

## CHAPTER SIX

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# LETTERS TO ZHOU HONG

In addition to the interviews I conducted, I was fortunate to obtain a collection of letters written by Chinese parents of deaf children. Their contents complement the information and views obtained from the interviews. The majority of these 168 letters are addressed to Zhou Hong, at that time principal of the preschool for deaf children whose parents were interviewed for my study. The remainder are addressed to Zhou Hong's daughter, Tingting (born in 1980), whose severe deafness was caused by ototoxic antibiotics when she was eighteen months old. The parents who wrote these letters were seeking advice concerning their own deaf children.

Zhou Hong has become widely known in China because of his success in educating his daughter. He taught her to speak and also taught her Chinese characters, so that she now reads and write proficiently. Rather than taking a traditional, formal approach to learning, Zhou Hong adopted an informal style of interaction with his daughter in order to make education seem interesting and attractive to her. At her father's instigation Tingting memorized the figure for pi to 1,000 decimal places, using a special mnemonic technique, when she was eight years old, and she recited it faultlessly in front of an audience of educators at a national conference. Her achievements were further publicized two years later when her father published an account of her education and upbringing titled *From Mute Girl to Child Prodigy*. Subsequently she was named one of the "Top Hundred Teenagers of China" and one of the "Top Ten Young Pioneers," and she and her father became nationally famous.

The first series of letters to Zhou Hong followed the widespread media coverage that began in 1991; and because Zhou Hong has encouraged journalists to continue producing articles about his

daughter and his educational methods, people continue to write to him—particularly parents with deaf children. Their persistence in doing so, in large numbers, clearly reflects the scarcity of information and support available elsewhere, as well as the tendency of these parents to look for help from every possible source. Zhou Hong has responded to many of the letters, sending parents copies of his and his daughter's book as well as teaching materials and tapes that he has prepared himself. He has also organized meetings for parents who travel hundreds of miles to hear him speak and to discuss their problems with him. With money raised through the sale of books and other materials, Zhou Hong has recently opened a private school for deaf children in Nanjing, staffed by parents of deaf children.

Zhou Hong offered me the letters to help with my research on families with deaf children in China. It was not possible to write to all the parents to ask their permission, both because of the number of letters and because in some cases the return addresses were missing or unclear. Nevertheless, it seemed acceptable to use the letters as research data, in part because their contents offer few details that parents would wish to conceal from others. The letters do reveal the parents' extreme unhappiness and frustration, but these feelings are shared by a majority of the parents. Nevertheless, I have been careful to maintain their privacy by preserving their anonymity.

Eighty of the letters are dated between 1991 and 1993, eighty-one between 1994 and 1996. Zhou Hong handed over the first series without prior examination or selection, straight from his files; at my request, in the second series he looked for letters containing "details of the family circumstances and descriptions of parents' experiences." Careful reading of the letters reveals no obvious difference between the two series; in particular, no obvious bias was introduced as a result of selection except length and detail. All of the letters include praise for Zhou Hong and appreciation of his achievement in educating his deaf daughter, so these elements were unlikely to have influenced his choice. Therefore, I treated the two series of letters as a group and analyzed them together.

In three cases, the same person wrote more than once, and in such cases all the correspondence was counted together as one "letter." Four criteria determined which letters should be included in the final sample:

1. The letters should be written by relatives of the deaf child; this excluded people who, although sympathetic toward the family, were unlikely to have access to key information and might not have been aware of the family's main concerns.
2. There must be clear evidence that the child was definitely hearing-impaired and not delayed or limited in speech for other reasons, such as mental handicap; in fact, most children in the final sample had had some form of audiometric testing that confirmed their hearing loss.
3. The child should not have started either mainstream primary school or deaf school.
4. The child should not be over ten years of age.

Using these criteria, I excluded 33 letters from the original sample, and I was left with 135 in the final collection. I selected ten of these letters to show the range of parents' circumstances and experiences, and these are included at the end of this chapter.

Certain specific characteristics of the writers can be inferred from the letters and the context in which they were written. First, simply writing a letter implies a good standard of literacy, especially when an ideographic language such as Chinese is used. Second, the letters were written after parents had read newspaper reports or magazine articles, or in a few cases watched television programs, about Zhou Hong and his daughter Tingting: with this kind of access to news and events they were more likely to be relatively well-educated urban families than uneducated peasants living in remote rural areas. Third, parents or relatives who wrote to Zhou Hong for advice felt motivated to seek help and believed that something useful might come of their action: clearly parents who were apathetic or too ashamed of their children would not write. While these letter writers are not representative of *all* parents with preschool-age deaf children in China, one can reasonably assume that their attitudes and views are to a large extent representative of educated, urban Chinese parents with preschool-age deaf children who are active in seeking help for their children.

Whether the letters are brief or discursive, they follow a basic pattern. Each letter contains three elements, often in the following order: an initial section of one or more paragraphs describing how

the writer came to hear about Zhou Hong and praising his achievements, a central section giving an account of the deaf child's situation and the parents' response to it, and a final section in which the writer requests help or asks certain questions (the letters at the end of this chapter provide typical examples of this form). The style of writing tends to be compact and economical. It is also very stylized in expression: that is, the parents use a limited number of phrases rather than a wide range of descriptors to relate their experiences. For example, they frequently use the metaphor "going into the soundless world" to describe the situation of deafness, and conversely "coming out of the soundless world"/"coming into the world of sound" to describe a deaf child's acquisition of speech.

The letters were all translated from Chinese into English before analysis. Each letter was read through and discussed with a native speaker of Chinese: letters 1 to 33 with a postgraduate student with a good knowledge of English, the remaining letters with an experienced medical translator. It became clear to me that I was in danger of overlooking some subtleties and connections that were more apparent to my Chinese assistants. For example, one letter about a deaf child living with his grandparents contains the sentence "His grandparents are unable to communicate with him." One of my Chinese colleagues commented, "The grandparents maybe don't like the child": on being pressed for further explanation, she responded, "It's hard to explain, but there is only one sentence; it seems like there might be a family problem here." Of course such conjectures are based on close familiarity with Chinese cultural behavior, including common attitudes toward deafness and its expression in language. In general, though, our perceptions concerning the explicit themes in the letters tended to coincide.

Key data about the parents, where available, were extracted from each letter: where they lived, and, in particular, whether they lived in an urban or rural area; educational level; and occupation. Key data concerning the deaf children were then identified: the child's age, age when hearing loss was suspected, age at diagnosis, and degree of hearing loss. I noted further details about each family, such as whether or not the family consisted of a married couple with one or more children, as well as the number of siblings, if any.

The letters were then read through carefully to identify the main themes. Once a theme was identified, it could be elaborated qualitatively with the help of descriptions in different letters. For example,

a recurring theme in the letters (as in the interviews) is the constant search for a cure for deafness. When this behavior starts, what resources—time, money, effort—are employed by parents, how parents find out about treatments, what their experience of the effects of treatment are (beneficial or otherwise), what causes parents to cease searching for a cure: all these details can be explored by sifting through all the letters. No one letter refers to all these elements, but a nuanced picture can be supplied by the cumulative description. In a few areas, a quantitative analysis is appropriate, as in comparing the number of parents who request information about cures or treatments for deafness with the number who ask for advice on speech training for their child.

My purpose in analyzing the letters was to uncover key preoccupations and understandings of the writers, not to provide a detailed linguistic analysis. However, it seemed important to focus on the exact words parents used in writing of deafness and deaf people in Chinese in order to build a picture of how parents construct these concepts.

## THE PARENTS

The writers of these letters were all blood relatives of the deaf children concerned, except in the case of one family whose deaf child was adopted and a niece of the child's adopted mother wrote to Zhou Hong. It is possible that because relatives by marriage may feel less closely concerned with the child, or feel the child is not their responsibility, they do not take the step of writing for help.

A breakdown of the different family members who wrote the letters is given in table 17 (distinguishing between paternal and maternal relatives of the child was easy, as there are different words in Chinese for these relationships). In a few cases it was not possible to tell either from the name or from internal evidence whether the writer—clearly the child's parent—was the father or the mother. Considerably more mothers than fathers wrote letters, and among other relatives, too, those on the mother's side tended to write more frequently than those on the father's side. Perhaps the disparity reflects a feeling that the children concerned, all of preschool age, are at this stage mainly the responsibility of their mothers.

TABLE 17: IDENTITY OF LETTER WRITERS

Relationship to Deaf Child	Number ( <i>N</i> = 135)
Father	47
Mother	67
Both father and mother	4
Parent (father or mother)	5
Paternal grandfather	0
Paternal grandmother	0
Maternal grandfather	1
Maternal grandmother	2
Paternal uncle	1
Maternal uncle	4
Paternal aunt	1
Paternal greatuncle	1
First cousin (mother's side)	2

Based on their names, the fact they were writing in Chinese, and the lack of any internal evidence to the contrary, I concluded that all the parents—even those writing from the autonomous regions, which have large populations of ethnic minority peoples—were Han Chinese.<sup>1</sup> This might seem unexpected, as China's national minorities constitute 8.3 percent of the population (Kormondy 1995), but the relatively low educational level of some ethnic minority groups might limit their access to information and possibly also affect their attitude toward seeking help; besides, they might not feel the same affinity toward a Han Chinese father of a deaf child as they would to someone of their own ethnic group. All the writers were hearing, and all but one of the deaf children concerned had hearing parents: she had deaf parents but had been adopted soon after birth by a hearing couple.

In only two cases do parents give clear evidence of their level of education: because one mother mentions her thwarted ambition to

go to college, she must be a senior middle school graduate; another mother states she is an economics graduate (i.e., she completed a three-year program at a vocational college). However, parents' level of education can be deduced from their jobs, as well as from the language and handwriting used in the letter. It appears that the majority of parents are well-educated, having completed at least senior middle school—in other words, twelve years of schooling. Similarly, occupations are specifically mentioned in only twenty letters, but they can be deduced from the letterhead, which gives the parent's work unit. Such evidence indicates that parents are mostly professionals, such as teachers or doctors, or workers in factories. Very few are farmers.

The letters came from all over the country: twenty-six of China's thirty provinces are represented. Nearly half the letters (48 percent) come from the densely populated eastern provinces—Shandong, Jiangsu, Zhejiang, Henan, and Anhui. Another fifth (21 percent) are from the six southeastern provinces—Fujian, Guangdong, Guangxi A.R. (Autonomous Region), Jiangxi, Hubei, and Hunan. The rest are divided among the remaining provinces and municipalities, as indicated in table 18. Whether parents live in urban or rural areas is of crucial importance, as it determines their access to medical facilities and special educational programs such as the provincial rehabilitation centers for deaf children. Therefore I attempted to deduce this information about their residence, concluding that the majority of parents lived in urban areas (44 percent lived in municipalities, provincial capitals, or main provincial cities; 33 percent in small cities or county towns; 7 percent in rural areas; and 15 percent in locations that could not be identified).

