

Evidence on Very Early Service Delivery: What Parents Want and Don't Always Get

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Introduction

While a number of key research issues remain unanswered in pediatric audiology and early amplification, there is now a considerable evidence base that can be used to guide service delivery. In some cases, this evidence base has been drawn together to provide guidelines for preferred practice (e.g., European Consensus Statement on Neonatal Hearing Screening 1998; Joint Committee on Infant Hearing 1994; NDCS 1996; NIH 1993; Pediatric Working Group 1996). These guidelines provide us with some benchmarks against which we can gauge the quality and extent of service provision for children with hearing impairments and their families.

This chapter reports the results of four related studies that investigate the current status of very early service delivery for children with hearing impairments relative to some of the benchmarks provided by preferred practice guidelines. The four studies were all carried out in the United Kingdom (U.K.), but are likely to raise issues relevant to service provision in other parts of the developed world. Some data from the U.S. clearly indicated cause for concern about the quality of service implementation (Arehart et al. 1998, Hedley-Williams, Tarpe, and Bess 1996). The data presented here are from a questionnaire (n=344) and interview (n=105) study of the parents of children with hearing impairments in the Trent region of England (Hind and Davis 2000); from an ongoing questionnaire survey of service providers across the U.K. (currently n=174; Reeve, Davis, and Bamford); from focus group meetings with parents of children with hearing impairments, carried out as part of a critical review of neonatal hearing screening in the U.K. (Davis and Bamford); and from an in-depth interview study with parents of children with very complex needs (n=14; McCracken).

We will start by considering the impetus provided by current interest in neonatal hearing screening, and then

examine comments about very early service provision from parents and some current U.K. service data derived from the Trent study. The interim results from the study of U.K. providers will then be discussed, along with some data from the interviews with parents of children with complex needs, before drawing all the strands together into a series of clinical implications, considering in particular how we might move toward *seamless services*, a term now being used by commissioners of health care and policy makers, as well as by providers and families. In reflecting upon these data, it is important for service providers to adopt a self-critical attitude toward their own standards of service provision. Across the developed world, we fall far short of the guidelines and standards that have been set on the basis of the existing evidence base, and parents tell us, in well-designed studies, that their satisfaction with services is in general far from adequate. There are, of course, notable exceptions where services for children with hearing impairments and their families are delivered across health, and between health, and education in a seamless way, and at the limits of our current knowledge base; but the performance of some good services should not hide the general limitations in current provision.

Early Identification

Table 1. Current U.K. data on age of identification (Fortnum and Davis 1997).

| Degree of Hearing Impairment | Median Identification Age in Months |
|------------------------------|-------------------------------------|
| Moderate | 35 |
| Severe | 11 |
| Profound | 9 |
| All | 20 |

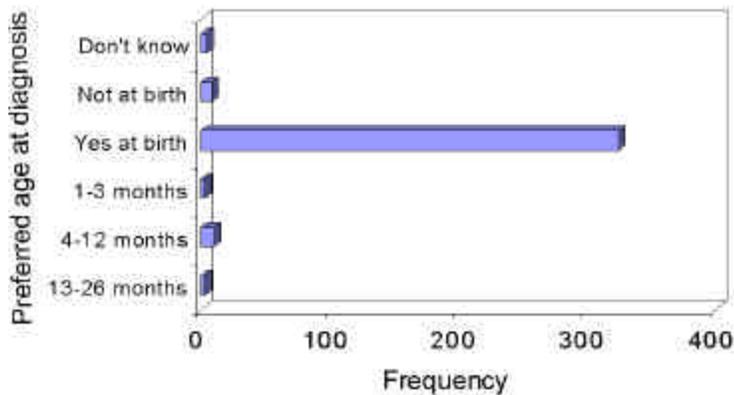


Figure 1. Questionnaire study. Parents of children with hearing impairment: preferred diagnosis age (n=344).

On the basis of later outcome benefit, parental right to knowledge of factors that affect their child's development, the value of early intervention, and the costs to child, family, and society of late identification, a number of targets have been set for early identification of permanent childhood hearing impairment. The NIH Consensus Statement (1993) suggested that all children with any degree of permanent childhood hearing impairment should be identified by 3 months of age. Although it is a commendable ideal, this is actually a somewhat unrealistic target since it would be extremely difficult to achieve and even harder to audit. The National Deaf Children's Society in the U.K. (NDCS 1994) set targets for the identification of permanent bilateral congenital hearing impairment of 50 dB or greater, which are challenging but achievable under current circumstances: the NDCS targets call for 40% of such children to be identified by 6 months of age and 80% by 12 months of age.

