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The deaf child—challenges in management: a parent's perspective

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Abstract

Diana Glover lives in Buckinghamshire, UK, with her husband, Ray, and their three sons, William (21), Robin (19) and Benjamin (10). Robin and Benjamin are profoundly deaf. Ray also has a hearing loss, which is unconnected with the children's deafness. Diana is a trustee of the National Deaf Children's Society.

Diana will compare Robin's experiences with those of Benjamin. She will show how difficult it was to obtain a diagnosis of Robin's deafness, in spite of her early anxieties about his hearing, and that this had a marked impact on Robin's speech and language acquisition. She will speak about the struggle she and Ray had to convince their Local Education Authority that Robin should move from mainstream schooling to a boarding school for the deaf at the age of 9. She will also express her current anxieties as Robin, who has only deaf friends, moves from Mary Hare Grammar School for the Deaf to mainstream Higher Education.

Robin's experiences will be contrasted with Benjamin's diagnosis at 7 weeks and progress in mainstream education. Diana will also highlight some of the issues that she and Ray had to consider when they agreed that Benjamin should have a cochlear implant at the age of 2.

It will be demonstrated that having one hearing and two deaf sons has a profound effect on relationships within the family and with professionals. Diana will show how she and Ray have learned that one can easily overlook the needs of a hearing sibling, and that it is equally important for deaf children to come to terms with their disability. She will summarise the difficult choices they have had to make over implantation, communication methods and schooling, and demonstrate that even within one family, the needs of deaf children are never the same.

Keywords: Diagnosis; Cochlear implants; Deaf identity; Education; Communication; Relationships

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1. Introduction

I offer some reflections on my experiences as a mother of three sons, two of whom are profoundly deaf. My eldest son, William (21), has normal hearing. Robin (19) and Benjamin (10) both have a hearing loss in excess of 105 dB, the cause of which is a recessive mutation in the Connexin 26 gene. By coincidence, my husband Ray has a high frequency hearing loss. The cause of this has not been established.

Through the pain of Robin's late diagnosis and the contrasting experience of Benjamin's early diagnosis, our family has had to face some difficult dilemmas about communication, cochlear implants, schooling and "deaf identity". In most of the choices we have made, we have learnt through our experiences and often through our mistakes.

2. A late diagnosis

Our introduction to all this began in 1983 when Robin was 4 months old. I accidentally dropped a saucepan on our quarry stone kitchen floor. Robin made no reaction to the loud crash. This surprised me and I began to make other loud noises to test if he could hear me. He rarely startled to sound and only seemed to react when he could see me.

This was the start of a lengthy process of visits to doctors and hospitals. My GP prescribed drops for wax. At Robin's developmental check, when he was 6 months old, the doctor was aware of my concerns. She shook the Manchester rattle and Robin turned his head. "He heard that," she said. I felt intimidated but not reassured. We saw an ENT consultant when Robin was 7 months old. Robin responded to none of the tests. From that time onwards, we paid regular visits to an educational audiologist who encouraged us to keep a diary of times when we felt that Robin was aware of sound. Every so often we would see a registrar who would look in Robin's ears and tell us to come back 6 weeks later. Robin was given grommets at the age of 1 year, and again at 16 months. There was no improvement in his hearing.

In our desperation, we asked to be referred to a different hospital. This involved another lengthy wait. Eventually at the age of 18 months, Robin was diagnosed as being profoundly deaf, a whole year after I had first been worried about his hearing.

3. An early diagnosis

Benjamin was diagnosed by brain stem audiometry at 7 weeks. Throughout the test, Robin kept asking: "Is he deaf? Is he deaf?" When Ray finally told Robin that his baby brother was deaf, he threw his arms in the air and shouted "hooray". His reaction greatly helped us in our coming to terms with Benjamin's diagnosis. This was also our first experience of "deaf identity".

4. Robin's progress

After Robin's late diagnosis, we were desperate to help him to communicate and to make up for lost time. It was very stressful to receive conflicting advice from the professionals we met. One group told us that if we used sign language with Robin, he would never learn to speak. Another group told us that unless we used sign language as soon as possible, Robin would never develop language.

