

PARENTAL CONCERNS

Bonnie Fairchild

Before we begin I'd like to know a little about you. How many of you have children? How many of you have children who are deaf? How many of you are members of IAPD?

A topic such as "Parental Concerns" is almost without limit. Some of what I say today will apply to all children. Some will apply specifically to children who are deaf and their families. Sometimes I think we tend to look at a deaf child and see only the deafness. IAPD is concerned with the whole child — that child's sisters and brothers, mother and father, grandparents — the whole family as a unit.

My involvement with deafness began with my daughter's diagnosis 13 years ago. She is now 15. My husband and I have 5 other children so you can see I have a lot of experience as a parent. My work with IAPD began four years ago when I was elected secretary of the organization. Last year I became more involved with the office itself when the director hurt her leg and was out quite a bit. When she resigned in July I became Acting Director. I have enjoyed myself a lot. I've enjoyed the people I've met and talked with from areas across the country and I have learned a lot.

The mail that comes into the office from around the United States and the world is truly astounding in its variety. The questions and concerns touch on almost every aspect of humanity. These concerns vary greatly depending on the age of the child, the background of the parents, where the family lives, and the parents' hopes and dreams for the child.

We have found that the support and sugges-

tions IAPD can give carries added weight because it comes from another parent — someone who has experienced the same frustrations, solved the same problems, and experienced the joys of seeing a deaf child grow. Our experiences and the knowledge of our many professional members merge to give parents a broad base of information. We also respond to many requests from students, relatives, friends, and the general public. Each month we mail hundreds of letters to those who write asking IAPD for information. We also publish a newsletter six times a year called the *ENDEAVOR*. IAPD was established in 1965 to be a source of realistic, reliable information for parents of deaf children. I wish I had known about IAPD when we first discovered my daughter was hearing impaired. I can well remember how I searched for information when my daughter was diagnosed. I wrote to everyone. The public library where I lived had almost nothing on hearing impairment. Perhaps they did have something on deafness but we had been told never to use the word "deaf". We were so broke paying for my daughter's speech therapy and new hearing aid that we couldn't have bought any books or joined any organizations or gone to any conventions — even if there were any back then.

When the IAPD Board was planning how we could participate here today we discussed several different ways. We thought about having several parents from different parts of the country come in to give different perspectives. But with the money situation being what it is

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we honestly couldn't afford that type of presentation. Perhaps that should be the first area of concern I mention — parent involvement. We appreciate the opportunity to be here today and we are grateful to be able to share our concerns. Parents across the country are very much aware of the current push for parent involvement and are wondering how they can best share their ideas and experience with you. I wish there were some way to finance parents' attendance at meetings like this. Not only would we learn a lot, but you would benefit too.

Anytime one parent talks about parents' concerns in general there is a risk of hearing a biased story. To try to avoid that I have collected a few letters from our files and put them on transparencies. Perhaps this will give you a feel for the types of concerns our mail brings everyday.

As I said before, concerns of parents vary depending on when and how the child becomes deaf, how severe the hearing impairment is, and the emotional, economical, and social background of the family. You all probably know that most parents make the initial diagnosis of deafness and that this diagnosis is then eventually confirmed by a doctor. And I suppose you all know that generally it is mama that takes the baby from place to place, listens to the advice, and then has to cope with telling daddy, and grandparents, and relatives, and neighbors, and the world at large what is wrong. So at the very beginning we have what we should call mama concerns. They are concerns unique to mamas.

(Overhead 1)

(Illustration of two female elephants and their children - "The only thing I don't like about childbirth is the stretch marks it gives me!")

I, too, truded around with my daughter when she was small, I was lucky because I was not put off and sent from doctor to doctor as so many parents are even today. We began almost immediately to deal with her deafness — although in those days we never said "deaf". In the diary I kept of those days I see

reference to the fact that I was ready to do whatever was possible to get Joyce progressing. I also see a sentence that says "my husband hopes that an operation will cure her and that she will become normal". Two very different outlooks. A while back we laughed at the elephants — but when a husband and wife don't have their act together concerns can become as big as elephants. And all those wrinkles are the day to day differences of opinion.

IAPD is concerned with the family as a unit. We want every family member to cooperate and work together. One special part of the Convention in North Carolina last summer was a siblings' rap session. No parents were allowed — and the kids really let it all hang out. They have their own concerns — and they want recognition for what they do and are, just as much as their deaf brothers and sisters.

We have printed the proceedings of that Convention — they are not fancy, but they are a collection of the speeches and discussions that happened throughout the three days. If you want a copy, the cost is \$2.00 to cover printing and mailing — there is a lot of information there for that price.

(Overhead 2)

"I remember one difficult morning when Wendy was four and I was taking my turn participating in her nursery school . . .