The large Trent study in the U.K. involved close to 100% retrospective ascertainment of all children with bilateral permanent impairment of 40 dB HL or greater born between 1985 and 1993 in the Trent region (Fortnum and Davis 1997). Table 1 shows the median age of identification for this sample, and it is clear that even for children with profound hearing loss, the relatively modest NDCS targets are not met.

Overall, the median age of identification is 20 months, and this despite the fact that the U.K. has a nationwide behavioral hearing screening test administered by trained nurses (Health Visitors) at about 8 months of age. These data and others like them have been instrumental in the development of the NIH Consensus Statement on Neonatal Hearing Screening (1993), the European Consensus Statement on

Neonatal Hearing Screening (1998), and the recently commissioned critical review of the role of neonatal hearing screening in the U.K. (Davis et al. 1997). These consensus statements and recommendations, all calling for the introduction of universal neonatal hearing screening, are in general accord with parental wishes. Certainly, parents of children with hearing impairments indicate a very strong preference for identification at birth rather than later. Figure 1, for example, shows the results from the parents in the Trent study who were asked at what age they would have preferred their child's hearing impairment to have been diagnosed.

Overwhelmingly, the response was at birth. Note, however, that this strong view has to be tempered with other comments that indicate marked dissatisfaction with the way in which identification was handled with the family and is in a very real sense dependent upon the existence of good and sensitive information and assessment. Although some audiologic procedures are easier to carry out with very early identification (e.g., electrophysiologic testing, probe tube microphone testing), and early identification of hearing impairment carries the potential for better progress and for earlier management decisions, it must not be overlooked that the identification of newborn and very young babies brings heightened sensitivity to the process. Often, later or late identification is accompanied by some degree of parental suspicion that may mitigate the challenging information being presented to the parents; in the case of very early identification following newborn hear-

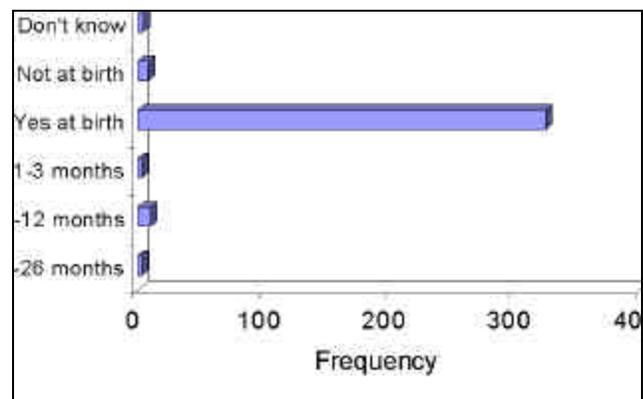


Figure 2. Questionnaire study. Distribution of the delay in months between parental first suspicion of hearing impairment and diagnosis.

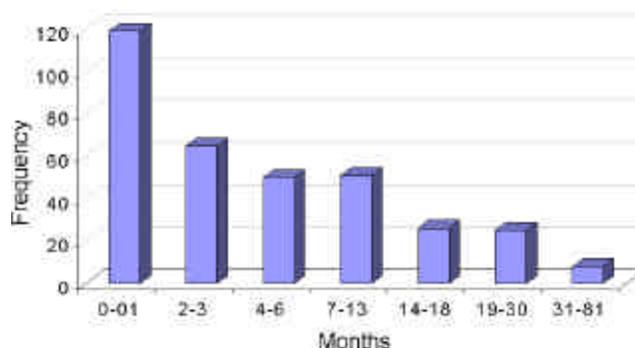


Figure 3. Questionnaire study. Distribution of the delay in months between diagnosis and fitting of hearing aids.

ing screening, prior parental suspicion is likely to be much less common.

