

Deaf Children and Their Families

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Chapter 1

The Handicap of Deafness

Without knowing a deaf child it is very difficult to comprehend what it is like to have one in the family. The deaf child looks normal, and yet his handicap is very real. For those people who have never encountered a young deaf child it is hard to understand how much difference it can make. One might think of what a person misses who cannot hear music, or church bells, or the birds sing. One might think of some of the practical problems of having a small deaf child, that he does not hear cars coming, a horn hooting; that one cannot call out to warn of danger and so one has to keep him close. But it is not these things that constitute the real problem. Life is impoverished without the joy that various sounds can bring, and there are situations which can be dangerous for someone who cannot hear; but there are greater problems than these. It is learning to understand other people, and to talk to them, that is the real area of difficulty.

A normal hearing child learns to talk because he is constantly being talked to. He comes to realise that the sounds made by the human voice are of special significance. How difficult it is, though, for the child who cannot hear the human voice, or who can only hear one or two sounds. Without special teaching he will not learn to understand other people, or to talk himself. Even with special teaching, one can never provide the vast experience the hearing child has of spoken communication. The deaf child with limited, or even no understanding of what is said to him and not being able to talk himself can be cut off in many ways from what goes on around him. In essence then, this is the problem: communication.

Helen Keller, probably the most famous deaf-blind person of our age, said of the handicap of deafness:

The problems of deafness are deeper and more complex, if not more important than those of blindness. Deafness is a much worse misfortune. For it means the loss of the most vital stimulus – the sound of the voice that brings language, sets thoughts astir, and keeps us in the intellectual company of man.¹

More recently, during a television programme² a man deaf from birth said :

Blindness cuts people off from things, deafness cuts people off from other people.

When the mothers were interviewed for this research, they were asked what they felt their greatest problem was in coping with their own deaf child. Seventy-six per cent of them gave answers indicating problems that arose from difficulties in communicating. When asked what they felt was the greatest problem from the child's point of view, 89 per cent replied that it was communication. Most of the remaining answers were problems specific to a particular child, and no one other problem was mentioned more than three times. Communication with, and for, the deaf child is by far and away the greatest problem.³

What does this mean in real terms? What do mothers need to be able to communicate to their children under six? Not being able to explain things can make it very difficult to get across to the child what he is, and what he is not, permitted to do.

Boy, 5 years

I think trying to tell him what is right and what he should do and what he shouldn't do – it's very difficult. He can't understand why it's wrong – you see. Like he'll see a lady in the garden, and he'll see that lady pick some flowers and of course he thinks he can do the same. It's her garden, you know, and this is our garden, you can't tell him right from wrong at the moment. The thing is getting through to him. It's very frustrating for yourself you know. To me it wears me out sometimes, it really wears me out trying to get through to him at times, it really does.

Even when it is possible to get the message across, it often has to be just a 'No' with no possibility of explaining to the child why. This makes some mothers feel they are somehow cheating their children.

Boy, 4 years

I mean you can't say, like when Janet (his sister) gets older, we'll say 'Now you won't touch the fire because it will burn.

Nasty. Hurts.' But all you say to Stephen is say 'No' and that's it. You just can't explain why. It's horrible.

Girl, 2 years

You can't temper it. It's either a definite yes or a definite no, which I find very difficult. That is about the most difficult thing for me.

Without any explanation, life may seem to be one arbitrary rule after another. One very common way of getting across to a child that what he is doing is wrong is the formula 'If you do that again I'll . . .' The child knows what he is doing is wrong and knows what the consequences will be if he does it again. For many parents it seems totally unfair to punish a child for something he does not know is wrong, and yet it may be impossible to warn a deaf child in this way.

Girl, 3 years

I think that, because she can't hear you can't tell her the first time. Like with a normal child you can say 'You do this again and I'll smack you next time you do it', but with Wendy, you've either got to let her get away with it, else turn away. She didn't use to look at me so I couldn't tell by expression on my face so it had to be a tap.

Another important area is persuading the child to wait for something. A busy mother is not always able to stop what she is doing to mend a broken car, or find a missing piece of a puzzle. Small children are impatient at the best of times, if 'Wait a minute' seems like 'No' to them, it may be just too much.