## THE CHILDREN

All of the parents had a single deaf child; none had two or more deaf children. Sixty of the children were male, sixty-six female, and in nine cases the sex of the child was not mentioned and could not be deduced. It is possible that parents with female deaf children were particularly encouraged to write to Zhou Hong because he also had a deaf daughter and they identified with him.

The number of children falling into each age group is shown in table 19. The exact age of eleven children was not known, but evi-

TABLE 18: RESIDENCE OF LETTER WRITERS

Region	Number	Region	Number
Beijing municipality	2	Hunan province	6
Shanghai municipality	6	Guangdong province	5
Tianjin municipality	2	Guangxi A.R.	4
Hebei province	2	Gansu province	2
Shanxi province	3	Qinghai province	0
Inner Mongolia A.R.	2	Ningxia Hui A.R.	0
Liaoning province	4	Sha'anxi province	3
Jilin province	1	Xinjiang Uygur A.R.	2
Heilongjiang province	3	Sichuan province	5
Shandong province	10	Guizhou province	1
Henan province	12	Yunnan province	1
Jiangsu province	16	Tibet A.R.	0
Anhui province	11	Hainan	0
Zhejiang province	12		
Jiangxi province	1	Hong Kong	1
Fujian province	5		
Hubei province	5	Location unknown	8

dence in the letters indicates that they were all of preschool age. The average age of the remaining children was 2.6 years.

Parents of forty-seven children gave figures from hearing tests (in decibels) for their child's hearing loss. In a further twenty-five cases the degree of hearing loss was described as "severe" or "profound" on testing, and other phrases were used to indicate the degree of deafness, such as "completely deaf." When parents simply reported a "severe" hearing loss, it was not always clear whether this meant "severe" or "profound" hearing loss according to the audiological definitions, so these were put into a separate category of "severe/profound" (see table 20). Thus of those children whose hearing loss was stated, the majority were profoundly deaf. None of the children were reported to have disabilities in addition to deafness.

TABLE 19: CHILDREN'S AGES

Age (in years)	Number ( <i>N</i> = 135)
0-1	1
1-2	25
2-3	41
3-4	31
4-5	14
5-6	7
6-7	2
7-8	3
Exact age not clear	11

TABLE 20: CHILDREN'S HEARING LOSS

Severity of Hearing Loss	Number of Children ( <i>N</i> = 135)	Percentage of Children
Mild	1	0.8
Moderate	3	2.2
Severe	12	8.9
Profound	47	34.8
Severe/profound	8	5.9
Not given	64	47.4

Nearly two-thirds of the parents (eighty-four) did not refer in their letters to the cause of their child's deafness. Of the remainder, ten said doctors had told them the deafness was "congenital." One child clearly had hereditary deafness, since her natural parents were both deaf. None of the parents admitted to or even raised the possibility of a genetic causation—an omission that suggests a strong element of denial, aversion to the idea of genetic causation, ignorance concerning the mechanisms of inherited deafness, or some combination of those factors. Twenty-two parents said their child

was deaf due to the effects of ototoxic drugs; a further eight parents gave this as a possible cause. Ten parents specifically stated that the cause of deafness was unknown.

## FAMILY STRUCTURE

Almost without exception, the 135 nuclear families represented followed the pattern of a married couple with only one child — the deaf child. The only parents who were not married were a father who referred to his “girlfriend” rather than his wife, but called his deaf son “their” child, and one mother who explained in her letter that she was a widow. In 3 of the 135 families the parents had a hearing child or children in addition to the deaf child. In one family, a boy who was deafened by ototoxic antibiotics had a hearing twin sister. In another family, living in the countryside, the father who wrote the letter explained he had two children: the younger one, a girl, was deaf. One family living in Inner Mongolia had four hearing girls and a deaf boy who was the youngest in the family.

Of the 132 families with only one child, only 4 mentioned the possibility of having a second child. This is probably because the letters were focused on obtaining help for the deaf child. In each case the parents wrote that they either did not want or were not able to have another child. In three instances, parents’ rejection of the possibility is linked to their devotion to their deaf child:

We never intend to have a second child, or give up searching for a cure for him [the deaf child]. (LZH, no. 98)

Even if there is only a glimmer of hope I’ll make every effort to find a cure for my son. . . . The leader of my work unit told me that since my first child is a deaf child, I can have a second child. But I don’t want to. (LZH, no. 93)

My mother-in-law, a warmhearted person who comes from a small village, said: “Don’t worry, when the child is three I will take him to the village and he can be a shepherd. Then you can have a second child.” When I heard this I was really upset — a shepherd? Is this the only choice for my son? Is this to be his fate? I wasn’t happy with my mother-in-law’s

attitude. We decided we wouldn't accept her help, we don't want our son to be an idiot and isolated from society. My grandmother told me my son was the cleverest boy she ever met. We must save money for our son, so he can go to primary school. (LZH, no. 16)

In the fourth instance, the mother wrote:

Because of the current family planning policy, I can't have a second child. So I should concentrate my efforts on the treatment of my son's deafness. (LZH , no. 66)

She does not explain the "can't": she may lack the permission of her work unit to have another child, or perhaps the deafness is congenital and she feels or has been advised not to run the risk of having a second deaf child. In any case, she and the other three writers all seem to associate the idea of investing in the welfare of the deaf child, specifically his or her recovery from deafness and rehabilitation, with rejecting the option of having a second, "normal" child.

## THE DIAGNOSIS

Some parents first suspected that their child did not react normally to sound when he or she was only a few months old. Other parents became concerned that something was wrong when it became evident their child was slow to speak. Many parents suppressed their suspicions for some time by finding explanations for the child's unusual behavior or assuming that he or she would grow out of it:

When she was four months old, we discovered she was rather slow to react to sound compared with other children the same age. At first we thought it was just slow development. (LZH, no. 55)

Last February I gave birth to a daughter. . . . Not long after, I found her hearing wasn't very acute. I thought maybe she was too young to concentrate her attention. I didn't consider she might have a hearing problem. Why should she? There was no possible reason. (LZH, no. 79)

One mother described her fear that her suspicions might be confirmed, which led to several months' delay before she took her son for testing:

When I was pregnant I had premonitions that something bad would happen. When my son was born he looked so handsome and intelligent my anxieties were swept away. But when my son was six months old, he wasn't reacting to sounds. . . . I didn't dare test my suspicions. I couldn't bring myself to go to the hospital. I just prayed. I just waited for another miracle to happen. So day after day passed. Other children the same age as my son were saying "*baba*" and "*mama*." . . . Finally one day during Spring Festival, the year before last, we went to Hebei Medical University. (LZH, no. 1)

When parents did decide to consult doctors concerning their child's hearing, they might not have had access to good quality medical care or the necessary hearing tests. Several parents mentioned unsatisfactory encounters with doctors: examinations were perfunctory and inadequate, misdiagnoses were made, or parents were told to come back when the child was old enough to have a hearing test. Some parents responded by traveling to larger cities with better facilities where they could get a proper diagnosis. Even when parents did manage to get access to good medical services, several reported being given only the bare facts with little explanation or discussion of what deafness implied for their child.

The diagnosis of deafness came as a terrible shock to parents. When they recalled the time preceding the diagnosis, it was to remember the happiness they felt at their child's birth and contrast it with the misery they felt now—the following passage is quite typical:

Last August I gave birth to a baby girl. With the arrival of our daughter, our whole family was full of happiness. My husband and I showed our love to her in every possible way. We devoted ourselves to her. But by and by we began to notice she wasn't reacting to sounds. So we took her for a checkup at our provincial hospital, and they diagnosed nerve deafness. When we got the result, my husband and I

were stunned. We seemed to fall into a bottomless chasm. Now we are always anxious, we can't put our minds to anything. Her grandparents are also worried and depressed. The happy laughter of the early days has gone. (LZH, no. 108)

Parents were often bewildered because they could see no reason why their child should be deaf. They often seemed not to understand how genetic deafness can be transmitted:

We felt greatly distressed. We had some doubts about the test result, because it seemed there were no possible causes for my daughter's deafness at all. During her pregnancy, my wife was very cautious and there is no hereditary factor. (LZH, no. 113)

Often "the whole family"—grandparents, parents' siblings, and other members of the extended family—is described as sharing the parents' grief and frustration:

[My sister and brother-in-law] cry all day long and don't even want to eat or drink. Our whole family feels greatly distressed, but we don't know what to do. (LZH, no. 112)

Thus in addition to the shock of the diagnosis, bewilderment at the seemingly inexplicable misfortune, and the anxiety, worry, and depression experienced by the entire family in coming to terms with the knowledge of the child's deafness, parents record the added distress of uncertainty about what action can be taken. None of the families mentioned any previous experience of deafness; in the absence of a professional support system, parents had to devise their own strategies and courses of action for dealing with a completely unfamiliar situation.

Most parents appeared to have withdrawn into the family circle, absorbed in trying to deal with their own grief, and did not say much about contact with neighbors or outsiders. But one severely depressed mother expressed her unhappiness that she was now vulnerable to other people's contempt:

Sometimes I think how much better it would be if it were only myself and my son in the world. Then we wouldn't be looked down upon by others, and wouldn't have to listen to those voices that sound like goodwill but are actually making fun of us behind our backs. (LZH, no. 60)

This mother felt so guilty about her son's deafness (caused by injections given to treat a high fever) that she had contemplated committing suicide; perhaps her depression colored her perceptions of other people. But she identifies another adversity faced by parents of disabled children in China, especially in the countryside—they become the objects of gossip, and they have to work harder to maintain their self-respect.<sup>2</sup>

In some families there were added twists to the shock of discovering deafness in their child. The national family planning regulations, in conjunction with a strong desire for male children, sometimes contributed to the difficulties. One man described the price his sister paid for wanting a son:

My sister has five children. The first four are girls. They are all very healthy, lovely, and clever. They're all doing very well at school. However my sister wanted very much to have a son. For the arrival of a son she paid a high price. But now it turns out her son is a mute. They are heartbroken. I remember she had a scan [to find out the sex of her unborn child] when she was pregnant—I wonder if her son's deafness is related to that. (LZH, no. 112)

In another instance, a mother had had repeated abortions (presumably after ultrasound scans to determine the child's sex), and eventually gave birth to the longed-for son—only to discover when he was eight months old that there was something wrong with his hearing; testing at the age of one year showed that he was completely deaf.

The only couple among the parents to have adopted a child had to endure the irony that the girl they chose was deaf:

My aunt—my father's sister—was married for many years, but never became pregnant. Because she was worried about having a baby at her age, she and her husband decided to follow the advice of some of their friends and adopt a baby.

