



Transforming Services for Children with Hearing Difficulty and their Families (Department of Health, August 2008)

British Society of Audiology Response (November 2008)

The BSA welcomes the Good Practice Guide "*Transforming Services for Children with Hearing Difficulty and their Families*" from the Department of Health. The following response to the Guide is based on comments from the British Society of Audiology (BSA) Paediatric Rapid Review Panel (RRP), and collated by the steering committee of the Paediatric Audiology Interest Group (PAIG), a special interest group within BSA.

Summary

Transforming Services for Children with Hearing Difficulty and their Families provides a timely overview of service requirements, describing roles and responsibilities at a range of levels. This focus on a relatively uncommon sensory condition is very welcome and warmly applauded. The concept of integrated networks goes to the heart of optimal care for these children and their families. However, in outlining its proposals for these networks, the guide leaves some important areas unclear, particularly in relation to ensuring equitable access to high-quality services for all deaf children and their families, wherever they live. Many services already promote multi-disciplinary and cross-sector working and advocate a key role for children, young people and their families in service planning, and although the document reiterates the importance of these elements in a quality service, it does not provide specific detail or guidance on how these optimal services can be ensured across the board for all deaf children and their families. The BSA welcomes the opportunity for further clarification of these important issues at the Department of Health's National Audiology Event on February 9th 2009.

Detailed concerns

Part 1: The Current Challenge in Children's Hearing Services

Permanent hearing impairment in children: an uncommon condition requiring vigilant detection

Service provision extends beyond detection and requires resources to support on-going good quality follow-up in Health and Education.

- Page 7, Section 6 – The examples of numbers of deaf children likely to be encountered at GP, Practice and Primary-Care-Trust level provide a clear context for the low-incidence nature of PCHI

Variable children's hearing services

There are services which currently combine the local and specialist skills outlined in the document and have well-established links to supra-specialist provision. The strictly tiered system proposed here may have the effect of making expertise less, rather than more, accessible.

- Page 8, Section 10 – The statement about the full introduction of NHSP in 2006 is misleading, implying that there was no detection of hearing loss at birth prior to this. This ignores the targeted hearing-screening programmes which had been in operation and also fails to take into account the staged introduction of NHSP.
- Page 8, Section 11 – '121 newborn screening programmes' is an inaccurate description of a national screening programme which encompasses 121 sites.
- Page 8, Section 12 – A reference to MCHAS aims and achievements would provide a useful background to the points made here.

Transforming Children's Hearing Services

Networks of services for children with hearing difficulty

Many services are configured in such a way that they have a dual role working at both the local and specialist level. The panel has concerns that any initiative which resulted in tiering of services into local and specialist levels would lead to workforce de-skilling at local level and would penalise children and families in more rural areas, for example, who might have to travel further to access services.

- Page 10, Section 14 – This section provides positive recognition of the role of parents as partners. However, the document fails to recognise that the resources to support CHSWGs should be made available by those commissioning paediatric audiology services.
- Pages 10/11, Section 14- Social care tends to be generic across disabilities or is adult-oriented. Exploring how a more tailored, age-appropriate approach might be developed is essential.
- Page 12, Section 15 – There is likely to be significant variation in the configuration of local and specialist teams around the country, with many services carrying out a dual role. Where this occurs, there needs to be acknowledgment that training, mentoring and support for local services will be needed.
- Page 12, Section 16 – There needs to be very careful consideration given to the care pathway for the individual child and family in a tiered system, balancing the need for specialist resources with ease of access. Moving expertise away from local services may lead to uneven provision.
- Pages 13/14 – *Table 1: Network of Children's Hearing Services*
- Cross-sector working – it would be helpful to include examples of good practice. Providing services for children and families beyond the clinic requires the establishment of good local links between Health and Education and between statutory and 3rd-sector agencies. Service planning needs to look at staffing and training issues beyond Audiology.

Strong local teams are currently providing more specialist services. There is concern about how existing skills will be preserved. Steps in service provision may be increased and waiting times extended in the centre-based model.

'Local children's hearing service'/'Specialist centre'

- Explicit reference to children under 3 years of age, or at a developmentally equivalent level, needs to be made. Provision for those over 3 years is seen to be with the local centre, but there is no specific mention of under-3s in the remit of the specialist centre.
- The additional challenges relating to dual sensory impairment should be recognised. Links with ophthalmology services and monitoring mechanisms should be incorporated into the networks.

'Specialist centre'/'Supra-specialist centre'

- Vestibular assessment requires a high level of expertise and expensive equipment. There is an urgent need to look at training needs, protocols and standards for vestibular assessment, as well as the funding and resources to support service development.

Achieving the Vision:

The conflict between accessible services provided by highly skilled local professionals on the one hand and the stated aim of moving expertise away from local services to specialist centres is not resolved here.

Planning service capacity

- Pages 22/23, Sections 36 and 37 – Recommendations on staffing levels and facilities (e.g. sound-treated rooms) for population size would be useful. There was concern that simply linking patient-load to local versus specialist status would have an adverse effect on accessibility to high-quality care for those living at some distance from the centres.

Technology

Hearing aids

- Page 26, Section 47 – 'Sensory devices' or 'Aids to hearing' might be a more appropriate title.
- A clear statement is needed here, indicating how it is planned that FM systems would be made routinely available for children who would benefit and how the pooling of budgets would be achieved. This is of particular relevance to those with Auditory Processing Disorder (APD) who are not explicitly mentioned in the document.

Part Two: Good Practice Commissioning Specification

- Pages 30-32, Sections 61-65 (and Annex 1) – A lack of linguistic precision, e.g. in terms such as 'diagnosis' or 'paediatrics', blurs the distinction between roles and responsibilities of staff at each service level. It would be useful to include a glossary which clearly defines what is meant by identification, assessment, confirmation, audiological management and medical diagnosis and for these terms to be used precisely throughout the text and in the figures and tables.
- Pages 31/32, Sections 63 and 64 (and Annex 1) – Further clarification is required regarding the skill mix for services offering vestibular assessment and providing care and management for children with balance disorders, as these services are not routinely available at present.
- Neurodevelopmental assessment of children should be included.
- Page 32, last bullet point – Change 'school-screen' to 'school-entry screen' to provide specific information on timing.

Indicators of high quality care

- Pages 32-35, Section 66 – The bullet points represent guiding principles underlying good practice. They are not measurable indicators of high quality care. The need for measurable outcomes remains.

Annex 1: Suggested Components of the Children's Hearing Service Network

- The headings and sub-headings were felt to be useful guides to the factors involved in service planning.
- More clarity is needed, however, in outlining the workforce skills required, and recognising the specific skills contributed by team members (e.g. audiology assistants are not trained in 'paediatrics' as the table suggests).
- A more careful use of terms, such as 'diagnosis', would help to differentiate the specific contributions of different professional groups to the integrated network.

Transforming Services for Children with Hearing Difficulty and their Families provides a useful guide to the services required to support deaf children and their families. However, by instituting the strictly tiered system proposed here this may serve to reduce expertise at local level rather than make it more accessible, and there is a risk that access to high quality services might prove more difficult for deaf children and their families. The document needs to go further in developing measurable outcomes to inform local audits and service-development plans and to guide commissioning decisions. Further work is also required on creating a blueprint for paediatric vestibular services and for integrating these with hearing services.

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