Girl, 4 years

The hardest thing to teach her is when she's got to wait a minute—to wait. She's got to rush here, and rush there. She can't understand 'In a minute'. If she wants something, she wants it there and then, not two or three minutes later.

For the next little boy, his desperation was because if his mother did not stop immediately he did not feel he was understood.

Boy, 4 years

Well I have to stop, because he gets terribly agitated, and he feels that I can't hear him, I think. I'll say 'In a minute, Peter, in a minute', or something like that and he'll fall on the floor because he seems to think he hasn't got across to me I think. He gets terribly upset so I have to stop.

The boot may be on the other foot, it may be that a mother needs to get a child to hurry. This is difficult with many normal children, but may be exacerbated if reasons cannot be given.

Boy, 4 years

He tends to get involved, and then the problem is communicating to him the urgency of the matter in hand – we may have arranged to go shopping on a Saturday morning. He'll accept it, but it's difficult. Having explained it to him and made sure he's understood, because if you whip him away and he hasn't understood you've still got a battle to fight. You have to make your peace there and then.

While many mothers of deaf children can explain to hurry, or to wait just a minute in the immediate situation, when the waiting extends farther into the future, it may be more difficult. One important thing that mothers need to get across is 'soon' or 'later', the idea that something will not happen now, but will in the future. To explain to a child that he cannot go out now but will be able to after dinner is another example.

Boy, nearly 3 years

It's things in the future that are difficult to get through to him, like 'After dinner we'll go out' sort of thing, he only understands things that we're doing at the moment, and as I say you can't promise him anything.

Once out playing, or at a friend's house, a small child often does not want to come home, and often it is the reassurance that he can go back another time which induces him to come away. But it may not be possible to get this across to the deaf child.

Boy, 4 years

When we're going somewhere, and he's really enjoying himself, and say we've got to go and it's late and the baby needs to be fed. Then you can't say to him 'Come on Stephen, we've got to go home now. We can come back tomorrow.' You've just got to say 'Come on Stephen, going now.' And he doesn't want to go. It's because you can't say why he can't do things and why he has to do things that really hurts me. You can't say, like when we go to Robert's to play, 'We're going now, we'll come back tomorrow. Just one more day and we'll come back', or when we take him to the park 'We'll come another day.' To him we're going and we're never going there again as far as he's concerned. You know, you can't explain that you will go back again.

Looking forward to Christmas, birthdays, holidays is an exciting part of a young child's life, but to explain to a deaf child that something exciting is going to happen can be difficult.

Girl, 5 years

If it's sort of a Santa Claus is coming thing it's ever such a job. See we've had some Christmas cards come to send off and she thinks it's a birthday, you know. Anything in the distance is difficult.

Even when a mother can get across that something will happen in the future, trying to recall the past can be difficult.

Girl, 4 years

You can say something will happen in the future, but you can't say 'Do you remember what happened the other day?' – she can't think backwards. It leads to confusion. The other day my mother was here, and last summer she took them to the seaside with a friend of hers who also took two grandchildren. One of these children was called Joan, and my mother came to lunch and we were eating and Brenda wouldn't eat her dinner and Mum said 'Try to say to her – do you remember at Skegness we used to have a race and Brenda and Joan would race to finish.' We tried to get this over to Brenda but Brenda thought we meant we were going to Skegness again, and after lunch we found she'd got her suitcase packed and her dolls all ready to go – which was awful. Very upset, and I had to raid my Christmas presents and so on. She can't . . . I've never managed to get over to her 'do you remember . . .' even yesterday. She thinks whatever happened that you're saying you're going to do it now.

Telling Daddy about the day, when he comes in from work, is a way of including Daddy in the day's events, for many hearing children.

Girl 4 years

She's just beginning to understand that we're going to do things tomorrow. But we can't talk about things she has done. I often try to say to her, 'Remember to tell Daddy', with things we've done. When Daddy comes I say 'What do you remember?' She doesn't know – I think she knows I mean she should talk about it, I don't think she can – she does remember the things but she doesn't understand you want her to tell someone what she did. You can't really talk a lot about things she did because she thinks that you're saying that she's going to do them again.