As hearing parents, we longed for Robin to be able to speak normally and were encouraged by the claims that his speech and language would snowball if we used the natural aural method of communication. However, Robin developed speech and language very slowly. He entered our local mainstream school with about 30 single words (either spoken or gestured) and half a dozen two-word bonds. A teacher of the deaf visited him for only 1 h each week, and a welfare assistant for an hour or two per day. Moving him into a department for hearing-impaired children within another mainstream school at the age of 6 ensured that he had help throughout the day. However, by the age of 9, his score on the Test for the Reception of Grammar (TROG) was equivalent to that of a 4-year-old. We had to fight hard to persuade Robin's school and our education authority that he should go to a school for the deaf. After 10 months of campaigning and assessment, we secured funding to send Robin to Mill Hall School for the Deaf—an oral residential primary school. Robin was keen to go although it was hard for all of us to get used to him being a weekly boarder, and for him to have to travel a hundred miles to and from school each weekend.

When he was 12 years old, Robin passed the entrance exam to the Mary Hare Grammar School for the Deaf. Not only did residential special education allow him to reach his academic potential, but it also gave him deaf friends—his only friends. As I look back to those early days, I find it hard to believe that Robin has recently managed to pass three General Certificate of Education Advanced Levels, and is about to go to Portsmouth University to study architecture.

5. Benjamin's progress

After his early diagnosis, Benjamin had a body aid at 14 weeks and began to respond very well with it, producing good vocalisations with varied intonation. However, at 9 months, he stopped responding and despite trying a series of increasingly powerful hearing aids, he became quieter and unaware of most sounds. When he was 15 months old, I tentatively enquired about his suitability for a cochlear implant. To our surprise, we were told that Benjamin might be a very good candidate.

Our anxieties prior to implantation focused on the operation itself. Would Benjamin's residual hearing be destroyed? Would the surgeon be able to insert a complete electrode array? We were concerned about the risks of the anaesthetic and surgery, as well as being anxious to prepare Benjamin for 3 days in hospital. Photos and homemade picture books were an invaluable aid to communicate with him at that time.

We also had to prepare Robin for Benjamin's operation. Knowing how thrilled Robin had been to have a deaf brother, we were anxious to reassure him that Benjamin would always be deaf.

Benjamin was implanted, with a full insertion of electrodes, at the age of 2 years and 4 months. When Robin saw Benjamin's scar after his operation, his comment was, "It's not my fault. You wanted a cochlear implant."

Benjamin's speech and language snowballed after his implant. It was a joy to see him responding to so many new sounds and wanting to know what they were. Benjamin's progress has far exceeded our expectations. His language escalated from individual words at 3 months after implantation to strings of words at 9 months after switch-on. He entered mainstream school with little language delay and was able to read. When he was 6 years and 5 months old, his reading age was assessed as 8 years. At 6 years and 9 months, in the Test for the Reception of Grammar (TROG), he scored at a 9-year level. Now, at the age of 10, Benjamin speaks fluently. People who have not noticed his implant do not realise he is deaf. He rarely relies on lipreading and, in most circumstances, overhears and can also understand much of what is being said on the radio, television and cassettes. He sings pretty well in tune, and it is possible to have a normal conversation with him on the telephone.

6. Some reflections

6.1. On diagnosis

After Robin's diagnosis, we felt strangely relieved and vindicated. Our feelings quickly turned to anger at the professionals whom we had seen and who had not acted quickly enough. Our anger drove us on a manic search to find out all we could about deafness. We read books during the early hours of the morning and visited schools for the deaf all over the country. Then we became depressed as we tried to cope with the difficulties of obtaining help for Robin, persuade him to wear his hearing aids and also pay enough attention to William, approaching 4 years old, who was beginning to resent his little brother. Robin spent the first 19 months of his life without any experience of sound. This is probably a major factor in his language difficulties and poorer speech quality.