They adopted a little girl from another family when she was three days old. The girl is now four years old. Both her natural parents are deaf. They have three daughters altogether; the oldest and the middle one are very healthy, without any hearing problem at all, and are doing well in school. That's why my aunt and her husband agreed to take their third daughter, this little girl, thinking she would be as good as her sisters. Unfortunately the girl said not a word after she came to my aunt's house, from that day until today. They brought her to the hospital for a checkup, and after that they finally had to accept the truth of her illness. (LZH, no. 22)

In view of the numbers of baby girls in China that are apparently adopted informally (see chapter 2), there must be a certain number who appear healthy at the time of adoption but turn out later to have impairments such as a mental handicap or deafness. We might well wonder if these children are more likely to be abandoned after their disability is discovered if they are not related by blood to their parents. The account above also illustrates popular lack of knowledge about the mechanism of genetic inheritance of deafness: this couple believed that the deaf couple's third child was unlikely to be deaf if the first two children were hearing.

The diagnosis of deafness forces parents to revise their picture of their child's future. Some educated parents who had special aspirations for their only child found it particularly painful to face reality. One couple had dreamed of bringing up their child to be bilingual in Chinese and English, since they themselves knew English well. When the mother realized that her son might never master even one language, she became very depressed and could not continue her job as an English teacher. She began working instead in a bank, where she could make more money to spend on her son's medical treatments (see LZH, no. 16, reproduced below). Another mother had hoped that her son would achieve her own unfulfilled ambition of going to college: the knowledge that her deaf son was unlikely to realize this goal seemed to revive feelings of failure and disappointment about her own life (see LZH, no. 2, reproduced below). Given the national family planning regulations limiting families to one child except under special circumstances, parents must find the shattering of their aspirations for their only children particularly hard to bear.

## FAMILY CONFLICTS AND STRESSES

Some of the letters reflected particular stresses and conflicts in the family arising from or intensified by having a deaf child; these were mostly related to parents' work and the need to earn money. Despite their obvious concern and feelings for their deaf child, very few — 3 out of 269 — had given up work to educate their children: the needs of the young child conflict with the necessity for both parents to keep on working to maintain a basic income. In addition, there is a strong feeling that mothers may be sacrificing their own lives and hopes for the future if they give up their jobs or devote less time to them, as one mother stated quite clearly:

Sometimes I feel so depressed. I know parents are responsible for their children's development, but that takes a lot of time, which means you can't put all your energy into your job, so you may miss opportunities and your chance for a good future. That's my situation and it makes me feel very uncomfortable. (LZH, no. 20)

Parents may feel added pressure to work hard and make money because of the cost of medical consultations and treatments for their child: as one mother wrote, "Our whole family wants to earn money, find money to help my son" (LZH, no. 16).

Current economic reforms have made new money-making opportunities available, but jobs in state-owned enterprises are increasingly poorly paid and no longer offer the same security and benefits that they once did. A common practice is for people to keep a foothold in their state job while moonlighting on some more profitable business venture. This leaves even less time for a deaf child. One mother who wrote works unofficially with her husband in a different province, periodically being called home by the leader of her work unit. Though she overtly expresses the wish that her work unit leader give her time off to spend with her son, her tone conveys her guilt at her neglect of him:

Nowadays I have no time to go back to work [at her official job]. So my younger sister in Henan looks after him because we are seldom at home. His grandparents are unable to communicate with him. So these days I'm quite worried

about him, whether everything is all right for him. If my work unit leader could understand my situation, I would take some time off to go home. I feel I haven't looked after him as well as I should have. I wish I could look after him every day and make him happy, and then I would feel at ease. (LZH, no. 1)

Sometimes tensions arose because parents did not share the responsibility of looking after their child equally. Several mothers complained of having to work full-time as well as look after their deaf child while their husband did very little:

Xuejiao's father is very busy. He often travels to other provinces. He has no time to look after Xuejiao. Sometimes I feel very tense and angry about this. I feel Xuejiao is not just my daughter; she is her father's daughter as well. (LZH, no. 20)

Another mother, with twins to look after, had similar problems; and although her mother-in-law was helping her, she herself could not find time to teach her deaf son:

As you know I have two children, and I have to work. So I have quite a heavy burden. Besides which my daughter isn't very well. She gets laryngitis very often and I have to take her to the hospital for injections. My son goes to the rehabilitation center with his grandmother during the day, and stays with her in the evenings. I only have time to be with him a short time after work. My husband is very busy with his job. He has no time to look after the children or do housework. I know you work as well as teaching your daughter. I would be interested to know how you manage your time. (LZH, no. 86)

Some have argued that the large-scale entry of women into the workplace in Western society has had a substantial and very harmful impact on the language development of preschool-age deaf children whose mothers no longer stay at home with them. Certainly in China, where all mothers are expected to work full-time, it is very

difficult for mothers—or fathers—to find time to give to their deaf children.

Under these circumstances the nature of parents' relationships with grandparents becomes even more important. Do the grandparents live nearby? Are they still employed, or are they retired and ready to assist during the day when parents are working? Are they well-educated and able to help parents train their child to speak, or are they illiterate and old-fashioned in their views? Do they support parents' ideas about how the deaf child should be brought up, or is there conflict over this or other matters? Some mothers-in-law, like the one who wanted her grandson to live with her in the countryside and become a shepherd, try to persuade parents to forget about the deaf child and try again for a "normal" one; others, like the primary school teacher discussed later in this chapter, both are supportive of parents' desire to devote themselves to their deaf child's upbringing and education and are able to contribute to this effort.

#### PARENTS' FEARS AND HOPES

The diagnosis of deafness in their child caused parents great anxiety for their child's future. Typical sentiments expressed were "We are worried about his future study and life" (LZH, no. 10) and "How can he go to school? How can he live when he grows up?" (LZH, no. 73). It was not clear to parents what the exact effect of their child's deafness would be on his or her future—and the uncertainty seemed to intensify their fears:

We can't imagine how our daughter will live in a soundless world for the rest of her life. (LZH, no. 3)

He is such an intelligent and handsome child, but when I think of his future I feel very depressed and anxious. (LZH, no. 16)

These feelings would be compounded by the lack of professional support and scarcity of information available to most parents.

As children approached school age, parental concern focused on whether they would be able to cope in an ordinary primary

school. One mother, who was pleased with her daughter's progress in learning to speak, was nevertheless apprehensive about her starting school:

When she speaks, her sentences are not clear, and there are a lot of mistakes. It's quite difficult for other people to understand her speech. She will be starting primary school this September. She will be studying with normal children. Her hearing and speech difficulties still exist and are still a problem. (LZH, no. 18)

The focus of her apprehensions also exemplifies how parents characteristically stress the quality of speech rather than considering more broadly the understanding of language that will be essential if the child is to be able to cope with the school curriculum.

When parents have already placed their child in an ordinary nursery school, and their child is unhappy, they may wonder how he or she can survive independently without the protection of the family:

I am worried about my son. He feels inferior and has no self-confidence. When he was in the nursery school he was always by himself, he never spoke with the teachers or the other children. When the other children picked on him, he just cried; he didn't know how to fight back. I am worried about him: later on, when we get old, will he be able to be independent in society and to survive? When I think about this I get very upset; I don't know what to do about it. (LZH, no. 23)

The lack of any apparent solution for his son's problems must have exacerbated this father's distress.

Parents' hopes for their deaf child focused on two main areas. Some parents simply desired a "cure." But the majority of parents expressed the wish that their children could learn to speak, would be able to attend ordinary primary school with "normal" children, and would be able to live like ordinary people:

We have only one thought—to work as hard as we can to teach him to speak, even if he only manages some words and everyday expressions. (LZH, no. 98)

If our child could speak, that would be the happiest moment of our lives. (LZH, no. 16)

How I wish [my daughter] could speak fluent standard Chinese so she could communicate with other people. (LZH, no. 65)

My one aim and desire in life is to enable my son to speak and to live like an ordinary person. (LZH, no. 42)

Again, the parents focus almost exclusively on the child's learning to speak as the key to education and life as a "normal" person.

#### THE SEARCH FOR A CURE

Fifty-three parents (39 percent) of the 135 who wrote to Zhou Hong mentioned they had already tried various treatments, and sixty-five (48 percent)—including some in the previous group—sought information about cures. Clearly this was a course that many parents were very interested in pursuing. Nor is silence on the subject evidence of lack of interest; some of the parents who did not mention medical treatments may have tried them, or may have intended to when their child was older, but chose to focus on some other matter in writing to Zhou Hong—for example, advice about speech training.

Parents generally pursued any information or advertisement that seemed to offer hope; typically, they had tried many hospitals and many forms of treatment:

My son is taking Chinese herbal medicine now, but there is still no effect after six months' treatment. In order to find a cure for him, whenever we hear of a therapy for treating deafness, we take him to try it. (LZH, no. 118)

My son is now three years and three months old. . . . Whenever we heard about a treatment for deafness, we took him there for treatment. From when he was two and a quarter to now, we tried everything to treat him. He's taken medicine and had injections—he has his medicine now just like he has his meals. (LZH, no. 52)

They persisted despite having been told by ENT doctors that there was no cure for sensorineural deafness.

My son is now seven years old. Since we found out our son was deaf when he was eight months old, we have been trying all sorts of medical treatments for him. At Shanghai ENT Hospital the diagnosis was nerve deafness, which is a severe deafness and difficult to cure. However, we still pay particular attention to information of this kind. (LZH, no. 36)

We took her to the departments of neurology and otology at all the big hospitals in Shanghai for treatment, but we were told “there is no cure.” When she was one and a half, she started *qigong* and acupuncture and moxibustion.<sup>3</sup> (LZH, no. 95)

One parent expressed the conclusion that many parents must have reached, before turning to Chinese traditional medical treatments:

As we know, modern medicine doesn't have any effective treatments for congenital or acquired deafness. (LZH, no. 85)

He and others seemed to view this more as a regrettable failing of Western medicine, in contrast to Chinese traditional medicine, which offers potential cures. This father, a surgeon, wrote to Zhou Hong asking for information on how Tingting had regained her hearing,<sup>4</sup> saying that if his son's hearing could be restored through treatment, “they were willing to do anything at any cost.”

Unfortunately, some parents who had previously been impressed by advice not to pursue treatment for their child's deafness

were persuaded by reading Zhou Hong's account to investigate its potential:

Originally we intended to take her to have acupuncture and moxibustion therapy at an army hospital in Shanghai. But the principal of No. 4 Deaf School in Shanghai told us acupuncture and moxibustion therapy didn't work. Almost all the students in his school had had acupuncture and moxibustion at some point, but the only effect was pain. So he advised me not to let my son suffer the treatment. However, after reading the report about Tingting I feel somewhat undecided. So I venture to write to you and would be very grateful if you could give me advice. (LZH, no. 126)

Twenty-eight of the parents who wrote of treatments did not specify what they had tried. Of the twenty-five parents who did provide details, thirteen had tried or were trying herbal medicine; five, *qi-gong*; and seven, various forms of acupuncture. Other treatments mentioned were high-pressure oxygen, "injections," desensitization treatment (used for deafness due to ototoxic drugs), another treatment for deafness due to ototoxicity (details not given), injections of an "energy mixture," and injections of ATP (adenosine triphosphate) and vitamins B and E. One father living in the countryside, having been told there was no cure for his son's deafness, followed advice to give his son a porridge made of walnuts every day, as this was said to improve hearing.