At first sight, not being able to talk about the past and the future may not seem an overwhelming problem, but it is these sort of conversations that enable a child to see life as continuous and structured. Christmas Day, instead of being a climax of wrapping presents and putting up decorations, can seem an isolated day. More important, if the deaf child is out playing, or at school, and cannot tell his mother about what he has been doing, his day, for him, may become divided into isolated segments. Communication is not just the imparting of information but has a wider significance in that it is a way of maintaining contact and continuity.

Of course, not all the problems mentioned above apply to all young deaf children. Many deaf children do learn to talk, but it can be a very slow process. In the 122 deaf children in this sample only a quarter could put two or more words together to make a simple sentence. A further quarter, while not putting words together at all, had a vocabulary of more than five words. This means that half the group had a vocabulary of five words or less, and half of these, a quarter of the total group, could not use the spoken language at all to communicate. Of course, the older the child the more likely he was to be able to use the spoken language. (See Table 1.1.)

| Age | Language Used | | | |
|----------------|---------------|-----------------------------------|-----------------------|----------|
| | sentences | over six words (not sentences) | five or less words | none |
| 2.0-3.5 years | 11% (3) | 19% (5) | 33% (9) | 37% (10) |
| 3.6-4.11 years | 21% (9) | 38% (16) | 21% (9) | 19% (8) |
| 5.0+ years | 56% (19) | 29% (10) | 12% (4) | 3% (1) |
| Total sample | 25% (31) | 25% (31) | 25% (31) | 24% (29) |

Table 1.1 Language used by the deaf child, by age
(this excludes children under 2 years and immigrant children)

When we come to consider how much of the spoken language a child can understand we face a problem. It is very difficult to determine how much a child can understand because when one speaks to a child the spoken word is not the only clue as to what is going on. Facial expression, gesture, and of course the situation itself all give clues as to the meaning of what is being said. Instead, then, of asking what the child could understand, we asked *who* the child could understand. A deaf child who can understand

almost anyone who talks to him, providing, of course, they make sure that they are in a good light, and are speaking clearly, and the child is attending to them, has some grasp of the spoken language. Only 30 per cent (36) of the children could understand anyone who spoke to them. A further 27 per cent (33) could understand people they knew. But 19 per cent (23) could not understand anyone at all, and 25 per cent (30) could only understand their mothers. This means that 44 per cent of the children were cut off from conversation with the people they came into daily contact with (excluding their mothers). (See Table 1.2 for a breakdown of these figures by age.)

| Age | People Understood | | | |
|----------------|-------------------|-----------------------|-------------|----------|
| | almost anyone | relations and friends | mother only | no one |
| 2.0-3.5 years | 22% (6) | 15% (4) | 37% (10) | 26% (7) |
| 3.6-4.11 years | 29% (12) | 38% (16) | 19% (8) | 14% (6) |
| 5.0 years | 50% (17) | 32% (11) | 17% (6) | 0 (0) |
| Total sample | 30% (36) | 27% (33) | 25% (30) | 19% (23) |

Table 1.2 People whose language is understood by the deaf child, by age (this excludes children under 2 years and immigrant children)

The general reader might well be asking why there is all this emphasis on spoken language—surely the deaf communicate by signs. The usual image of a deaf person is someone who gesticulates, who speaks with his hands. But current educational practice with very young deaf children discourages the use of any form of sign language.⁴ The ultimate aim is to get children integrated into normal society, to be able to communicate with hearing people. It is felt by many that this is best achieved by the intensive use of language. Certainly there had been no attempt with any of the children under consideration here to teach signs. Of course there was a great deal of communication using gesture, but this mostly took the form of an exaggerated version of the normal gesture of communication and could only be used to get across simple ideas. It consisted mainly of pointing and miming, and had nothing like the range of possibilities for communication that the formal sign language used by many deaf adults has.

The mothers were asked how they usually communicated with

their deaf children. Some mothers relied almost exclusively on gesture.

Girl, nearly 2 years

If she's not looking at me I touch her face and then point at what I want, and get through to her that way.

Others combined gesture and speech in various ways.

Boy, 4 years

We'll we find that we've got hand gestures and signals and speech. We use the speech as well but we use the hand signals to get it over to him.

Girl, 2 years

I talk to her, and then if she doesn't understand I put in a few signs. But quite obviously any young child uses a lot of signs at this age, as well as talking, and so I haven't stopped her. I think it's all right for her to – and speech will come.