In our focus groups with parents, and our questionnaires to parents in the Trent study, parents indicated low levels of satisfaction due to late identification, delays in hearing aid fitting, inappropriate first hearing aids, poor information, and poor service coordination. They indicated poor responsiveness to parental concerns and considerable worry about the ability of services to deal with hearing screening failures quickly and authoritatively. When asked to indicate what aspects of service provision they would wish to see improved, parents suggested earlier identification; better information; a more holistic view of child and family; better coordinated services; less delay in hearing aid fitting; better hearing aid fitting; and better support after identification.

Parental comments about delays are reinforced in figures 2 and 3, which, using data from the Trent study, show the delay from parental first suspicion to identification and the delay between identification and the fitting of hearing aids. While there are sometimes good reasons in individual cases for management delay between identification and fitting of hearing aids, such occasional cases cannot explain away the data in figure 3. Both figures 2 and 3 show a depressing picture of unnecessary and long delays.

Parental comments about the first hearing aid fitting and about the ongoing support and assessment were broadly positive, but with a significant minority concerned about the lack of advice and information at first fitting accompanied by a degree of uncertainty about management and expectations of the child's aided responses. With regard to ongoing support and assessment, there are a significant number of comments from parents indicating concern at irregular hearing aid review appoint-

Table 2. Components of early audiologic profiling.

Audiologic Profiling

- Parental observations of whole child in the family context
- AC and BC ABR-notched noise for low frequencies? Steady state potentials?
- Otoadmittance battery
- OAEs
- Behavioral observation audiometry, then insert ear phone VRA by 6 months

ments, a culture in which parents were deskilled and not regarded as equal partners in the process, earmold and hearing aid repair problems, lack of information (again), and the important effect of the wider family. By this is meant the influence that other members of the family, grandparents, for example, can have on the acceptance of the diagnosis and the management plan, an effect that can be either positive or negative, but that speaks to the wider family being included wherever possible in the development of the plan.

Authoritative Audiologic Provision

Current knowledge, reflected in the published evidence base and the existing preferred practice guidelines, indicates a reasonably clear consensus about what should be provided at the stage of early audiologic profiling, early hearing aid provision, and early monitoring of progress with hearing aids. This consensus is summarized in tables 2, 3, and 4, with question marks indicating areas that look to be promising, although not yet certain enough for practice guidelines and that are currently being researched.

Review of Current Services

Table 3. Components of early hearing aid fitting.

Hearing and Provision

- Based upon good audiologic profiling and family-centered approach
- Use of published prescription procedure to guide selection and verification
- Individually measured RECDs to speed optimal fittings
- Verification with probe tube microphone measures
- Steady state potentials for very early aided thresholds?

Table 4. Components of early hearing evaluation.

| Hearing Aid Evaluation |
|---|
| <ul style="list-style-type: none"> • Parental views and observations—use of checklists, diaries, questionnaires, etc. • Goal-setting and contingent management decisions • Frequent amplification reviews • More detailed audiologic profiling? E.g., ULLs, assessment of residual frequency selectivity using notched-noise VRA? |

We have recently carried out a questionnaire review of current services in the U.K., seeking to establish the extent to which pediatric audiology services are following the service targets and guidelines set out in NDCS (1994; 1996). Although we are still collecting data from this survey, the results presented here are based upon 174 returns that represent more than half the service providers in the U.K. Figure 4 indicates that more than 50% of respondents did not have service targets for the age of detection or for the age of first hearing aid fitting. Of those who did have targets, fewer than 40% confirmed that they audited their performance against the targets. While an encouraging 72% of respondents were aware of the NDCS Quality Standards (vol. 2), which are concerned with hearing aid fitting and audiologic management, this still left 28% who were unaware of the guidelines. Considering the effort put into dissemination in the U.K., this finding gives some cause for concern.

The NDCS Quality Standards call for each area to set up an audiology working group to monitor pediatric audiology service provision and to make recommendations for policy improvements. Figure 5 indicates that

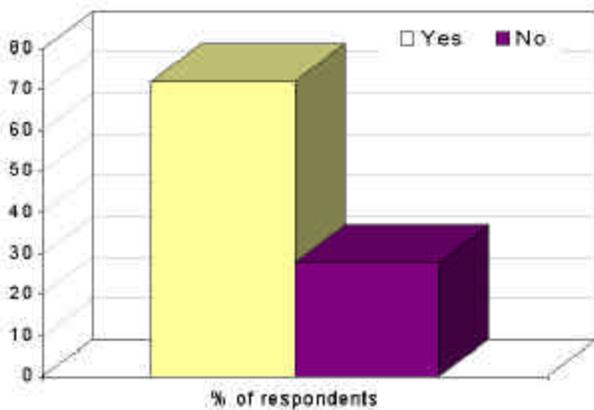


Figure 4. Survey of services. Percent of respondents aware of NDCS Quality Standards (vol. 2).