Parents sometimes traveled hundreds of miles to faraway provinces to seek treatment. One mother living in the eastern province of Anhui mentioned journeys to Beijing and Shanxi province in northern China, as well as to Changchun in the far northeastern province of Jilin (LZH, no. 91). For each trip parents would have to bear the expenses of travel and accommodation in addition to the cost of medical consultations and treatments. There was a high cost, too, in repeated disruption to their lives:

During the last few months [my brother] has taken his son to all the major hospitals all over the country trying to find a cure for his son, but without any result. Seeing my brother and sister-in-law mentally and physically exhausted, I feel really sorry for them. (LZH, no. 90)

On the fifth of November my wife, my son, and I came back to Fujian by plane [from Nanjing]. The next day I went to work. A week later, I asked for leave again and took my son for treatment to a hospital in the south. As you know, even if there is just a glimmer of hope I will make every effort to find a cure for my son. . . . If the treatment in the hospital in the south has no effect, I intend to take my son to Shanghai next year for treatment. (LZH, no. 93)

The same parent mentioned the enormous sums he had spent so far:

Recently we took our son on a two-month trip to Tianjin, Beijing, Shanxi, and Nanjing for examination and treatments. The fees for examination and treatment, and the accommodation and traveling expenses, altogether cost us nearly 30,000 yuan. And then we also spent quite a lot on the treatment in the hospital in the south. Some of the money is borrowed from our relatives and friends . . . so you see my financial situation is not so good at the moment. (LZH, no. 93)

Most parents did not say exactly how much money they had spent searching for a cure, but one other parent detailed the huge amounts in relation to his income:

The monthly income of my wife and myself together is less than 500 yuan. Therefore our financial situation isn't very good at all. But for our son we took all our savings, less than 1,000 yuan, and borrowed 2,000 yuan from our relatives and colleagues. Then we took our son to Beijing for a checkup. . . . Because there wasn't enough money left, we had to go back to Shanxi. But the cause of my son's deafness still remained unknown, I couldn't just give up. So I raised more money every way I could, and got 8,000 yuan, and once again we went to Beijing. . . . After coming back from Beijing, we kept on looking for treatments for our son at the same time as paying back our debt. We tried traditional Chinese herbal medicine, Western medicine [e.g., injections of ATP and vitamins], even *qigong*. . . . Altogether we spent 20,000 yuan. (LZH, no. 44)

Some parents felt that the expense prevented them from embarking on courses of treatment they wanted to try:

We often read about good therapeutic methods in newspapers and magazines, but we earn very modest wages and simply can't afford the expensive treatment. (LZH, no. 34)

Of the fifty-three parents who had tried treatments, six reported some improvement in their child's hearing (in two cases described as "slight"). The remainder (89 percent) said that treatment had made no obvious difference.

Some parents turned to the possibility of speech training their child only after they had exhausted their money and hopes in seeking a cure:

We have tried traditional Chinese herbal medicine, Western medicine, even *qigong*. Every time we were filled with hope, and every time hope turned into disappointment. . . . But the chances of my son being cured were too small. So we had to accept the fact, and began to consider how to educate my son. (LZH, no. 44)

Others were pursuing both courses of action at the same time; as one wrote,

We are determined to give him rehabilitation training while giving him medical treatments. (LZH, no. 89)

Although the decision to give their child speech training indicates a partial acceptance of their child's deafness, the impression given by these parents is that they have not yet surrendered the hope that the deafness can be eradicated and are still holding on to an image of their child as whole and "normal." In practical terms their resources and efforts are divided between two aims — eradicating deafness and eradicating its effects; in emotional terms they are still far from accepting the reality or the permanence of their child's deafness.

## HEARING AIDS AND COCHLEAR IMPLANTS

Thirty parents out of 135 (22 percent) mentioned they had bought hearing aids. In all but two cases, only one hearing aid was purchased. Only two parents reported the cost of the aid: 750 yuan and 3,000 yuan respectively (the latter was imported). Six mentioned they had bought foreign brands; one mother said she had initially bought a box-type hearing aid for her son, and later a Chinese-made behind-the-ear model; otherwise there was no information on the types of hearing aids purchased. None of the letters contained information concerning ear molds.

Nine parents gave the age of their child when a hearing aid was obtained. The youngest was one year old and the oldest six at the time of fitting: the average age of this group was 2.4 years. Parents considered buying a hearing aid at different stages: after an extensive trial of medical treatments, after a brief period of treatment, or as the first option. Thirteen parents made no further comment about their experience with hearing aids beyond the fact of purchase, although two wrote that their children were making good progress with their speech, suggesting that they had achieved some success with hearing aid use and speech training.

Seven parents reported that the hearing aids they bought for their children were "ineffective": five of these children were profoundly deaf, with hearing losses of 100, 105, 120, 120, and 120 dB respectively; the exact hearing loss of the other two children was not clear, though one was described as "severe." Although most parents did not mention the price they paid or the type of hearing aid they bought, four of this group of parents did, as if to emphasize that although they had purchased an expensive or high quality foreign aid, the result was still unsatisfactory. Two parents were concerned that the hearing aid was not functioning properly, but they did not have access to any service that could check the aid for them.

Four parents reported that their children would not keep the hearing aid in their ear, thereby frustrating attempts at speech training. One, whose child was nearly three years old, wrote:

She is very unwilling to wear her hearing aid. Even if she wears it, reluctantly, she can learn for only a very short time.  
(LZH, no. 91)

This parent appeared to have no strategies for dealing with this behavior. It is not clear from the letters whether parents expected their children to wear their hearing aid only when they were having formal speech training sessions or they tried to get the children to wear them throughout the day.

Five parents reported that the hearing aid their child wore was effective, but two had qualifications: “her hearing is a bit better, but her speech is still poor” (LZH, no. 39); “he is fairly sensitive to surrounding sounds with the hearing aid in, but his discrimination of sound is poor (LZH, no. 42).”

Some parents explained in their letters why they had not purchased a hearing aid for their child, at least yet. Their reasons included lack of access to centers selling hearing aids, or aids of adequate power; advice from doctors that their child’s hearing loss was too great for a hearing aid to be useful; and their need for advice before buying an aid. In general, most parents did not exploit assistive technology appropriately or adequately, a failure that reflects not only their lack of understanding concerning the role and usefulness of hearing aids but also, and above all, of the dearth of professional services essential to support children’s use of these devices. Expense may also have been a consideration for many parents. It is also possible, as the interviewees suggested in chapter 5, that some parents resisted because buying a hearing aid for their child would mean acknowledging to themselves the reality of their child’s deafness or would provide others with a definite and visible sign of their child’s deafness; but the letters are silent on this point.

Two parents brought up the subject of cochlear implants. One father, who had recently gotten a job in Malaysia and been told by a doctor there about the “artificial cochlea,” was interested in passing on details to Zhou Hong, wondering whether such technology was available in China yet. And one mother had heard about a cochlear device available in China that she was interested in for her three-year-old son:

I have some information for you. It is about an artificial cochlea. I’ve heard that the Beijing ENT Institute can do this kind of operation: Professor H—— D—— is the person to contact. I wrote to him, and he wrote back that they can do the operation for the single-channel device. But the opera-

tion is very expensive—it costs 50,000 to 60,000 yuan. I want very much to take my child to Beijing to have the operation, but I can't afford that amount of money. So I intend to sell one of my eyes or my kidney to raise the money for the operation. (LZH, no. 60)

Although cochlear implantation programs for children are beginning in China, the vast majority of parents cannot afford them. However, the implants were discussed and considered by these parents, who perceived them as a means of eliminating deafness; it seems that the actual benefits and drawbacks of cochlear implantation for children are not well understood in China (or indeed by many parents or nonprofessionals in Western countries, either).

#### TEACHING THEIR CHILD

Three children of the 135 children in the sample had experience of “rehabilitation training” in a rehabilitation center; the speech training of the remaining 132 children was the sole responsibility of their parents. We should keep in mind that the average age of these children was 2.6 years, so many of these children might in the future attend rehabilitation centers, some of which do not accept children until they are three or four years old.

Parents' level of education appeared to affect the degree of confidence with which they undertook their child's education. This is clearly seen, for example, in the letters reproduced in their entirety at the end of this chapter. In number 80, the mother argues that because she and her husband are only workers and not very well-educated, they do not feel able to teach their daughter—she asks Zhou Hong if he will teach her. By contrast, the mothers in numbers 81 and 82 emphasize that they and their husbands are well-educated and therefore in a very good position to teach their child themselves. It may also be the case that better-educated parents are more likely to get an earlier start in giving their child speech training rather than persist in searching for a medical cure for their child's deafness; however, even well-educated parents seemed to show a marked interest in medical treatments.

The majority of parents were employed in full-time jobs. Only three parents, two mothers and one father, said they had taken leave

from work or given up their jobs to stay at home and devote themselves to educating their child. One mother, who had spent three years at home with her daughter, said that although they were short of money, she was very pleased with her daughter's progress. She was now thinking about sending her daughter to an ordinary nursery school.

Most of the parents writing to Zhou Hong about speech training had experienced difficulties and discouragement. They felt it was difficult and were disappointed at the slow progress of their child:

It takes a lot of effort for me to teach her to speak. (LZH, no. 83)

After wearing a hearing aid for one month, Zixuan is able to say some words . . . but there hasn't been much improvement on that so far. I know we must have great patience and willpower with children of this kind. Sometimes I think—I am at the end of my resources, and my daughter still isn't speaking. (LZH, no. 46)

We have given him some training, but there has been no effect. When my child was two and a half years old, he could say "*baba*" and "*mama*," but at three years old he hasn't improved on this. We intensified our efforts to train him. After three months' concentrated training, day and night, he could say a few words. But his pronunciation is poor, and he has difficulty saying some words. (LZH, no. 35)

When my son was two years old we bought him a hearing aid and sent him to a speech training class to have speech training for an hour and a half every day. When he gets back home, we help him with his speech training. It is over one year now since he began training, but there is no obvious effect. (LZH, no. 56)

I've been teaching my son to speak for over a month now, but he still can't produce a sound. What is the problem? How can I achieve the goal of enabling him to speak? (LZH, no. 93)

Parents often lacked confidence and they felt that they were not using the proper technique:

Maybe our teaching method is wrong—the more we teach him to speak, the more unwilling he becomes. (LZH, no. 44)

I wonder whether my method is wrong, or whether I am not strict enough with her. (LZH, no. 46)

(*letter to Tingting*) We sent her to study in the language training center. Now she can say some simple words and everyday expressions. She can read *pinyin* and say several nursery rhymes by memory. How I wish she could speak fluent standard Chinese so she could communicate with other people, just like you! But she can't at the moment, because we don't know how to guide her correctly and give her training. (LZH, no. 65)

He has been wearing a hearing aid for over a year, but the effect is not so good. He is already two and a half, but he can only say “*baba*.” I think the training methods we're using aren't right. (LZH, no. 92)

Some parents described specific problems they had encountered, mentioning the children's inability to “remember” what they had already been taught to say; difficulties with specific sounds, such as distinguishing “*wawa*” and “*bua*” or pronouncing the retroflexive initials *zh*, *sh*, *ch*, and *r*; associating words they could say such as “*mama*” (mommy) and “*baba*” (daddy) with the right people; making sentences out of words; and understanding and formulating questions.

