geographical basis so that professionals can develop better working relationships.
- More psychology support to the Child Protection Intake and Assessment Team
- Implement the 'tiered system' approach for CAMHS as recommended by the H.A.S. report. These include more than the appointment of additional consultant psychiatrists i.e. family therapists, psychologists, and community psychiatric nurses.

2. The provision of information to parents/guardians

Provision of information is patchy. Keeping leaflets etc up to date (either home produced or bought in) is expensive. This activity is largely unfunded. Further cost is introduced by the NHS Trust and LA changing its name every 2-3 years. An Interagency Information Officer was appointed in Cardiff recently but needs to be fully resourced in terms of adequate premises and materials to provide a desirable quality of service. There are still major financial blocks to obtaining translations of information

materials for ethnic minority groups. We know from research that parents' number one priority is access to information. This needs to be reflected in funding.

3. Co-ordination of care

We have recently developed a key working system in Cardiff with key workers from both Health and Social Services. This is the best model but it is already further identifying the huge deficits in respite care, interagency funding of equipment and support for difficult to place children. Politicians need to insist that local authorities implement true interagency joint funding for these issues as recommended by the Disability Discrimination Act 1995. The legal bars to pooling of interagency funds were removed by the recent Health Act 1999. Local Authorities are in danger of being accused of discrimination against disabled children.

4. Availability of care and treatment

There are problems:

- The Health Authority and Trust is unable to meet the therapy needs of children at an increased number of delivery points as required by the inclusion and mainstream agenda without an impact on quality and hands on clinical input. Solution is investment in additional physical therapists.
- Problems around administration of medication in schools have been largely resolved but there are still isolated schools where staff do not volunteer to help the child (at the moment there is no legal requirement for educational staff to give prescribed medication in school). In Cardiff there are locally agreed protocols, health care plans, school nurses trained to investigate and resolve issuing in problem schools.
- There is poor continuity between in-patient chronically ill and disabled children and community nurse, which has not been resolved by a shared discharge policy etc. Investment in a community paediatric nursing service and specialist nurses is the solution.

5. Support for families and other carers

There are well-documented long-standing deficits in respite care particularly for physically disabled children, children with challenging behaviour and children with autism.

Three 1-2 week summer schools are held in special schools in Cardiff and the Vale but are always organised and partly funded on an adhoc basis usually by parents themselves and/or healthcare staff. Parents value these summer schools highly. They cost relatively little yet there is a scramble for funding every year.

The new key working system in Cardiff has been established. Research shows that personal support and

liaison in relating to children with special needs is rated highly by parents. The key working system needs to be extended further – currently it reaches only 1/3 of disabled children and their families. The ‘good enough’ key worker has a pro-active relationship with the family and acts as a ‘single door’ to other agencies.

Key workers need to be supported by services which are a) available (extremely little respite care) b) where interagency joint funding issues re: respite care, continuing health care, equipment and assessment have been resolved.

6. Equipment and other social services needs

There are delays in the assessment for and provision of equipment, aids and adaptations.

The solutions are:

- A Joint aid store involving all the statutory agencies in the assessment, provision, storage, maintenance and funding of most equipment/aids.
- Appointment of an independent Interagency Funds Manager (Children’s Services Manager) to oversee interagency joint funds. At present the bulk of Welsh Assembly funds for children with special needs goes to the Local Authority and is not usually directed into existing structures but into time limited projects with associated high administration and managerial costs. The resultant improvement in services to children and their families is subsequently often marginal and can conflict with existing services.
- Health Trusts are crying out for additional funding for therapists (particularly Occupational and Speech therapists, clinical psychologists and relevant clinical assistants). There is usually no lack of user confidence in existing services just that they are often insufficient to meet the identified needs of children.

7. Children with special educational needs

The Health trust is unable to meet fully the therapy needs of children in mainstream schools (physio/occupational speech and language therapies) due to an insufficient number of posts and recruitment problems. The implications of the educational inclusion policy for the health services have not been reflected in funding for additional resources.

