

# The Newborn Screening Programme - Challenging Professionals

## *The parents' perspective*

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The Newborn Screening Programme to identify deafness in babies is undoubtedly well intentioned, providing greater opportunities for deaf children to reach their maximum potential. However, the programme at present is focused on the diagnosis of deafness and in order to maximise the benefits of early diagnosis, professionals working in the field need to understand the impact on families both in emotional and practical terms. Our own daughter was diagnosed as being deaf at three weeks old; this is at a very precious stage when a newborn baby and their family are adjusting and bonding. Hearing aids were fitted when our daughter was ten weeks old. The discovery that your child is deaf is a bombshell and needs to be handled very carefully by professionals, and most of all, parents need to feel they, and their wishes, are fully supported.

Sadly, our own experience of professionals was not one of support for us as parents and the provision for our daughter was at times nothing short of incompetent. After approximately fourteen months of despair at the lack of structured support we found in public services, we turned to professionals in the private sector. We received another devastating blow. The Audiology professionals had wrongly diagnosed the extent of our daughter's hearing loss and her hearing aids had been incorrectly set up. Professionals in the private sector saved us from the incompetence and general mediocrity we experienced in the public services. Those professionals in the private sector have supported us, both in terms of our aspirations for our daughter and emotionally, and more importantly, they have given our daughter exemplary care and attention. However, the key factor is not money, but attitude. It is attitude that truly separates the mediocre professional from the true professional, and this is not related to money or whether in the private or public sector, but dedication to excellence.

I could write extensively about our experience of the Newborn Screening Programme and the post screening services, but give below a summary of the more significant aspects:

To begin, the way in which we were told of our daughter's deafness was to us quite shocking. We were told by an audiologist who clearly had no training in how to handle the situation of breaking this type of news to parents. She had a smile on her face and offered no support. At this point we were told that our daughter had a moderate hearing loss; fourteen months or so later we would learn that this was incorrect and in fact her loss was severe to profound. Worse still, at a review meeting with all of the professionals involved in our daughter's care, the consultant paediatrician informed us that they do not like to use terms such as 'profound' or 'severe' as this may discourage parents from using the hearing aids!

Even worse was to come; the teacher of the deaf appointed to work with us did not appear to work to any structured plan

of action, made no attempt to discover what we wanted for our daughter, did not work with our daughter and was opposed to the presence of our elder hearing daughter who at the time was two years old. We therefore refused to have her services. The response from the professionals was that she was highly qualified and there was no recognition that she had been totally ineffective. It would be some months before a suitable replacement was found.

One of the most irritating and distressing issues we had initially, in common with many others, was that our daughter would not wear her hearing aids. There was almost constant feedback from the hearing aids due, in the main, to ill-fitting ear moulds. It took an inordinate amount of time to obtain replacement moulds when they were required. No assistance was offered to address the wearing of the hearing aids and we were simply told that this was a phase our daughter would grow out of in time. It would come to light fourteen months later that in fact the hearing aids were incorrectly set up and we were also told our daughter would not have received any useful information from the hearing aids.

Over the first nine months of our daughter's life, my wife made something in the order of 50 visits (on top of routine visits) to the Audiology clinic and other departments of our local hospital trying to sort out our various concerns for our daughter. At no time were we as parents asked what we were aiming to achieve.

In a state of desperation after months of emotional turmoil and frustration with the National Health Service, we turned to the private sector. First we had hearing aids sorted out and new ear moulds made. These were like pieces of engineering and the turn around time was almost immediate. We went for our first session of auditory verbal therapy just before Christmas and this was a revelation. They listened, they planned, they supported, they understood and empathised, most of all they wanted to help us achieve the best for our daughter. I cannot describe the massive benefits we as parents, and our daughter have derived from these professionals. Since Christmas, with properly set-up hearing aids, excellent ear moulds and the therapy sessions once a fortnight our daughter's progress has been meteoric. We have never looked back and we will always be grateful to have discovered a bunch of true professionals.

I have described our own experiences; other parents will have very different stories to tell and different aspirations and goals for their children. What matters is the support that we as parents receive – only then can we help our children. We attended a weekend for parents at The Ear Foundation led by the American Professor David Luterman. Another true professional, David was a great inspiration and not afraid to criticise the practices of some professionals and their handling of parents

devastated by the news of the child's hearing loss. Most of all he recognised our grief and the importance of our welfare as parents in order to be able to nurture our deaf children to ensure they are happy and fulfilled. Professionals can be immensely valuable to parents of deaf children and equally professionals can be immensely damaging to families.

If newborn screening programmes are to succeed, professionals must listen to the experiences and wishes of parents. At present there does not appear to be in place sufficient services to adequately support families after screening and to address the key issues in a competent way. Many of the professionals we have encountered clearly have not been trained to deal with the specific issues arising from newborn screening. Often they are too caught up with inflicting their own philosophies on parents, whether it be the use of sign language or the auditory verbal approach. Their energies would be better spent concentrating on achieving excellence whatever their approach, and not being satisfied with mediocrity. Time will tell whether the professionals involved with the Newborn Screening Programme have what it takes to make this programme a success, or whether it will be

undermined by those who are not true professionals, whatever their paper qualifications may say.

The introduction of the Newborn Screen Programme is a good thing and offers exciting opportunities for parents and their deaf children. However, I believe we need to consider further two areas: first, when the screening should be carried out and second, the services that should be available to address specific issues raised by newborn screening. In my view the first few weeks of life is too soon to carry out the screening and this can seriously affect the bonding process, particularly between mother and child. Over recent years there has been a great deal of progress with technology and knowledge in relation to deafness; sadly in this context many of the professionals we have encountered appear not to have kept up. The challenge for professionals is to get a grip of the full potential provided by newborn screening, move into the 21st century and work alongside parents and families to achieve excellence for all deaf children.

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