Parents were concerned their children would not be able to speak well enough by the age of seven, when they were due to start primary school:

I simply have no idea how to teach him. I've no confidence that I can teach him so he can go to school some day. (LZH, no. 86)

I think his progress is so slow. If he keeps going like this, I'm afraid he won't have the same ability to speak as normal children when he goes to primary school. In that case, how can he go to an ordinary school? (LZH, no. 115)

Parents saw the goal of speech training as their child's acquiring sufficient speech to attend primary school; when they realized that this goal might be difficult to achieve, they experienced pressure, frustration, and uncertainty. The apparent lack of results, despite their best efforts, clearly made parents lose confidence and feel hopeless; again, lack of professional support and advice greatly exacerbated their difficulties.

#### THE DEAF CHILD AND ORDINARY SCHOOLING

Some parents hoped that by placing their child in an ordinary nursery school they would stimulate his or her speech development and social interaction with other children. However, preschools in China, especially in urban areas, may have several hundred children and a high pupil:teacher ratio, making it difficult to give individual children special attention.

Four parents mentioned sending their deaf children to ordinary preschools. In one case, the child's grandmother was a primary school teacher and was able to stay with her granddaughter all day in the nursery class attached to her school. At the age of two and a half one boy was sent to nursery school where the teacher picked up his hearing problem, prompting the parents to get his hearing tested. The other two children experienced difficulties, which included being picked on by the other children. One father, as we have already seen, was deeply distressed about his son's treatment and inability to defend himself. Another parent wrote:

I sent her to nursery school so she could play with the other children and learn from them. But she was left on her own there, she's even been bitten by the other children. When she came home, she showed us the marks, and it upset me. I went to see her teacher to ask her to take special care of her. (LZH, no. 26)

Parents' perceptions of how well the home environment satisfied their child's requirements seemed to affect their decision on sending him or her to an ordinary preschool. Other considerations, such as how protective parents felt, or whether there was a grandparent at home able to look after the child while they were working, must also have played a part. One mother explained:

She is growing up in an atmosphere of love and affection at home. We haven't sent her to nursery school, so she is never hurt by others. (LZH, no. 82)

Another mother had stayed at home for three years to educate her daughter, and now wanted to go back to work; she was thinking of sending her child to an ordinary nursery school:

I'd like to send my daughter to an ordinary nursery school next year. I don't know how it will turn out, and I would like your opinion. I know that Tingting did well through rehabilitation at home, in the family. But we have not got such a good family environment as Tingting. Sending [my daughter] to nursery school may be better for her. I don't know whether I'm right about this or not. You know much more than I do about deaf children. Have there been any successful instances before, as far as you know? If there has, then I will send my daughter to a nursery school. (LZH, no. 53)

Such letters reveal parents' uncertainty and anxiety when faced with decisions about their children's education. Informed professional advice, along with professional support in the mainstream educational setting, would do much to help parents make appropriate decisions on their deaf children's education: for now, however, most lack this needed assistance.

## REQUESTS FOR HELP

The letters to Zhou Hong were written to ask him for help. Some parents asked simply for "help and advice." However, most were seeking specific information or materials; the nature of their re-

TABLE 21: PARENTS' REQUESTS FOR HELP

Specific Request	Number of Parents ( <i>N</i> = 135)	Percentage of Parents
Information about treatment	65	48.1
Information about speech training	46	34.0
Information about both treatment and speech training	25	18.5
Help with child's pronunciation	13	9.6
Help with reading and writing	4	2.9
Information about educational methods	19	14.0
Materials and books	25	18.5
Admission to Zhou Hong's nursery school	12	8.8
Information about meetings	4	2.9

*Note:* The number of requests totals more than 135 because some parents made more than one request.

quests (listed in table 21) reveals how parents perceive their child's deafness and what they consider appropriate action to be. Nearly half the parents (48 percent) wanted information about treatments for deafness, substantially more than asked for information concerning speech training (although more than a third of parents who asked about treatments also asked about speech training methods). Thus, as a whole, these parents were more interested in medical than educational measures.

The reports and articles in newspapers and magazines about Zhou Tingting mentioned that she had had a number of treatments, including acupuncture, that had apparently resulted in a slight improvement in her hearing. For this reason many parents asked for the exact details, so they could go to the same hospital and have the same treatment from the same doctor:

We know that with acupuncture and moxibustion therapy, even if the same acupoints are used, different manipulation by different doctors can produce a very different effect.

Therefore we would like to ask about the following points: Which hospital did your daughter have treatment in? Which doctor gave her acupuncture therapy that had a good effect? Did she have hearing tests before and after treatment? How long is the course of treatment? (LZH, no. 95)

We learned that Tingting once had acupuncture and moxibustion therapy. Although it didn't improve her hearing permanently, it did help for a little while. I am wondering if the transient improvement in her hearing had a significant effect on the accuracy of her pronunciation. Do you think long-term treatment is worthwhile, or not? (LZH, no. 82)

*(letter to Tingting)* I'm writing to ask you — in which hospital did you have your treatments? What's the name of the doctor who treated you? How long did the treatment last? How much money did you spend? How could you endure the pain of the acupuncture? (LZH, no. 72)

Some parents felt measures that had been effective for Tingting would only be effective for their child if the two had the same degree of hearing loss, etiology, and age of onset of deafness. If so, they reasoned, then following the course that had helped Tingting should bring similar results for their child. While some parents were satisfied with the facts presented in the articles they had read, others wanted more precise information:

From the description in the report of your daughter's condition when she was young, it seems to me it's nearly the same as my son's condition now. So I'm writing to ask for help and advice. (LZH, no. 101)

I heard that your daughter was unable to speak before the age of three. So I'd like to know if she had some hearing or no hearing at all at that time. Could she say simple things like "baba" and "mama"? . . . Is her deafness congenital or acquired? Please let me know in detail. (LZH, no. 117)

I'd like to ask about the following: How old was Tingting when you found she had a hearing problem? After that,

which hospitals did you take her to, and what kinds of checkups did she have? What were the results? Does Tingting have some residual hearing? What is her level of hearing? What caused Tingting's deafness, drug poisoning or some other cause? (LZH, no. 69)

In the article I read, it didn't mention the degree of your daughter's hearing loss. Did she have a BSER [brain stem evoked response] hearing test? What was the result? I'd like to know this because I read in the article that the treatment your daughter had had some curative effect. But my child's hearing loss is 100 dB—I don't know if treatment will have any effect. (LZH, no. 92)

Some parents sought information on speech training as well as or instead of advice on medical treatments. Usually they simply asked for general guidance. Any specific questions tended to focus on pronunciation and how to correct it. Thus the parents emphasized the correct articulation of speech rather than the acquisition of meaningful language.

## IMAGES OF DEAFNESS

Parents reveal their attitudes toward deafness in the imagery they use to describe it and the opposing states with which they contrast it.

### *Health and Illness*

The deafness of the deaf child was often contrasted with his or her "health" before the diagnosis was made:

Before he was one year old his health was very good (*ta de shenti hen hao*). Then we discovered his hearing was very poor. (LZH, no. 129)

Alternatively, the contrast might be made implicitly between a "normal" outward appearance—just like other healthy children—and the hidden defect of deafness:

Fangfang looks pretty, intelligent, and healthy (*jiankang*); people are glad to see her. (LZH, no. 4)

Deafness was consistently perceived and spoken of as an illness or disease:

I have a girl who is three years old. She suffers from deaf-illness (*long bing*) and has never spoken. (LZH, no. 132)

Why did heaven give me such a lovely son but make him suffer from an incurable disease (*bing*) so he is unable to live like a normal person? (LZH, no. 44)

Because it is a disease, parents discuss their efforts to find a cure:

Whenever we heard about a treatment for deafness, we would follow it up, in order to cure his disease. (LZH, no. 52)

We want to do everything we can to cure her illness before she is seven, because after that age the organs for hearing and speech stop developing, so it will be more difficult for her hearing to recover. (LZH, no. 4)

The doctor said there was no effective treatment for this disease at the moment. (LZH, no. 75)

In the second case, the father is aware of the critical period for language development during the early years: the search for a cure acquires a particular urgency as the child grows older.

The “disease” of deafness is portrayed as a malign force that disrupts family life, and some parents depict it as an entity that must be opposed and fought against:

The rhythm of our life and work is disturbed by her sickness. (LZH, no. 3)

At present we are greatly affected by my daughter’s illness, which interferes with our work and life. (LZH, no. 55)

We would like to learn from you, to fight the disease with all possible means, and create a miracle. (LZH, no. 100)

The word used to describe the speech training provided in pre-school—translated into English as “rehabilitation”—is *kangfu*, which literally means “health restore/recover.” This officially sanctioned term, which appears in such contexts as the name of the speech training centers (*kangfu zhongxin*), is also taken up by parents:

We should learn from you and try our best to get Ruirui rehabilitated as soon as possible. (LZH, no. 105)

Here, the parents envisage that speech training will definitely end the deafness just as treatment cures disease.

### *Deafness and Muteness*

The well-known saying about deaf people in China—that “out of ten deaf people, nine are mute” (*shi long, jiu ya*)—simply reflects the reality before special education programs began providing aural/oral training for deaf children. Deaf adults and children are frequently labeled *yaba* (mutes). The words for deafness (*long*) and muteness are frequently combined: for example in the phrase “deaf-mute school,” *longya xuexiao*, or the colloquial phrase for a deaf-mute person, *longya ren*. The combination implies a link, and clearly for many parents deafness and muteness are synonymous:

My brother’s son is now three years old, but he still can’t speak. So he had a checkup at a hospital, and they found he was a deaf-mute person (*longya ren*). (LZH, no. 90)

I have a three-year old son who is also deaf-mute (*longya*). (LZH, no. 96)

We’ve discovered he has a hearing problem. We are afraid he is deaf-mute (*longya*). (LZH, no. 109)

My son is completely deaf and completely mute (*quan long quan ya*). (LZH, no. 134)

Some parents were surprised to learn that a deaf child can speak. The mother of a eighteen-month-old profoundly deaf child wrote:

How shall I give my daughter training? Can I teach her to speak now? I've heard that children who can't hear can still learn to speak. (LZH, no. 79)

One mother asked, "Does deafness mean a mute child?" (LZH, no. 108). That a "deaf-mute girl" like Tingting learned to speak seemed miraculous and unusual:

Tingting was completely deaf and completely mute at the age of three and a half, but now she has become a student of great character and scholarship. It is really a miracle. (LZH, no. 85)

(*letter to Tingting*) I read about you—a completely deaf, completely mute girl who has learned to speak and studied in an ordinary school like normal children. I'm greatly inspired by your achievement. (LZH 131)

For some parents, acquiring speech somehow implies that the deafness vanishes, too.