Boy, 4 years

We always try and get him facing us. We try and tell him without the actions if we can.

Other mothers were able to rely almost totally on speech.

Boy, 3 years

We just talk to him normally. It just comes natural. We always just touch him and then talk to him.

Overall, when the mothers were asked how they usually communicated with their deaf child, 28 per cent (34) said they usually communicated by talking to him, albeit more slowly and clearly than to a hearing child. On the other hand 30 per cent (36) of the mothers did not use speech but normally used gestures and pointing. The remainder used a combination of gesture and speech. As one might expect, the older the child, the more likely the mother was to use speech as the medium for communication.

The mothers were also asked how their deaf child communicated with them. Just over half the children, 57 per cent (68), relied exclusively on gesture, showing or pointing.

Boy, 4 years

He uses his hands. He does a lot of miming. He doesn't seem to bother with speaking now. He sort of mimes it to you.

Boy, 4 years

Mostly by showing me. He'll come and show me, then do a few of his signals.

Girl, nearly 2 years

She brrs to get attention, and then she points. If she wants me to look she'll point to her hand and then point to something, so I've got to look.

Boy, 3 years

He just takes me by the hands and leads me to wherever it is he wants to go, and then points. That's his only way.

Some children had very ingenious ways of communicating without using speech.

Boy, 5 years

He usually explains with his hands, and tries to say the word of what it is. If it's something in particular he's looking for, if he remembers that it's in a book he'll fetch the book and he'll show me what he's looking for, and then I usually know straight away. For anything he eats he'll go (points to mouth) like that, and if he wants to go to the toilet he holds himself. If he wants to go to bed he does this (points upstairs).

Girl, 4 years

Well, if she wants a drink she usually goes like that, or points if she wants a biscuit, if she wants anything in a cupboard she usually points. If she wants to go to the toilet she points to herself or holds herself, but she gets through all right.

Twenty-four of the children used speech and gesture, mainly resorting to gesture when they could not get the message across by speaking.

Boy, 3 years

If he can't make me understand by saying, he will then show me what he wants. In fact if I can't understand him I will say 'Well you show Mummy.'

Girl, 3 years

Mainly language – the odd thing she'll try and tell you first, and if I just can't understand she'll show me. When she's showing you, you know what it is. There's no problem in communicating.

Boy, 3 years

Yes it's one of those things. We can understand what he's on about but you wouldn't understand him but we can. Sometimes he might show you, other times he'll try to tell you with actions.

Girl, 4 years

She tries to say the words she knows but she also mimes. She's

taught a lot of mime and gesture at school and she uses these and school never tells us what they mean so Nicky teaches us. She's quite good – she tells us what she means.

Only 24 per cent (28) of the whole group normally communicated by speech. For those children who did use speech as a means of communication, it was felt by many of them to be a very real achievement if they did manage to make themselves understood.

Boy, 3 years

(Q136: Is he pleased when you understand, or does he take it for granted?)

Yes. Well if it's something new he's saying he seems to know it's new and gets ever so excited.

(Q: He doesn't take it for granted you'll understand?)

If it's things he's said over and over again – yes, but if it's new – no.

Boy, 4 years

(Q136: Is he pleased when you understand, or does he take it for granted?)

He does show pleasure, because we obviously reiterate what he's said for him to say yes to – so he knows that we've understood and this sort of thing. He will say 'Oh – that's right.' He'll be quite open and quite joyful about it – it may take three or four tellings.

For the majority of children, trying to communicate was at times frustrating. Such gesture as they used was inadequate for communicating more than very simple ideas. These children wanted to talk but often they could not. For many of them their attempts to speak just did not work.

Girl, 5 years

She tends to move her mouth and there's no voice coming out and yet she thinks she's talking.

Girl, 2 years

She wants to talk to you, you can see she does, but she just doesn't know how.

Girl, 4 years

She wants to use the word, but it can't come.

Girl, 3 years

I think, if only she could talk. She gets very excited and she can't tell you. She can't tell you that she's pleased with it. She

shouts and she screams. When I say she screams it's not temper. It's because she's overjoyed with something, but she can't explain herself.

And for some, their attempts to speak actually inhibited communication.