Solutions

- Joint funding of therapists through Welsh Assembly monies to support inclusion in mainstream.
- Management of such jointly funded therapists could rest with the Local Authority but clinical supervision with existing community child health therapy departments to prevent professional

isolation and promote a common understanding of good practice and allow ongoing clinical supervision and education with specialist paediatric therapists.

Good practice_

- Ask parents/carers to identify good practice.
- Ask professionals to produce the following:
 - **Protocols for waiting lists**
 - **Prioritisation of referrals**
 - **Evidence of clinical effectiveness**
 - **Evidence of ongoing training within professional groups and between disciplines.**
 - **Flexibility and creativity in deliver of services-to reflect the changing lifestyle of most adults and fit in with children's schooling.**

Finally all Wales Interagency guidelines for children with special needs were agreed in 1994 (copy attached) and have not yet been fully implemented. It is time Children's Services received the same level of investments as adult services. The resultant outcomes may well be greater.

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**Review of Services for Children with Special Needs
Response from Daniel Phillips, Women, Children & Community Service Group**

1. Early identification and diagnosis of Special Health Needs

To ensure equality of access the following are required:

- Enhanced training for Health Visitors re autism/communication difficulties.
- To accommodate earlier referrals an improved skill mix within professional groups (especially speech therapy, clinical psychology, school nursing services) is required by appointing more support workers/assistants who will then be supervised by fully trained professionals. This would in turn lead to early intervention.

- More psychology support to primary care teams.
- More joint training initiatives between primary care teams, community child health staff, child and adolescent mental health staff (CAMHS) and social services staff on emotional and behavioural disturbance. These are best organised on a geographical basis so that professionals can develop better working relationships.
- Continue to implement the 'tiered system' approach for CAMHS as recommended by the H.A.S. report by enhancing the staffing establishment for family therapists, psychologists, and community psychiatric nurses. (In addition to Consultant expansion).
- Further investment in specialist support for those groups who traditionally have difficulty in accessing services such as travellers/unstable families.
- Additional investment in extra Consultant Community Paediatrician posts to enable more rapid assessment and treatment.
- Early identification for hearing impairment and equality of access is only feasible with the implementation of universal newborn hearing screening programmes. Evidence exists that early diagnosis of hearing impairment and provision of early intervention will reduce language, mental health and educational problems in future.

2. The provision of information to parents/guardians

- Disclosure of diagnosis should be in line with joint agency guidelines.
- Verbal information on diagnosis is provided directly to parents by Consultants/Special Needs Health Visitors. Support organisations are contacted and requested to forward information to parents and the key worker support parents in understanding where necessary.
- An Inter-agency Information Officer has been appointed in Cardiff recently but the service needs to be fully resourced in terms of adequate premises and materials to provide a desirable quality of service. Obtaining translations of information materials for ethnic minority groups is a key issue.
- It is important that an explanation regarding choices and range of services is provided by a professional who has the relevant experience and knowledge regarding available and appropriate services.
- Genetic counselling is available for those family members who require this service.

3. Co-ordination of care

- Currently there is a shortfall in the co-ordination and care planning between various agencies particularly at a strategic level. However operational links between health, social services and education are being developed. Physical links including the shared accommodation for locality teams and joint operational policies are needed. This partnership needs to be developed in parallel with the establishment of new services on a multi-agency basis accessing funding from a range of national initiatives.
- The opportunities to joint fund projects need to be enhanced with a view to establishing joint budgets.