### *The World of Sound and the Soundless World*

The metaphor opposing the world of sound to the soundless world is very frequently found in writing about deafness, including professional publications. The worlds are envisaged as two separate places, into which a child goes or from which he or she emerges. Set apart, the child is painfully separated from his or her family and from other people. Teachers or parents who succeed in teaching the deaf child to speak are pictured as bringing the child out of the soundless world, into the world of sound. The letter writers used the same image, in various contexts:

Seeing our child live in the soundless world, while other children live in happy laughter, we feel greatly distressed. (LZH, no. 110)

We can't bear to see our child live in the soundless world all his life. We must do our utmost to help him enter the world of sound. (LZH, no. 117)

You finally enabled Tingting to leave the soundless world. . . . I'd like to do my best to educate my child so that some day she also can live in the world of sound. (LZH, no. 105)

[Zhou Hong] put in untold effort to teach his daughter, and finally brought her to the wonderful world of sound. . . . I'd like to follow his example and do my best to try to bring my child to the world of sound as well. (LZH, no. 135)

Some parents referred to their child's "returning" to the world of sound, even when he or she had been born deaf. One mother, with a daughter whose sensorineural deafness was detected soon after birth, wrote:

I also have a deaf child. I really hope that someday she can be like Tingting, and come back to the world of sound and live like a normal person. (LZH, no. 94)

This metaphor is significant because it is so firmly rooted in the parents' perspective: when a child "enters" or "returns" to the world of sound by acquiring speech, the world is still "soundless" to *them*—although the parents may now have a child who produces speech and so is, in a superficial sense, participating in their world.

### *Being Deaf and Being Normal*

Parents are first and foremost aware that their child is different; the contrast is most painful when they see other children speaking or laughing and playing. But they also distinguish a part of their child that is normal, or perceive that their child is entirely normal—except for his or her deafness. Typically, parents' pride in their child's perceived intelligence and quickness to understand is set against their grief over the aspect of the child that is defective.

As deaf children grow older, the gap between their achievements—in learning to speak and in their progress in school—and

those of other, normally hearing, children becomes more obvious. When parents look to the future, they express the hope that their children will be able to “live like normal people,” or “live a normal life.” In this sense “normality” means following the main path; deaf children have fallen by the wayside, and unless they can get back on the road early in their life, they will never be able to keep up with everyone else. Normal education—in an ordinary nursery or primary school—is every parent’s hope; the prospect of special education fills them with dismay. These parents, like those I interviewed, sometimes insisted that they treated their deaf child “as normal.” They too meant that they do not treat him badly just because he is deaf; but here again, the phrase and the behavior seem to indicate a kind of wishful thinking—if the child is treated as normal, then he or she will somehow become normal.

Thus parents perceive deafness in a number of different ways, some of which are interlinked. Deafness is seen as a disease, non-deafness as a state of health. Deafness is a contrast to, and a deviation from, normality. Deafness implies muteness, inability to speak, which makes deaf children different from others and isolates them from their family and other people. In the imagery of the two worlds, with and without sound, deaf children are envisaged as being in a different place, as if they were physically removed from others; to return to their parents’ world, they must acquire speech. In all these polarities of meaning, there is never any doubt that for parents deafness and its related meanings are negative, while not-being-deaf and its related meanings are positive. Furthermore, speech is the outward manifestation of normality; its opposite is the dreaded state of being “deaf-mute.”

#### PARENTS’ SEARCH FOR SOLUTIONS

These letters from parents of deaf children underscore the difficulties they face in their efforts to educate their children. It should be emphasized that most live in cities or large towns, are well-educated, and are interested in seeking help for their children; parents living in the countryside far from medical and rehabilitation facilities, who have less education and fewer financial resources, or who feel less

able or less willing to seek solutions would be able to do far less for their children. In the analysis of the letters, six main points emerged.

1. Diagnosis of deafness depended solely on parents' acting on their own suspicions. The quality of the audiological services they received depended on what was available locally or how far parents were prepared to travel to reach a hospital with the appropriate equipment for testing.
2. As it is for hearing parents in Western countries, the diagnosis was a severe shock to parents. However, while audiological centers in the United States and Britain routinely arrange follow-up appointments with parents to provide counseling and support, as well as to put them in contact with other parents of deaf children, no such support was available to these parents in China. In coming to terms with the diagnosis and deciding what to do, parents had to rely on their own resources, and those of their family and friends. Only one letter mentioned contact with other parents with deaf children — the kind of contact that might have led to more information and made possible mutual support.
3. Following the diagnosis parents typically engaged in “doctor shopping”: they went from hospital to hospital to confirm the diagnosis and to ask doctors if there was a cure. When Western medicine failed them, parents turned to Chinese traditional medical treatments. Some parents long persisted in seeking cures — for years, in some cases — and expended substantial amounts of money. The decision to begin speech training occurred at different times for different parents; some parents continued to seek medical treatment even after their child had begun speech training.
4. Only a small proportion of parents (22 percent) had bought hearing aids, and those who had did not necessarily find them helpful. An often-cited problem was that children refused to wear their aids; parents also were not clear about the benefits of using them and how they might help in training deaf children to speak. Without information, materials, and qualified support, parents lacked confidence in what they were doing. In this area — establishing good practice in wearing hearing aids

and helping parents in their efforts to educate and give speech training to their children — there was obviously a very great need for professional advice and support.

5. The parents' concepts of deafness and the language they used to refer to it rely on consistently negative imagery, starkly contrasting with the positive connotations attached to "normality," its perceived opposite. None of the letters mentioned any experience of or acquaintance with deaf people. Thus parents' ideas about deafness were not informed by contact with deaf adults, and there was no suggestion that they felt such contact might be helpful in any way. Parents believed that their children could be restored to normality by learning to speak, joining "normal" children in ordinary mainstream schools, and leading ordinary lives.
6. Parents saw entry to primary school as the fateful moment in their deaf child's life. If children had not been cured by that time, or had not acquired sufficient speech through speech training, they could not be enrolled in mainstream schooling; the only alternative was to enter a school for the deaf. Some parents also realized that the preschool period was critical for the development of speech,<sup>5</sup> lending added urgency to the pressure on them and their children.

We can speculate about what will happen to these children as they get older. The evidence suggests that only a small minority will have acquired enough speech by the age of seven to enter mainstream schooling. Even if a deaf child has made good progress in the preschool years, parents may still find it difficult to persuade a local primary school to accept their child — many schools are reluctant to enroll children with special needs. The children most likely to gain entry are those who have some residual hearing, whose parents have access to and support from rehabilitation services, and whose parents (with other family members) have been able to establish an effective program of education and speech training at home. Their only other educational option is to go to deaf school; and since parents so strongly desire speech acquisition (by medical cure or not) and mainstream schooling for their child, they see deaf schooling as representing the utter failure of their efforts and the

futility of their hopes for their child's future. Clearly, many of the parents who wrote these letters will be severely disappointed.

Government policies for the preschool rehabilitation of deaf children were initiated only in 1988, and the facilities and resources available even in the cities are still far short of what is needed. However, the system is being expanded and improved year by year, and in the future many more parents will have a much better chance of obtaining the advice and support they need. As the system develops, it will have to deal with a number of critical issues.

1. While parental initiative should continue to be respected as an important element in identifying deafness, effective screening programs should be devised to ensure that deafness is diagnosed at an early stage. If national or regional programs seem too expensive, then other, more cost-effective avenues can be introduced or reinforced, such as educating parents who attend mother-and-baby clinics about the importance of taking a baby to be tested early if he or she is not responding to sounds.
2. More systematic procedures need to be implemented at the time of and immediately after diagnosis. Parents should receive information, advice, and support from professional services; prompt fitting of hearing aids should be arranged by the center where the diagnosis is made; and medical and rehabilitation services in each area must be better coordinated. The experience of audiologists in the United States and other countries has shown that having a network through which parents can be introduced to other families with deaf children greatly helps parents come to terms with the diagnosis of deafness in their child.
3. The process of serial consultation of doctors and of trying different treatments to cure deafness wastes parents' financial and emotional resources terribly. It prevents parents from focusing on the constructive actions they might take to develop effective communication with their child, including establishing hearing aid use and speech training. As rehabilitation services become more widely available and more information is disseminated through books and the media, it is possible that the parents' tendency toward multiple consultations will diminish. The government could help reduce the abuse and exploitation of parents by

encouraging them to try treatments that are scientifically proven and accredited, perhaps through a licensing system.

4. There is a great need for trained, qualified personnel to provide support for parents with deaf preschool-age children, to help them establish proper use of hearing aids, and to assist them in developing their child's speech. Although the government recognizes that programs to train such specialized personnel are crucial, it lacks the resources to implement them fully.
5. At the moment government policy is focused exclusively on auditory and speech training in early intervention programs, but future preschool rehabilitation services might support some parents in developing sign communication with their children, particularly if the children are profoundly deaf or if the parents themselves are deaf. Increasing these options would make it more likely that individual families could effectively support their deaf child's acquisition of language.
6. As in Western countries, in China many hearing parents with deaf children have only negative ideas about deafness. The expansion of rehabilitation services should help nurture more constructive attitudes; but before long-standing prejudices can be erased, society as a whole must acknowledge deaf people as different rather than simply defective; the same, of course, is true in Western countries.
7. In the rehabilitation of preschool-age deaf children, the acquisition of speech by school age receives disproportionate emphasis, exacerbated by a system in which placements either in mainstream or deaf schools are made at age seven and are difficult if not impossible to reverse afterward. A major difficulty for children with special needs is that schools are exam-oriented, and children are moved up to the next class only if they pass regular tests. Successful integration of large numbers of children with disabilities, including deafness, will require major changes in the curriculum and in teaching techniques, as well as the training of teachers to support special needs children in the classroom.
8. As preschool services develop, more deaf children entering deaf schools will have first attended rehabilitation centers or had speech training at home; it will thus be feasible to expand aural/

oral programs at least in some deaf schools. This change will help erode the current sharp distinction between mainstream schools, where deaf children use speech to communicate, and the deaf schools, where sign is used to teach the curriculum. Such convergence might lead parents to feel more positive about deaf schooling as an option for their child and less inclined to see it as the end of their hopes that their child will gain a full education, social acceptance, and a good job. Of course, parental dismay at the prospect of deaf schooling would also be lessened if deaf people achieve better status and a higher profile in Chinese society, and if indigenous Chinese sign language is given greater recognition and currency as a language in its own right.