Boy, 3 years

When he's speaking to me, and I say 'What's that you say baby?' he'll pull his mouth wide open, you know, and his eyes will go and it's worse then, you know. He can't say anything at all. He'll just take my hand and show me what he wants. He tries that hard to make himself understood, the words come out worse.

If we look at the mode of communication by age (Table 1.3) it seems apparent that there is a shift to communication by the spoken word between the 3·6-4·11-year-old group and the children over 5 years.

It thus seems that the transition to communication by the spoken word only gathers impetus after the age of 3½ for the young deaf child, whereas hearing children increasingly use the spoken word from the age of 2 years. Although the proportion of children using the spoken word doubles between the 3½-5 age group and the over-5s, still at 5 years less than half the deaf children are using the spoken word as their mode of communication. Even at 5 years, a third of the group are still relying totally on gesture to communicate.

| Age | Mode of Communication | | |
|----------------|-----------------------|----------|---------|
| | spoken word | gesture | both |
| 2·0-3·5 years | 11% (3) | 67% (18) | 22% (6) |
| 3·6-4·11 years | 21% (9) | 62% (26) | 17% (7) |
| 5+ years | 44% (15) | 32% (11) | 23% (8) |

Table 1.3 Mode of communication of young deaf children broken down by age (excludes children under 2 years and immigrant children)

Hence it is clear that the problem of communication is a very real one. The children who were communicating by signs and those communicating by gesturing were incapable of getting across anything like the range of a normal child. Clearly they have the feelings, preferences of a normal child, but communication by gesture tends to be 'black and white' - lacking subtlety and

qualification and being blunt and to the point. This issue will be seen to lie at the root of most of the other problems that are described and discussed in later chapters.

Until now, in this book, deafness has been discussed as if it was a simple handicap – simple in the sense that a deaf child is just a child who cannot hear. Of course this is not the case. There are various degrees of hearing ranging from normal hearing (normal for humans) to total deafness, though in fact total deafness is very rare. In the majority of cases described in this book, the child has some hearing, although it might only be a small amount.

Some attempt was made at the interview to derive an assessment of the child's functional hearing, i.e. the range of sounds he would respond to in his day-to-day life. It must be made clear that this is not purely a description of the child's hearing loss but will depend on other things as well: his level of intelligence, his past experience of sounds, the use to which he puts his hearing aid if he has one. While not being an assessment of hearing loss *per se*, it seems the most realistic approach to take with young children. With older children and adults it is usually possible to obtain an audiogram of response to pure tones in a clinic setting, which comes close to providing an indication of the true degree of hearing loss, but this is often not possible with small children. At this age, and particularly with children under 3 years, it is very difficult to get an accurate assessment of how much the child can hear. The assessments given here then, while basically reflecting a child's hearing loss, must not be taken to be an absolute measure.

In assessing the hearing loss of a child, all relevant answers were used, although special attention was paid to the following questions.

- 6⁵ I wonder if we can get an idea of how deaf N is. Can he hear anything at all?
- 7 Can he hear if you shout (or talk normally) close to him when he's not wearing his hearing aid?
... and with his aid?
- 8 Does he take much notice of sounds?
(Note any in particular)
- 17 Have you been told how deaf he is? If yes:
Do you know the results of his last hearing test?
- 19 Do you know if his hearing has got better or worse?

- 104 If you needed to stop him doing something, is there any way you can get his attention without actually going over to him?
If yes: How?

After the interview, the interviewer noted down all incidents of communication between the child and anyone else during the interview.

On the basis of all the various evidence, a description was then written of the child's hearing. For the purposes of scoring, the hearing was classified into the categories shown in Table 1.4.

| Category | % |
|---|----|
| 0 No response to sound with or without aid | 5 |
| <i>For children with aids</i> | |
| 1 Response to few loud noises only | 14 |
| 2 Limited response to voice when attending | 30 |
| 3 Response to voice even when not attending | 30 |
| 4 Near to normal responses | 9 |
| <i>For children without aids</i> | |
| 5 Responses to loud noises only | 0 |
| 6 Response to voice when attending | 2 |
| 7 Response to voice even when not attending | 2 |
| 8 Near to normal responses | 2 |
| 9 Not known ^a | 7 |

Table 1.4 Incidence of different degrees of deafness in this sample

^a See the end of the guided interview schedule, Appendix I, for the hearing assessment key.

