

*Conference Endnote Address***Reflections on Quality***John Bamford*

A major driver in pediatric audiology for over half a century has been the assertion that earlier identification of permanent congenital hearing loss and the harnessing of technological advances will lead to higher expectations and better outcomes for the individual child, the family, and society as a whole. While most people would accept this assertion with little questioning, the statement does beg a number of quite profound underlying questions. For example, which outcomes do we mean? Are the outcomes that are of most importance to the hearing impaired child (and later, the hearing impaired adult) equally important to the parents, and to society? In what way might outcomes be improved with early identification, by how much and how can we measure that improvement? How early is early identification (for example, is identification by one month “better” than at two months of age? Two months better than four? And so on ...), and how does the answer to that question interact with degree of hearing loss? What are the conditions following identification that likely lead to better outcomes? That is, what are the fine details of interventions, family functioning, and child development that can be manipulated to the benefit of the child and family?

While these and other related questions remain answered only incompletely and in rather general terms, nevertheless we know enough to be able to say with confidence that early identification alone is not enough, and that intervention and family support are key. The links in the chain that lead to outcomes are newborn screening – identification and precise characterization of the hearing loss – hearing instrument selection, fitting, ver-

ification and validation – early family support, and the strength of the chain depends upon each of these links being performed well. But how can we ensure this “service quality,” in every part of the chain?

One way, that we are engaged in through this conference and its proceedings, is to disseminate good practice widely. Since the first Sound Foundations conference in 1998, over 2000 pediatric audiologists from over 40 countries have come together to interact and to hear expert clinicians and scientists present and discuss the best evidence-based practice; the conferences have always been firmly anchored in clinical practice and in the sharing of ideas and approaches that clinicians could take back to their own services to effect change to better practice. The conference closing address given so ably in 1998 by Fred Bess dwelt precisely on this issue: how to change services for the better? Fred argued that audiologists should see themselves as agents for change, working through training and education, continuing professional development, the use of evidence-based practice, and certification, and with the development of centers of excellence to act as beacons for change. As in politics, the aim should be to leave behind better services than those that went before.

We can point to a number of significant developments in pediatric audiology services since the first conference in 1998, encouraging us to feel confident that change for the better is indeed underway. Newborn hearing screening is much more widespread and governed within a high-quality evidence-base (but note Karl White’s caveats in his chapter in this volume); the audiology community has developed excellent diagnostic protocols (but note Pat Roush’s case examples in her chapter and the concerns that remain about the quality of ABR interpretations); great innovation and progress has been made in the technology of hearing instru-

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ments, FM systems, implants, and in the procedures for their selection and fitting (although the increasing complexity brings its own challenges - see the chapter by Leisha Eiten; and perhaps there is a growing inequity in the services offered to those with hearing aids as opposed to implants – perhaps now is the time to encourage the convergence of implant and pediatric audiology services, in parallel with the convergence of technologies and business structures); there is increasing use of face-valid outcome measures (but are they the most appropriate?); and there is a greater understanding of what is meant by parent-centered services and the facilitation of informed choices (but how far does this increased understanding actually translate into better practice?).

According to Professor Muir-Gray, until recently the Chair of the National Screening Committee in the UK, there are only four questions for a health service – or indeed for “change agents” within a health service:

- What works (issues of efficacy and effectiveness¹)?
- What should we be doing (issues of efficiency and legitimacy)?
- How do we do it (issues of equity, acceptability and optimality)?
- Are we doing it (issues of audit and quality improvement)?

These questions can be posed by all levels – by individual clinicians about their own practice, by service teams, by professional groups and even by national and international groups. In asking these questions in our own field, and in attempting answers, we will need to audit the processes and procedures being used by services; we will need to monitor and measure child outcomes; we will need to ask about parents’ and young persons’ views of and satisfaction with services; and we can then attempt to relate intervention processes, satisfaction, and outcomes in order to expand our knowledge of what works for whom (see the chapters by Marlene Bagatto, Mary-Pat Moeller, and Alys Young).

Alys Young has pointed out that ensuring service quality is more complex than it may appear at first sight. Quality of a service may be as much a product of parents’ appraisal of what counts as quality to them, as the nature of the intervention process itself. Furthermore, the outcomes that professionals think are important (‘the destination’) may not be the same for parents (or for the child/young person in due course). The Joint Committee on Infant Hearing 2007 Position Statement states that

the goal is ‘to maximize linguistic competence and literacy development’ and that a *sine qua non* for that is ‘intervention before 6 months of age from health care and educational professionals.’ As part of a recent review of services in a European country, we interviewed parents of newly-identified deaf children, and they gave us valuable insights into what matters for them. For example, with regard to processes, three comments (as examples) indicate how valuable it is to listen to parents and how much we are able to learn from service users that could help with service improvement:

“Being young parents of young children with a hearing loss is very frightening and one feels very vulnerable and it is a time when you really want the best for your child and the support from the service are vital to help one cope.”

“There we meet a whole team and it is much easier for us to make decisions regarding our son’s needs. We meet everyone from surgeon to audiologist to visiting teacher to speech therapist under one appointment and the service is very efficient with no time lost. This is easier on our son and on us as his parents.”

“At no stage in all of this had anyone explained the plan of care my son should get or what we should expect. No one explained the management of hearing aids, the planned follow up, the assessments, the time frame, nothing. My greatest source of information was ...[a charity], which incidentally I heard about by chance. I felt I was totally alone with the care of my son and had no idea what the future would hold.”