After reading the letters to Zhou Hong and his daughter written by parents of deaf children, one is left with the strong impression that the actions these families have taken to help their deaf child are of central importance. To a large extent, the family's financial resources are a key factor: urban, educated parents, in contrast to parents in the rural regions, are in a position to afford medical consultations, expensive tests, good-quality hearing aids, information and teaching materials, and the fees of a rehabilitation center. Parents' attitudes and priorities are also critical to the child's success: they must decide how much time and effort they are able and willing to devote to their deaf child's education. The letters that follow provide a glimpse into the burdens, conflicts, and decisions that parents face in preparing their deaf child for the future. They are presented in no particular order.

## SELECTED LETTERS

(letter 43)

Principal Zhou:

Greetings. I am sorry to trouble you. I am a student at Anhui Education College. My name is C—— G——. The Mental Development Center at Wuhan University told me about you and your daughter. I feel very sympathetic about your daughter's misfortune, and very pleased and excited at her miraculous transformation. Thanks to your training and the treatments she received, from being a mute girl she has become a child prodigy.

I have the same suffering as you. My daughter Chen Yang is now two years old. She is a lovely child and very lively. She was just learning to speak when, about six months ago, misfortune befell her. She had a severe illness, and was given an injection of penicillin, gentamycin, and streptomycin. At the time we did not know how toxic these medicines could be. Then recently we realized something was wrong with her hearing, so we took her to a hospital in Hefei and had her hearing checked. The result of the test was that she is completely deaf in both ears. When I heard this I was very shocked. My dream of a child prodigy was shattered. What made me even more upset was that my daughter is only two years old and she was just beginning to understand the world, but soon she will lose this and become a disabled person for life.

I took her to see doctors everywhere, but they all said they had no means of curing her. Finally she was given a desensitization treatment at the hospital attached to Anhui Medical College, but there was no improvement. Then I wrote to the Mental Development Center in Wuhan to ask for help. They told me that your daughter had been in the same situation. So I am writing to you to ask for advice. Could you please tell me what treatments your daughter had for her deafness? Thank you very much.

With best wishes, C—— G——  
29 November 1994  
Hefei, Anhui province

(letter 4)

Principal Zhou:

Greetings. I am the father of a three-year old deaf girl, Fangfang. My name is X—— F——. When Fangfang was one year old, we discovered she wasn't able to say "daddy" and "mommy" and so we tried testing her hearing—we stood just behind her and clapped our hands and shook some toys. She didn't respond to these sounds, and we knew then she was deaf.

Several big hospitals said Fangfang's ears looked normal and they could find no reason for her deafness. Eventually, when we went to the Beijing Deaf Children's Rehabilitation and Research Center [China Rehabilitation Research Center for Deaf Children], we were told she had "severe sensorineural deafness in both ears." At that time we bought a high-quality Swiss hearing aid, but it didn't seem to make much difference.

When Fangfang was between fifty days and one year old, she had several high fevers and had between three to six injections. We have for-

gotten the name of the medicine—perhaps it was a toxic drug such as kanamycin or streptomycin.

Fangfang is pretty, intelligent, and healthy. People are always happy to see her. She reacts to the sound of fireworks 100 meters away, and if there's thunder she covers her ears and says “pong!” imitating the sound of the thunder. So we think she still has some hearing left. We have given her a great deal of speech training, and she can now say “daddy” (*baba*) and “no” (*bu*) quite well. But she can't pronounce “mommy” (*mama*), “grandma” (*nainai*), or “airplane” (*feiji*) clearly, although the shape of her mouth is right. She relies mainly on gestures to communicate with people. She is an intelligent girl.

I read your and Tingting's story in the magazines *Guide to Family Life* and *Life* recently. I was very moved, and feel there is some hope of solving Fangfang's problem. So I'm writing this letter to you, and look forward to hearing from you as to where and how we can get Fangfang good treatment, or any other useful information. We want to do everything we can to cure her illness before she is seven, because after that age the organs for hearing and speech stop developing, so it will be more difficult for her hearing to recover. I hope you can give us some suggestions and help. Thank you very much.

Best regards,  
X—— F——, Center for Agriculture and  
Science,  
13 November 1995  
Ningchen county, Inner Mongolia

(letter 80)

Comrade Zhou Hong:

When I write to you I feel the pen in my hand is as heavy as lead. I know very well how busy you are. I feel compelled to write but importunate in bothering you. Perhaps you can understand my feelings.

Lately I have begun to feel more and more distressed and worried about my daughter, because she is getting older and will soon be school age. But she can't speak at all. I feel completely helpless. I'm out of my mind with worry. I think only you can help us save our daughter, and I am confident you can effect the miracle of teaching our daughter to speak. So I intend to rent a house in Nanjing or live in a hotel. I beg you to spare several hours each day to give my daughter individual coaching. I am sure you know the right method to teach her. The question is whether you will accept her. As you know, both my husband and I are workers

and we are not very well-educated. We really don't know how to educate her. Therefore we have to turn to you for help. As well as that I'd like to ask you to help me get in touch with the doctors who gave your daughter medical treatment. I would like my daughter to have medical treatment while she's having speech training. As for payment, I don't mind how much it costs, so long as my daughter can be cured or can learn to say some words and expressions for everyday use. I'm prepared to go to any lengths and spend any amount of money. How I wish my poor girl could get her hearing back and become a lovely, intelligent, and healthy child.

Comrade Zhou, I beg you to give us help and save our child. I will feel very indebted to you even if you just agree to a trial period at first. I am very much looking forward to your reply.

With best wishes,  
W—— H——  
Jiangsu province

(letter 81)

Teacher Zhou:

We received your letter after an anxious wait. We're so pleased to hear from you.

Our child is now over two years old. He is lovely, intelligent, and always eager to learn. He particularly likes playing chess. He can recognize all the pieces and arrange them on the board, and knows how to play a little. Of course we spend a lot of time and put in a lot of effort teaching him. He is very interested in drawing now, and he can write the numbers 1 and 2. We teach him to write and draw every day. We find it very difficult to give him speech training. When we try and teach him to say "mama" he can only produce the sound "ah." He won't wear his hearing aid, so we have no way of knowing how useful it is.

We learned that you have put together a set of materials based on Tingting's study from when she was a little girl up to now. We'd very much like to have a copy. We hope to obtain some advice and enlightenment from you and find a set of educational methods that is appropriate for our child so that he can be a second Tingting. Both my husband and I are teachers, one in arts, the other in sciences. So conditions are favorable for our child. As you said, if we make unremitting efforts, we are bound to succeed. We long for that day to come.

Teacher Zhou, we are both unfortunate people. For the sake of our children, I hope we can keep in contact. You live in a large city, so you are bound to be better informed than us. I hope you can give us help.

I am enclosing some money. Please mail us a set of materials and the book *From Mute Girl to Child Prodigy*. Thank you very much.

With best wishes,

Y—— G——

10 April 1992

Qinzhou district, Guangxi province

(letter 82)

Teacher Zhou:

Greetings. When I read your article, I felt my situation was similar to yours. So I am venturing to write to you to ask for further advice and help.

I also have a lovely daughter who is deaf. She is now two years and seven months old. After she was given a checkup and found to have a hearing problem when she was nearly two years old, I bought her a hearing aid and began to teach her to speak. Her deafness is very severe. She has had two brain stem potential tests, and the reports showed hearing losses of 100 to 105 dB in the right ear, and 110 to 117 dB in the left. But I have doubts about these results. From our own observations at home, I think her hearing loss is less, about 80 dB. She refuses to wear her hearing aid, so to teach her to speak we have to speak loudly near her ears. She can say more than twenty words now. I also try to teach her to recognize the characters for these words. I think maybe this is helpful, but I have some questions to ask you about this. First, when I teach her to read, should I teach her *pinyin* first and characters later, or vice versa? Second, how did you teach your daughter *pinyin* and how did you teach her to read? Could you please advise me from your experience? I am just starting to educate a deaf child, and I don't know how to go about it. I'm very interested in learning from someone who has succeeded in this. I know you must be very busy, but I hope you can spare the time to send me a short reply. Maybe you have written down your experiences and published them. In that case, I sincerely hope you can send me all your articles and your book *From Mute Girl to Child Prodigy*, as well as related materials. I'll mail the money to you soon after receiving them.

Just like you, I also love my daughter very much, and I am determined to teach her to speak. Not only that—I also want her to catch up with normal children. Both my husband and I have received higher education and my mother-in-law is a primary school teacher. All of us feel the same way about my daughter's education, and we work together very well. My daughter is very intelligent and eager to learn. And our financial

situation is good. Our situation is favorable. So we are full of confidence. At the same time we know we will have to put in a lot of effort, and I am prepared for that.

I am sure that since you and your daughter became well-known you must have received many letters like this. I feel sorry to trouble you, but I think you can understand the feelings of parents with deaf children.

We are looking forward eagerly to your reply. Thank you very much.

With best wishes,

C—— X——

31 December 1992

Guangzhou, Guangdong province

(letter 44)

Teacher Zhou:

Greetings. To begin with, please give my best wishes to your family.

I am writing to you with tears in my eyes. It was a warmhearted aunt who showed me your article "From Mute Girl to Child Prodigy—A Miracle Created by a Father" published in the Shenzhen evening paper on 18 March. I burst into tears after reading it. I feel deeply moved by your courageous actions and sincere love for your daughter. I know very well how much love and hard work you must have put in to your daughter's upbringing. The same misfortune happened to me as well. I had lost all hope that my son could be cured. Your account led me to see some light amid all the darkness. It gave us hope again. My wife and I read the article again and again in tears. I think you are the only one who can help our Peng. Maybe you will be our son's savior.