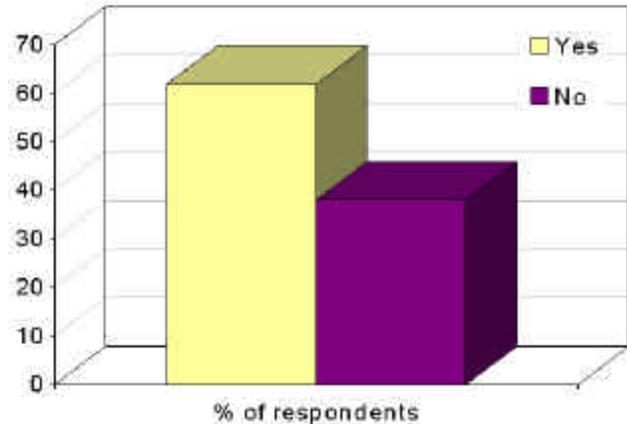


Figure 5. Survey of services. Percent of respondents with an audiology working group (AWG) in their area.

nearly 40% of respondents do not have such a working group in their area. The NDCS Quality Standards also call for educational personnel usually teachers of the deaf and parents of children with hearing impairments to be included in the membership of the working group. Interestingly, and worryingly, 30% of those with a working group reported no educational personnel, and a huge 81% of those with a working group reported no parental involvement (figure 6).

Another indicator of the extent to which services provide good information and are family centered is given by the next set of responses to the survey. The Quality Standards call for copies of audiograms to be given to parents routinely, for parents to be given some sort of written management plan (at its simplest, this would be

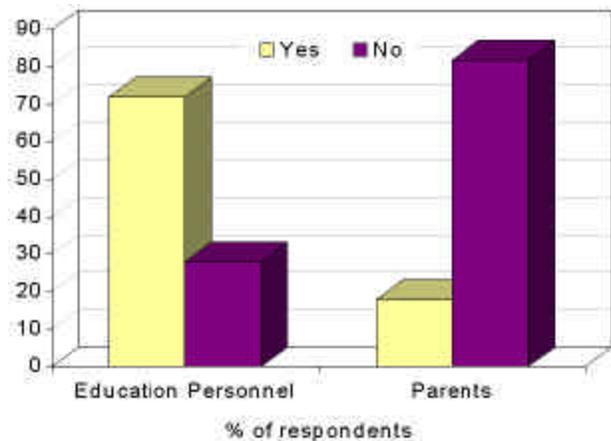


Figure 6. Survey of services. Percent of those with an AWG including education personnel and including parents of children with hearing impairments.

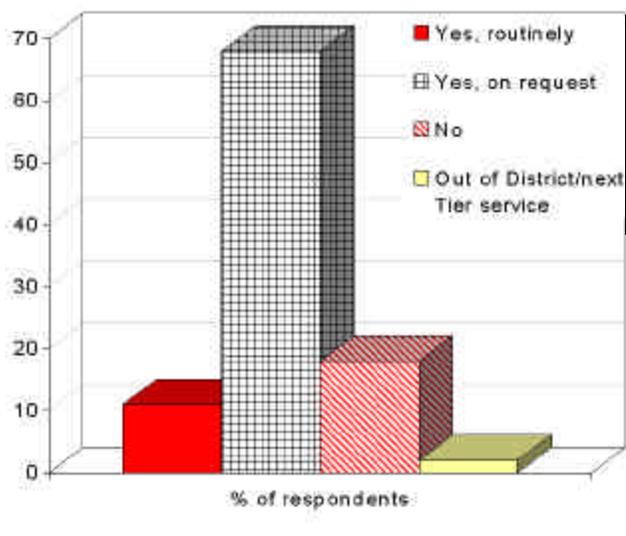


Figure 7. Survey of services. Percent of respondents giving copies of audiograms to parents of children with hearing impairments.