It is not necessarily true that this distribution is typical of the deaf population in general, or even the population of young deaf children. In order for a child to be included in this sample, deafness had to be diagnosed, and many cases of deafness are not picked up until the child reaches school-age. For this reason one would expect this sample to be weighted in favour of the more severely deaf, for these are the ones most likely to be diagnosed at this early age.

Throughout the book quotes taken from the tapes of the interviews are given to provide illustrations.⁶ In order to provide a context for each quote it is labelled with a description of the

child to whom it applies in terms of age, sex and hearing loss. The hearing loss is described by the following terms.

- profoundly deaf: little or no response to sound, no response to the human voice
(Categories 0, 1, 5 – 19% of sample)
- severely deaf: response to human voice but limited to situations when the child is attending
(Categories 2, 6 – 32% of sample)
- moderately deaf: response to voice in favourable situations
(Categories 3, 7 – 32% of sample)
- partially hearing: near to normal responses, though hearing loss constitutes a handicap
(Categories 4, 8 – 11% of sample)
- not known: hearing loss not possible to assess, either because the child is very young or presents particular problems
(Category 9 – 7% of sample)

The following examples may make these categories clearer.

Collette is 4½ years old and profoundly deaf. Occasionally she seems to hear very loud noises, but not consistently, and she never responds to the human voice. She was a premature baby, only weighing just over 3lb at birth and her deafness is attributed to this. She was kept under observation for her first year although deafness was not confirmed until she was 2 years old, as originally her slowness in speech and lack of response was thought to be due to mental retardation. She is now thought to be of average intelligence.

She does not say any words or understand anything that is said to her, although she is now beginning to look at people's lips when they speak. She communicates by gestures alone, and her mother finds not being able to explain things to Collette the biggest problem. To get Collette's attention her mother stamps on the floor and sometimes Collette will respond to the vibrations, but it is impossible to rely on this.

She has a hearing aid which she was reluctant to wear at first but now wears all the time. There is no peripatetic service⁷ in her area and since the age of 3 she has been a weekly boarder at a school for the deaf.

Emily is 2 years old and severely deaf. She seems to hear one or two loud noises: a cuckoo clock, aeroplanes, the door bell and a whistle. She occasionally responds to a person shouting to her, but not consistently.

The cause of her deafness is unknown. She passed a routine hearing assessment test at 8 months, but at 12 months her mother was worried as she showed no signs of starting to talk. Further examination showed Emily to be severely deaf and this diagnosis was confirmed at 15 months.

She has a hearing aid which does not seem to help her much, and which she is reluctant to wear although she generally wears it for some time each day. She communicates by gestures but is beginning to watch people's lips when they speak to her. Not being able to get her attention by calling her, but having to go over to her every time she is wanted, is her mother's biggest problem at this stage.

Joyce is nearly 7 and severely deaf. She cannot hear high-pitched sounds at all, either with or without her hearing aid. She can hear some sounds with her hearing aid, including the human voice, if the person is close by and speaks fairly loudly. However, because she does not hear high-pitched sounds at all, the human voice is completely unintelligible to her.

She has been deaf since birth. The cause of the deafness is unknown. Her mother visited her doctor when Joyce was 14 months old because she was worried about Joyce's response to sound. He referred her to a specialist who diagnosed her as deaf. She was then about 18 months old.

She has a hearing aid which she wears continually. From 18 months she has had help from a peripatetic teacher who visited about once every two months. From the age of 3 years she has attended a day school for the deaf, 15 miles from her home.

Her mother communicates with her by gestures and the spoken word. Joyce is beginning to lip read and recognises about fifteen words. Joyce herself communicates by gesture, and occasionally drawing pictures of what she means. Her mother finds the biggest problem is explaining the whys and wherefores of various situations to Joyce.

Robin is 3 years old and moderately deaf. He usually hears someone calling to him if they shout, and he can understand simple phrases.

He was a rhesus baby and kept under observation for his first year because of this. Deafness was suspected at a year, though because of his erratic response to sound it was difficult to be sure. He had hearing tests at 18 months and 2 years, and at 2 the diagnosis of deafness was confirmed.

Robin has had a hearing aid for a year which he wears occasionally, and he has had two visits from a peripatetic teacher.