A year after we got married we had a lovely son. We named him Peng, hoping he would have a bright future when he grew up.<sup>6</sup> I am a guard in a labor reform camp and my wife is a temporary worker.<sup>7</sup> After work I used to enjoy looking after our son. But unfortunately fate played a cruel joke on us. One day when my son was eight months old, I realized he didn't react to sound. Even when I shouted in his ears he still had no reaction. So we took him to have a checkup in Taiyuan, the capital of Shanxi province. The doctor said my son had lost his hearing, but they couldn't identify the cause. So they recommended we take our son to Beijing to have a thorough checkup. At that time it was not long after we got married, and we had just paid back the money we had borrowed from our friends to get married. The monthly income of my wife and me together is less than 500 yuan. Therefore our financial situation is not

good at all. But for our son we took all our savings, less than 1,000 yuan, and borrowed another 2,000 yuan from our relatives and colleagues. Then we took our son to Beijing for the checkup. In 301 Hospital they found that he suffers from nerve deafness. They said they couldn't cure him. Later we went to another big hospital and the result was the same. Because there wasn't enough money left, we had to go back to Shanxi. But we still didn't know the cause of my son's deafness, so I couldn't just give up. So I did everything I could to get money, raised 8,000 yuan, and we went back to Beijing. Tongren Hospital and Xiehe Hospitals are said to be the two best hospitals, so we took our son there. In Xiehe Hospital my son was given a hearing test. His hearing is only 85 to 95 dB. They refused to take him into the hospital. They said they couldn't cure him, nor could any of the big hospitals in China. When I heard this I despaired completely and felt my heart was breaking. I just held my son in my arms and cried. Why has heaven given me such a lovely son but let him suffer an incurable disease and made him unable to live like a normal person?

After coming back from Beijing, we paid back our debts while still seeking treatment for our son. We have tried traditional Chinese medicine and Western medicine, even *qigong*. Every time we were filled with hope, and every time hope turned into disappointment. Altogether we spent 20,000 yuan. But the chances of my son being cured were too small. So we had to accept the fact and began to consider how to educate my son.

My son is now four years old. Following doctor's advice I bought him a hearing aid. It seems to make a difference when he's wearing it. He reacted when I tried shouting from next door. My wife and I began to teach him to speak. After countless repetitions, he gradually learned to say "daddy" (*baba*), "mommy" (*mama*), "no" (*bu*), and "go" (*zou*), and so on, but not very clearly, and he doesn't seem to understand what the words mean. He can't distinguish between "daddy" and "mommy." We found his hearing was better in the evening, so we arranged most of our teaching in the evening. Maybe the way we're teaching him isn't right—the more we teach him to speak, the more unwilling he becomes. He shows obvious feelings of resistance. He enjoys playing and eating, so it seems to me he is completely normal apart from the deafness. Later I bought some books to teach him to read, but he didn't want to look at them either. And he has a bad temper. Sometimes he cannot be coaxed to learn to read, even with the promise of play or treats to eat. Sometimes in order to avoid learning to write, he opens the drawer, takes all the things out, puts his workbook at the bottom of the drawer, and puts everything back on top of it. When he does that I feel upset and yet pleased as well—he is so unwilling to study, but sometimes he does things that seem more intelligent than other children his age.

Teacher Zhou, I have told you all this about my child in the hope you could give me help and advice. I want very much to try the methods you have summarized in *Methods of Learning the Mother Tongue through Play* and *Method of Learning the Mother Tongue through Family Education*. How I wish my son could gradually learn to speak, read, write, and go to school just like Tingting. I really want to send my son to the school where you work, and entrust you with his education. But I am heavily in debt, and I can't really afford it. Besides, I don't want to trouble you too much. I just have one small request—could you please send me the materials you used to teach your daughter? I will mail the cost to you later. I am sure you can understand my feelings. My child is now over four years old. If I don't devote time to him now, I will miss the best period for educating him. I earnestly ask for your help.

Just to be on the safe side, I mailed two copies of this letter, one copy to each of your work units. I hope you will give us advice as soon as possible.

With best wishes,  
Z—— G——  
19 April 1995  
Shanxi province

(letter 87)  
Tingting:

How are you? I read the account of you being elected one of the Ten Best Young Pioneers in *Chinese Children's Newspaper* on 16 October. The account inspired us and gave us hope. From the report we know that when you were three and a half you were completely deaf and mute. After various treatments you finally learned to speak and made great progress. We are deeply moved by your achievement. So I am writing to you to ask—(1) What kind of treatment restored your hearing? (2) How did you learn to speak?

I have a daughter who has just turned three. She has been diagnosed as having nerve deafness. We have taken her to see various doctors, but they all say they have no means of curing her. They said she would have to have special education. That means she will have to go to a deaf school and learn sign language. We feel very upset about this. Now, after reading your story, I'd like to find out from your parents, through you, about your treatments. We also want to give our daughter treatment early on so that she can be like you some day and go to an ordinary school and receive a normal education. Our whole family are eagerly looking forward

to your reply. I hope you can spare the time to write to me after receiving this letter and tell us in detail about your treatments.

With best wishes,  
 W—— P——  
 11 November 1991  
 Industrial Chemicals Institute  
 Wuhan, Hubei province

(letter 2)

Principal Zhou:

Greetings. I heard about Tingting some time ago—two years ago when I brought my son to Lianyungang for treatment for his deafness, at the Second Railway Convalescence Center. And now the magazine *Family* has published a detailed article about her—when I read it I felt very much encouraged. You bring us, the parents of deaf children, hope.

I am the mother of a deaf child named Zhu Tianyi. My son is three years old. He can't speak. The hearing loss in his left ear is 100 dB, and in his right ear 105. We feel very dismayed by this. There is a little bit of reaction to sound in his left ear. For two years we have kept on taking our son for treatments and have borrowed a lot of money—we have lots of debts. But the treatments have all been disappointing.

I failed the national exams for university. I used to be very good academically, but in the end I gave up because my health wasn't very good. I have to tolerate the pain of failing. Now heaven has sent me a deaf child, and that has shattered the dream I once had of my son going to college. When I talk to other people about my child, my eyes fill with tears, and my nerves are very weak.

Principal Zhou, I think you have experienced the same kind of pain. I admire you very much. So I decided to write to you. I would like to learn from your experience of educating deaf children, but because of our bad economic circumstances it is not possible for us to send our son to your school. So I have to teach him myself, but I don't know where to start. My son is very naughty. I used to try to teach him to speak and read words. But it didn't work. He can only say "daddy," "mommy," "grandpa," and "grandma," but not clearly or correctly. I don't know if it would be better if I bought a hearing aid for him. Which kind of hearing aid is best for children? When teaching, is it better to read the words, write them, or learn how to speak them—should they all be started at the same time? Or some other way? I used to try to teach him, but it didn't work. Even though we live in the countryside, I don't want to destroy

my child's life just because I don't have enough money. I am eager to teach my son with your help, and hope you are able to write back to me.

Principal Zhou, I am really eager to hear from you, because I have had so many disappointments. I hope you can give some fresh hope to this mother in pain. My husband and I will pray for you, and look forward to hearing your news.

I hope you will take pity on our unfortunate son,

With best regards,

M—— Y——

16 November 1995

I look forward very much to hearing from  
you.

(letter 16)

Principal Zhou:

Greetings. How is Tingting? She seems to be making even better progress than she was before. On 20 July, I saw you on the China Central TV program *Follow You*. Later I read about your experiences bringing up Tingting published in *Family Friend* in August. I was deeply moved, it is a real miracle! I so admired your story, and it gives me hope.

Yuanyuan,<sup>8</sup> my son, is three and a half today. We had so many dreams for him, and now they are all shattered. When he was six months old, he got diarrhea and it took him a long time to get better. While he was in hospital, a disaster occurred that destroyed his whole life [he was given injections of ototoxic antibiotics that damaged his hearing]. When he was eight months, we noticed something odd about his behavior. At ten months, we took him for a brain stem check in Lanzhou in Gansu province. The professor at the Air Force Hospital gave us the final and terrible diagnosis: deafness caused by drug poisoning. His hearing is 110 dB. He can't hear voices so he can't learn to speak. He is a deaf child. Everyone in my family took a long time to get over the painful news. He is such an intelligent and lovely child, but what sort of future does he have now?

I used to be an English teacher. My son's father is an English-speaking tourist guide. We had a wonderful dream of the future, which was that we would teach our child both Chinese and English. But the reality is so cruel. He has a mouth but he can't speak, let alone learn a foreign language. All he can say is, "A mama, a ba. . . ." Every day I would be teaching basic English to innocent students, but my mind would wander. I couldn't concentrate; when I thought of my son, unable to speak Chinese, I couldn't bear it. So a year ago I gave up teaching and got a job in a bank. Now I keep myself to myself and just work hard.

Our whole family wants to earn money, find money to help my son. We tried treatment with Chinese medicine made in Yuncheng in Shanxi province for over six months, but we are disappointed with the results. He is growing bigger every day, and our anxiety is increasing. We did go to several hospitals, but in the end we gave up. I think advertisements are just advertisements and the treatments are just experimental. I don't think these treatments can help him, and what is worse, they may cause even more damage. Language training should begin as soon as possible. It is you who inspired me to believe that we shouldn't depend only on medical treatment. But in our small city, renowned as it is for its Buddhist landmarks and hometown of the flying apsaras,<sup>9</sup> there is little in the way of education for deaf-mute children. I want to teach my son to speak, but feel confused about where to start. I bought a speech trainer from Beijing, a DJ-1000 Sirui speech trainer, which cost me 1,500 yuan. But he refuses to use it. I need your help. If only our child could speak again, it would be the happiest day in our life.

I look forward to hearing from you.

Best regards,  
 Yuanyuan's mother, S—— H——  
 18 August 1995  
 D—— branch of the People's Construction  
 Bank of China

(letter 37)

Teacher Zhou,

After reading "A Father's Love Makes the Iron Tree Blossom"<sup>10</sup> I am deeply moved by your sincere love for your daughter. I am so happy at Tingting's miraculous transformation, and greatly inspired by your success.

I am eagerly writing to you as soon as I read the article, because I also have a deaf-mute daughter just like Tingting. At a time when I despaired of my daughter getting better, you gave me fresh hope. So with renewed expectations of enabling my daughter to leave the silent world, I am writing to you for help. I sincerely hope you will be able to give me some advice.

My daughter, now seven years old, suffers from congenital deafness, resulting in both deafness and muteness. She has a little bit of hearing but reacts only to very loud sounds. As a mother, I have had similar experiences to yours. I took her everywhere to see various doctors, but without much result. I once tried teaching her to articulate sounds, but she could not understand what I said. Sometimes when she was in a good

mood she would learn, but when she was unhappy she would not listen at all. So it is very difficult for me to teach her. From your article, I saw you had a method for educating Tingting, but it was not described in detail. I hope you can tell me more about your educational methods. I would greatly appreciate your help.

I hear that about 80 percent of deaf-mute children in the A—— Rehabilitation Center for Deaf Children have recovered owing to your educational methods. So I would like to ask about the center's conditions for accepting deaf-mute children and the environment of the center as well as how much the tuition fees are.

I hope you will write to me although I know how busy you must be.

I live in a remote mountain area in Sichuan province. I am not well-off, and my husband is dead. So I bear a double burden of financial and emotional stress. Nevertheless, for the sake of my daughter's rehabilitation, her future and her happiness, I will do my best to make her better whatever the cost. I am eagerly looking forward to your reply.

I wish you success always.

L—— X——

10 August 1995

Chongqing, Sichuan province