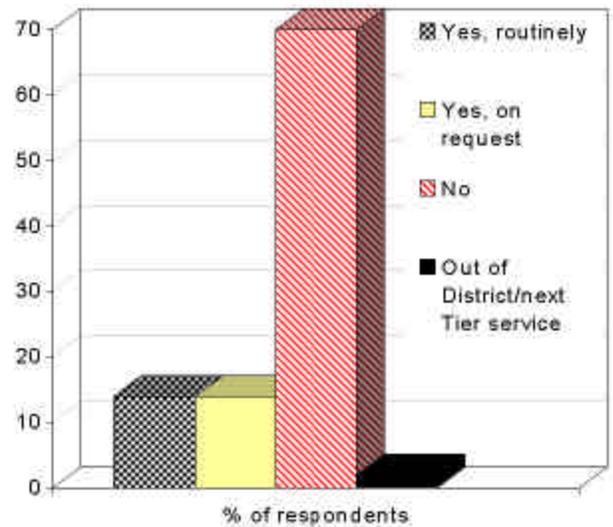


Figure 9. Survey of services. Percent of respondents informing parents of children with hearing impairments about their local NDCS branch.

copies of all letters and reports), and for parents to be informed of the existence and address of their local NDCS branch. Indeed, this latter is a statutory requirement in the U.K. in that parents of children with special needs must be informed of local voluntary support organizations. Figures 7, 8, and 9 give the results of these survey questions. Only just over 10% of parents are routinely given audiograms, with a similar number routinely being

given written management plans. Information about the local NDCS branch was better, with more than 70% being informed, but still a significant minority did not carry out even this basic statutory task.

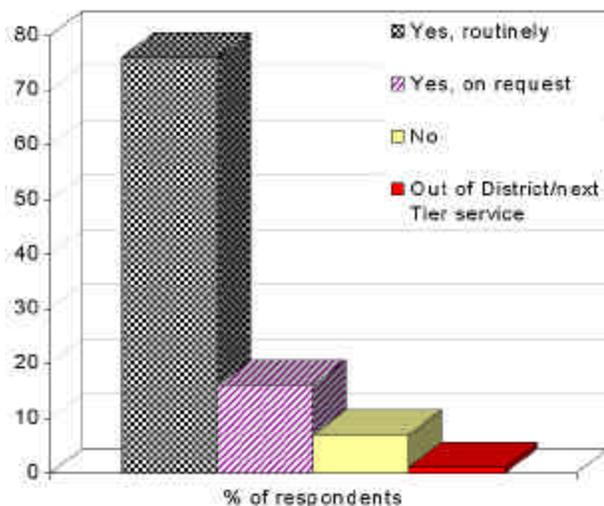


Figure 8. Survey of services. Percent of respondents giving written management plans to parents of children with hearing impairments.

One of the requirements for service provision is that all aided children receive regular hearing aid reviews. Our survey indicated that this was the case in more than 90% of providers. As an indicator of the quality of these hearing aid reviews, and again using the NDCS Quality Standards as a benchmark, we asked whether these included aided threshold measurements and probe tube microphone measurements. Figure 10 indicates that almost all those carrying out hearing aid reviews include aided threshold measurements, while only about 45% include probe tube microphone measurements. These findings are consistent with those reported by Hedley-Williams et al. (1996) and Arehart et al. (1998) and must be regarded with some dismay.

Aided threshold such measurements, while better than nothing and often a useful source for discussion with parents, do not reflect the functioning of hearing aids with higher level speechlike inputs, and one would have expected the use of probe tube microphone measures to be more widespread. We also asked about two other quality markers: specifically, whether the pediatric audiology service offered visual reinforcement audiometry (VRA) and whether it used one of the published prescriptive procedures for guiding hearing aid selection and verification. The use of VRA in the U.K. has been some-