How will she ever catch up?

When will she understand connected speech?

When will we have a long conversation?

How will she learn the information other children so effortlessly obtain?

Where will she go to school?

What will she do with her life in the future?

I read this article from which these quotes were taken last month in a magazine called "Hearing & Speech Action". These questions are typical of those asked by parents of children who are deaf. I'd like to look for a minute

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at the question "When will we have a long conversation?" This is where the communication comes in.

Communication — perhaps the most vital link in the life of any person — deaf, hard of hearing, or normally hearing — young or old — communication has to be one of the biggest concerns of all parents.

The advantages of total communication have become so apparent that school after school is adopting this philosophy. I think it very strange that so many professionals, both groups and individuals, often those who first talk with parents, hesitate to take a definite stand for total communication. They emphasize that each child is an individual and that the **parents** must make the decision as to what is best for their child. It is very true that each child is different. However, parents need guidance - decisions, important decisions, are often made by parents who are confused, shocked, scared, and who still do not fully understand what it means to be deaf. Parents need guidance - it is ironic that we have so many requirements for licensing and certifying lawyers, doctors, and Indian chiefs, yet anyone at all can try his or her hand at being a parent, simply by having a child!

Most parents of deaf kids already know how to talk. It is a job to sell them on the idea that their deaf kids will succeed if they talk, talk, TALK. IAPD supports the use of speech and the importance of speech therapy as part of a total package. For IAPD that is total communication. We have developed a Position Paper on the importance of total communication. We encourage parents to as soon as possible, to accept their child's deafness and begin to spend the time, effort, and money necessary to learn, to use, and live with total communication. There are many obstacles parents need to overcome before they learn to sign, to fingerspell, and to use total communication on a day to day basis. Time passes quickly and soon our children are grown.

It breaks my heart to talk with parents who say "It is too late now — my son is almost grown and he will be gone. I can't learn to communicate now." I know you see that frequently. I wish we could have some place

where we could totally immerse these parents in total communication classes. I want them to experience the job of sharing their child's hopes and fears and dreams.

(Overhead 3)

"I am the parent of a young woman suffering a progressive hearing loss. Your agency has been suggested as one which might provide information on counseling programs and periodicals, such as your "Endeavor" which I would like to receive, on this subject. Please forward any literature on information you have available. I would be interested in counseling programs in both the Pittsburgh, Pa. and Columbus, Ohio areas..."

Letters from parents of older children are the most difficult to answer. Often the letters are so hopeless that one wonders how the family can continue. Our entire Convention last year was entitled "The Older Deaf Child". Parents came like flies to honey. They are desperate for information about their teenagers. They don't want the kids to grow up, leave and never come home again. Where are the counseling programs for older parents?

Employment is another area that causes concern to parents — especially as their children become teenagers. Most parents have limited contact with deaf adults — and some of that contact may not have been pleasant. One example immediately comes to mind: On the way down here yesterday I was sitting in the airport waiting for the plane to be ready for boarding. A man came up to me and held out a card — need I say more? I glanced quickly at the card — sure enough it said "I am deaf." I read no further but questioned "Deaf?" My daughter is also deaf." Shock registered on his face and I expected him to disappear. However, he asked if I lived there and I told him we lived in Delaware and that my daughter went to school in Washington, D. C. He wanted to know if she went to Gallaudet. I told him "no", to MSSD, the high school in Gallaudet. By this time everyone in the waiting area was watching us. Then I wished him luck and he continued on his way - handing out cards - begging.

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No parent would do that for a child!

(Overhead 4)

"One boy in school for deaf - one mainstreamed. My biggest problem is program for child that is mainstreamed. Right now I want material on how a speech teacher should help a hearing impaired student 30 min a day."

That first note came on a 3x5 index card. We couldn't answer it because she forgot to include an address. But it is obvious that she needs help — and what has been happening for 9½ years?

We receive many letters and telephone calls from parents and interested friends who want to know what work deaf people can do. I often think of Mary Beth Miller — a wonderful, funny deaf lady who is a professional actress. Several years ago I was honored to interpret for her while she conducted some deaf awareness classes in a public school near the school for the deaf in Delaware. The workshops were aimed at the hearing kids in the schools where deaf kids would soon be mainstreamed. Employment was a question that often came up and Mary Beth's reply was "We can be just about anything — except maybe a telephone operator." And suddenly Mary Beth would become that TV actress working as a telephone operator — "one ringadingy, two ringadingies . . ."

The kids loved her — I loved her — that was deaf awareness in action. Those workshops were a wonderful way to prepare the kids and teachers for the deaf kids and interpreters that were on the way.

The mainstream program at the Delaware School has some problems. However, from what I've seen and read it was an outstanding example of the way mainstreaming should be done. Unfortunately, when the federal money ran out, that portion of the program was also finished.