4. Availability of care and treatment

There are problems:

- There are considerable difficulties in meeting the therapy needs of children at an increased number of delivery points as required by the inclusion and mainstream agenda in education services, without an impact on quality and hands-on clinical input. There is therefore a requirement to further enhance the staffing establishment for the full range of therapy staff offering support to children with special needs.
- Problems around administration of medication in schools have been largely resolved but there are still isolated schools where staff do not volunteer to help the child (at the moment there is no legal requirement for educational staff to give prescribed medication in school). In Cardiff there are locally agreed protocols, health care plans, school nurses trained to investigate and resolve issues in schools. However to address this issue appropriately, a more Comprehensive Children's Community Nursing Service is required.
- There is poor continuity between chronically ill and disabled children receiving inpatient care and the discharge arrangements with the community nurse, which has not been resolved by a shared discharge policy etc. Investment in a community paediatric nursing service and specialist nurses is the solution.
- There is a recognised shortfall in therapy provision for children with special needs.
- Further investment is required to deliver a family friendly paediatric audiology service, appropriately staffed and equipped and operating on an inter-agency basis.
- It is recognised that training and recruitment of teachers for the deaf is currently problematic.
- There is a need for a service, which is not restricted to term time only.

5. Support for families and other carers

- There are well-documented long-standing deficits in respite care particularly for physically disabled children, children with challenging behaviour and children with autism.
- Three 1-2 week summer schools are held in special schools in Cardiff and the Vale and have been organised and partly funded on an ad hoc basis usually by parents themselves and/or healthcare staff. Parents value these summer schools highly. They cost relatively little yet there is a no designated recurring funding to support the schemes.
- The new key working system in Cardiff has been established. Research shows that personal support and liaison in relating to children with special needs is rated highly by parents. The key working system needs to be extended further – currently it reaches only 1/3 of disabled children and their families. The key worker has a pro-active relationship with the family and acts as a 'single door' to other agencies.
- Key workers need to be supported by services, which are a) available (extremely little respite care) b) where interagency joint funding issues re: respite care, continuing health care, equipment and assessment have been resolved.
- Respite care for children with sensory impairments is currently not available with no out of hours youth clubs and limited provision during school holidays.

6. Equipment and other social services needs

There are delays in the assessment for and provision of equipment, aids and adaptations. This is due in part to a lack of clarity regarding the respective responsibility for funding for each agency, particular items of equipment that fall between the definitions of health, education and social needs. Lack of joint funding often results in a delay in the equipment being received and professional staff assisting parents in seeking charitable funding to support such purchases.

The solutions are:

- A Joint aids store involving all the statutory agencies in the assessment, provision, storage, maintenance and funding of most equipment/aids.
- Appointment of an independent Inter-agency Funds Manager (Children's Services Manager) to oversee inter-agency joint funds. At present the bulk of "new monies" for children with special needs eg Surestart goes to the Local Authority and is not usually directed into existing structures but into time limited projects with associated high administration and managerial costs. It is therefore sometimes difficult to maximise the benefit to children with special needs utilising this method of funding.
- NHS Trusts have recognised the need for additional funding for therapists (particularly Occupational and Speech therapists, clinical psychologists and relevant support workers/assistants). There is usually no lack of user confidence in existing services just that they are often insufficient to meet the identified needs of children.

7. Children with special educational needs

The Trust is unable to meet the therapy needs of children in mainstream schools (physio/occupational/speech and language therapies) due to an insufficient number of posts and recruitment difficulties. Unfortunately the implications of the education inclusion policy on the health services have not been reflected in the provision of additional resources. There are major diseconomies of scale in delivering services in mainstream schools and problems associated with suitability of premises. It should also be noted that there are no specialist speech and language therapists for high school hearing impaired children.

Solutions

- Joint funding of therapists to support inclusion in mainstream.

Good practice

It is recommended that the following proposals are considered in the context of good practice namely:-

- Commission external evaluation.
- Ask parents/carers to identify services, which they value.
- Ask professionals to produce the following:
 - Protocols for waiting lists
 - Prioritisation of referrals
 - Evidence of clinical effectiveness
 - Evidence of ongoing training within professional groups between disciplines and on a multi-agency basis.
- Flexibility and creativity in delivery of services-to reflect the changing lifestyle of most adults and fit in with children's schooling.
- Establish parent representatives on such groups such as audiology working group to assist with the monitoring/evaluation of services.
- Continued research and development work on services for children with special needs.