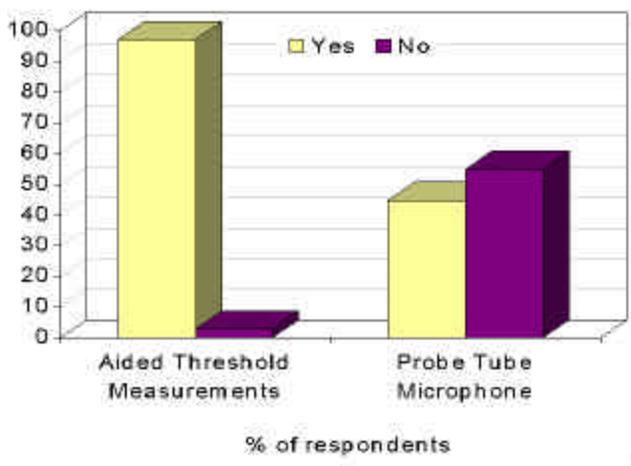


Figure 10. Survey of services. Percent of respondents using aided threshold measurements and probe tube microphone measurements in hearing aid reviews.

what held back by the widespread (and often high quality) use of the distraction test first described by the Ewings in 1944. However, since the distraction test cannot offer the same versatility as VRA, and in particular the opportunity to identify accurately thresholds for each ear as early as 6 or 7 months of age, it was argued that VRA would be a good indicator of quality provision. The NDCS Quality Standards call for the use of one of the published prescriptive procedures for hearing aid selection and verification. Figure 11 shows that only 57% of services offered VRA, and only 50% a hearing aid prescription procedure.

The interviews carried out with parents of infants with very complex needs indicated considerable levels of dissatisfaction with audiologic services (see Tharpe 2000). Fifty-seven percent were not satisfied with the way the audiologic tests were carried out; 43% were not satisfied with the explanation of the tests and the results; 36% had little confidence in the results of the assessments; and half the parents claimed that their own observations were not sought. Sixty-four percent of parents thought that the testers were inexperienced with children with complex needs; and yet all the parents interviewed regarded hearing status as particularly important for their child's development and well-being.

Lessons for Clinical Practice

Drawing together the results from these four studies, we can suggest the following lessons for clinical practice

that services should move to implement as quickly as possible:

1. There should be good and detailed information for parents, written in an easily accessible form.
2. Services should be well coordinated with clear procedures for exchange of information between different aspects of the services.
3. Parents should be treated as equal partners in the management of their child with hearing impairment.
4. It is important to involve the wider family (e.g., grandparents) in the audiologic management decisions.
5. Identification of children with permanent bilateral hearing impairment should be early and followed by fast and thorough audiologic assessment with the minimum of delays.
6. Hearing aid fitting should take place without delay and should be appropriate and guided by a prescription procedure.
7. Services should adopt appropriate service targets and should audit their performance against these targets on a regular basis.
8. Families of children with hearing impairments with complex needs require audiologic assessment that is sensitive to the implications of these complex needs.
9. Parents of children with hearing impairments should be involved in service planning and policy discussions.

Recent work on the quality of family life in families with children who are hearing impaired by two of us (Davis and Hind) has suggested an association between

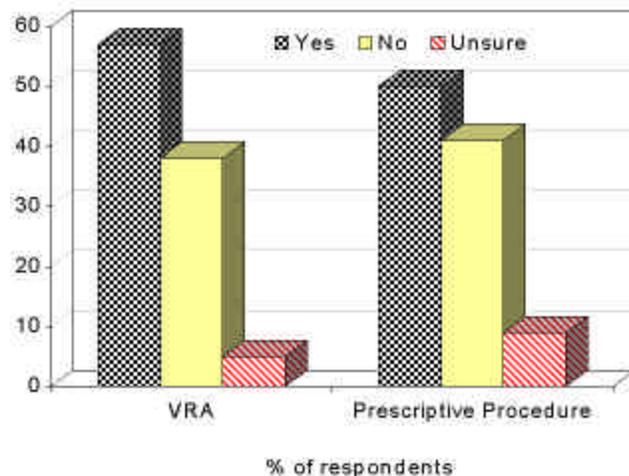


Figure 11. Survey of services. Percent of respondents offering VRA and a prescriptive hearing aid selection procedure.

one of the quality of family life metrics and parental satisfaction with services. Although we cannot be sure that this is a causal relationship, it is nevertheless becoming clear that there are important links between the two. Not only do parents have the right to expect services to offer a standard of care that reflects current evidence-based knowledge, but it may be that the consequent increased level of parental satisfaction itself works to further improve the outcomes for children with hearing impairments and their families.

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