With regard to outcomes, the two comments below reinforce the view that we should be aware that parents may have very different hopes than the destinations we as audiologists may think are crucial:

“Right, our hope would be for her to be happy, happy in everything, you know just a happy person, obviously. And confident, a confident person and proud of who she is and successful in whatever she wants to do in life.”

“I was talking about this with my husband and probably our biggest hope for her, because we’re Christians, we’d love for her to become a Christian...so that would probably be our biggest hope for her. Next would be that she’s happy, and she has loads of friends would be the third one.”

Before coming to this conference, I contacted a number of colleagues (n=13) each of whom heads up what I know to be services that could confidently be characterized as at the high end of the quality distribution; I asked them for the three things that they would regard as the most important for a quality pediatric audiology service. There was considerable agreement; these were their answers (in no particular order):

¹ The concepts in parentheses here have been added and reflect those in the chapter by Martyn Hyde.

- First class staff
- Good teamwork
- Good leadership
- Quality standards backed up with peer review
- Good infrastructure/equipment
- Family centered, family friendly, with parent support networks

It is worth dwelling for a moment to consider what we mean by the first two in the list. We often talk about good staff and good teamwork, without stopping to reflect on exactly what we mean (and therefore, whether we have them in place). I would suggest the following properties are essential to any definition:

First class staff: they carry out a volume of testing which enables them to maintain and develop their skills; they sub-specialize within their team; they are identified as the Pediatric Audiologists (if working within a mixed service); they are willing to learn and participate in peer review; they are well-trained and work to agreed protocols and guidelines, yet retain flexibility within their service delivery to best meet the needs of the child and parents.

Good Teamwork: Clear team composition; coordinated approach to the child and family; clear lines of communication; awareness of limitations; the service is willing to ask for help and support; and clear referral pathways are in place.

The recent country-wide review of services that I have been involved with included parental representation on the review group; I asked one of these parents (the parent of a severely deaf child of primary school age) what would be their top three 'must haves' for quality services. The answer was:

- Good leadership
- An evaluative and learning culture taking account of all contributions (including parents)
- Good organizational structures with clearly defined roles and responsibilities

Taking all these together, I would suggest that the two most important factors without which the development of high quality pediatric audiology services is highly unlikely are a) leadership and b) education and training. By a good leader in this context (there are other contexts which might require different attributes), I mean:

- A person who is a team worker and a good communicator with a high level of emotional intelligence, who is supportive of staff training needs, outward looking, keen to embrace change and who is committed to evidence-based practice;

- A person who is self-aware, who has good self-management and personal integrity, is flexible with a drive for service- and self-improvement;
- A person who leads change through people, holds them to account, empowers others, has clear strategic vision and therefore strategic influence, and who works collaboratively.

And education and training should *inter alia* be able to:

- produce reflective and flexible audiologists committed to lifelong learning and improvement;
- produce audiologists who use and help to improve evidence-based best practice guidelines;
- produce (or select) audiologists whose style, approach and attitude towards service delivery and towards patients is above all facilitative.

If we now bring this all together into an overarching 'vision for pediatric audiology services' I would suggest the following:

The vision for pediatric audiology services is of high quality, safe, effective and efficient services, meeting and responsive to the changing needs of those from birth to adulthood, with potential or suspected difficulties with their hearing, auditory function, or balance, or with tinnitus. The services should be accessed without undue or unnecessary delay, and as far as possible be geographically convenient. Services should offer clear and accurate information upon which clients (or caregivers) can exercise their rights to make informed choices and should result in a high level of client (or caregiver) satisfaction. The services should be staffed by a well-trained, dedicated, caring and competent workforce with good governance and accountability, have excellent clinical leadership, and be committed to an evidence-based and evaluative service. They should work cooperatively, efficiently and collaboratively with closely allied disciplines as a multidisciplinary team, especially Otolaryngology, Pediatrics, Speech and Language Therapy, and with other agencies, such as Education, and have parents at the center of decision-making. They should use techniques, procedures, facilities and equipment that reflect best practice.

To me, this represents a summary statement of what good quality pediatric audiology services should look like, and can serve as a marker against which we can reflect upon individual services, wherever they may be. But as we have seen from the Opening Address in Chapter 1, there are countries less fortunate than those in which most of us are privileged to live and work that have only minimal services. Does the vision statement have any relevance for these countries? I think it does;

it would be wrong to lower our sights for those who start from a lower base. But what can we do to help the delivery of better services more equitably across the globe? This is, of course, a massive and challenging issue, but this should not stop us from addressing it. And international conferences such as this – arguably the leading conference on clinical pediatric audiology in the world – should not ignore the issue of service quality in *all* countries. There is a role for international bodies (WHO and UNESCO, for example), and for NGOs, but there can also be a role for professional groups and for individuals; indeed, there are good examples of projects in some developing countries (e.g., the Dominican Republic, Rwanda and Cambodia), which are culturally appropriate and self-sustaining in the medium to long-term, and which may be models of how service improvement can be applied across all countries and cultures. To quote Neil McGregor, Director of the British Museum:

“...the notion of the human family is not an empty metaphor, however dysfunctional that family usually is; we have the same needs and preoccupations, the same fears and hopes. Humanity is one.”²

The same could be said – and should be – of pediatric audiology.

² A History of the World in 100 Objects, The British Museum and the BBC, 2010; book version published by Allen Lane, 2010.