It is painful for all of us, and particularly unfair on the children, to make comparisons between Robin and Benjamin. However, we are convinced that Benjamin's early diagnosis and use of hearing aids played a crucial part in his swift language development and natural sounding voice. We also recognise that with Benjamin, we were already experienced parents of a deaf child. We felt neither the shock nor the anger that had followed Robin's diagnosis, and thus were able to begin communicating with him with confidence. Cochlear implants were not available to prelingually deaf children when Robin was born. Benjamin's implant, which he received at the optimum age of 2, has given him access to all the speech sounds. Even with the most powerful hearing aids, that access is not available to Robin.

6.2. On deaf identity

People often ask us why Robin does not have a cochlear implant. Unlike Benjamin, who was too young to make that decision for himself, Robin has had to be fully involved in discussions about implantation. Mainly for reasons of self-awareness and identity as a deaf person, Robin has chosen not to have an implant.

Robin's joy at having a deaf brother has helped us understand how important it is for deaf children to have deaf friends. Both boys share a bond that has remained even though it has been painful for Robin to witness Benjamin's progress with his implant. Robin has learnt to sign from his deaf friends and we have learnt sign language too. However, Robin chooses to speak at home with all of us, including Benjamin. For about a year, Benjamin has been putting on a "deaf voice" when he speaks to Robin. I suspect that this is a combination of awareness that Robin does not speak like himself, and also a desire to identify with Robin.

From the age of 8, both boys have expressed their anger at us that they are deaf. In spite of sounding and functioning like a hearing child, Benjamin found it lonely being the only deaf child in his school. When we had to move to a new area in 2001, we responded to Benjamin's feelings of isolation by sending him to a school with a hearing impaired department. Although he now attends a school where there are other deaf children, Benjamin has nevertheless chosen not to be friends with any of them. By contrast, Robin has only deaf friends. We wonder, as he prepares to go to University in September 2002, how he will cope in a predominantly hearing environment.

6.3. On family dynamics

For several years after Robin and Benjamin's diagnoses, people reminded us not to forget William, our hearing child. This has been a constant source of guilt to us, and inevitably, William has had far less attention than his deaf brothers. We had family therapy, shortly after Robin's diagnosis, when the boys were constantly fighting. At the age of 6, William had to write about himself for a school assignment. He wrote all about Robin. Somehow we have all survived those early difficulties. The boys now share a love of computers. Communication between us has been enhanced by our ability to send emails or text messages on mobile phones. This has given Robin both independence and street credibility, and also allowed Ray and me to feel like teenagers once again.

6.4. On relationships with professionals

Our relationships with doctors, educational audiologists, speech and language therapists and teachers of the deaf have not always been easy. I have found it painful to admit that my tendency to put professionals on a pedestal may have contributed to Robin's late diagnosis. If I had been more assertive and insisted that Robin was not hearing us, he may have had an earlier diagnosis. It has been difficult for us to cope with feelings of both dependence and anger towards the same professional. Several teachers of the deaf have adopted the role of "family rescuer" and I have willingly complied with that sort of relationship—only to feel very let-down when we have had to challenge that professional's decision. Asking for our child to leave a school felt like a rift in a friendship with the teacher of the deaf. Such feelings have taught me how important it is that there are boundaries between parents and professionals, but also that parents are respected as professionals in their own right.

7. Final thoughts on letting go

Perhaps one of the hardest lessons that we have had to learn as parents of deaf children is to be able to let go of our children. I spent so much of Robin and Benjamin's early years trying to interact with them to help their language development, fighting to get the best schooling, the correct social security benefits or the latest hearing aids. Letting go of these things feels like an abdication of responsibility. However, I take courage from William, our hearing son, who has managed to grow to independent adulthood in spite of, or maybe because of, receiving the least attention of all our children. I am equally encouraged by Robin who has begun to use his minicom and the "Typetalk" service to negotiate with the Local Education Authority about how he should spend his Disabled Students Allowance.

So, as we attempt to let go of our three sons, my expectations are that we shall, as a family, come to experience what the National Deaf Children's Society highlights in its Vision and Values Statement.

"If support is given and positive attitudes are fostered, the challenge of deafness can be a rewarding experience for deaf children and their families."