There is a lot of concern now about mainstreaming, Public Law 94-142 (I'm sure you'll hear more about that law later in your workshops) and least restrictive environment. This concern is not limited to parents or to special ed teachers.

(Overhead 5)

"We have identified an inventory of services (i.e., speech therapy) and facilities (i.e., loop system) which should be, but are not, provided by the school. These items show up as deficiencies in the "IEPs" of individual children and in the State Plan submitted pursuant to P.L. 94-142.

"We would be interested in hearing your advice and the experience of others who have refused to sign the "IEPs" or objected to the State Plan as a method for demanding the State to provide services and facilities which we feel sound professional opinion will support as essential elements of an "appropriate" education. We are seeking answers to such questions as:

- should all of our parents be encouraged not to sign the IEP for their child?
- how do you obtain from diagnostic and placement services a definition of the needs of a child?
- how effective have due process hearings been?
- how successful have people been in defining an "appropriate education"?
- how have those that have been successful proved the elements of an "appropriate education"?
- what have been the tactics of States and education agencies in defending these actions?
- are there any instances of retaliatory tactics (i.e., through placement changes) against parents?"

What is IAPD doing to solve some of these concerns? We are working very closely with the Gallaudet Task Force on Public Law 94-142. We sponsor workshops that look at the law from a parent's perspective.

You should know that we are working now on the schedule for a seminar to be held June 2, 3, and 4, 1979, in Kansas City. Titled "IEP and You and Me" the focus will be on how parents and students can better plan their

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student's education by working together with school personnel.

One of the things that bothers parents about education for the deaf is the apparent lack of continuity. New ideas come and are tried — and even if they are successful — are often discarded for newer ideas. Sometimes parents feel their kids are in laboratories — part of an experiment — rather than in school.

I'm sure you are well aware of the success rates of schools for the deaf. You work with clients everyday who have gone through the schools. It is a bitter pill to swallow when suddenly a parent is told "Oh, no, Billy can't go to college — he can't read well enough to qualify." And then the parents discover Billy can't read well enough to fill out an employment form, or manage a checkbook, or live independently. That's why so many parents are concerned about education. I'll have to rank education as the Number One Concern of parents.

(Overhead 6)

"I would like to ask some advise for my 19 year old brother who is deaf. He presented no problem until he was 14 years old. He went to school in Pasay, Phillippines. After the sixth grade, he does not want to go to school anymore. He is hard to get along with now and sometimes if he will not have his way, he becomes violent. My mother tried to communicate with him and even attends conferences for the deaf to understand him.

Do you have any suggestions on how to handle him. I will appreciate it very much if you can recommend any books that might help us communicate and understand him better."

Here we are back at communication again. And what about counseling for older teenagers? So many kids today have real, deep-seated emotional problems — what help is available — and where?

(Overhead 7)

"Personal attitudes about profes-

sionals play an important part in establishing effective communication. Barriers to communication must be overcome through analyzing your own feelings and working through them with the help of the professional. Parents of deaf children must also assume responsibility for proper instruction in areas that oftentimes are neglected or paid lip service by schools and other programs as

1. Sex education
2. Independent Living Skills
3. Language Training
4. Awareness of the World Around Them
5. Establishment of a Moral Base
6. Monetary Matters
7. Proper Relationships with Others

Although parents have found it difficult to understand and give guidance to their deaf children because of inadequate communication skills, the specialization of parent training and education must be present so that the parents will be able to provide much that is missed in the schools and other social service related areas."

This is an example of the kind of recommendations that came out of the last IAPD Convention. It illustrates well the need for parents and professionals to work together. IAPD has established committees to work on this and many other related areas. They are collecting information now that will become part of our "library" and serve as an information base for responding to parents' concerns.

When you read recommendations like this again you must consider the lack of training most parents receive. Are they able to do things like Mr. Harrelson recommends here?

(Overhead 8)

"Five years ago we found our deaf son had retinitis pigmentosa and would probably be blind by the time he was 30 years old. My husband summed up his feelings, "I felt the day the doctor gave us that diagnosis that I would never be

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happy again . . . If all this sounds depressing, let me assure you that watching your child go blind is *very* depressing.”

“We are moving to Mississippi. What schools for the deaf are there?”

“We just moved to be near a wonderful school and now that we bought our house we find we are outside the district.”

More and more emphasis is being placed on deaf-blind and other multi-handicapped deaf children. These are concerns that must be worked with now and in the future. This is another area where an IAPD Committee is gathering information. We urge you to contribute any information you may have in these areas. Another important concern is finding a new school when parents move. In this mobile society we get many requests for that kind of information. What we are doing now is putting families in touch with local people who can share their experiences and knowledge of that particular part of the country.

(Overhead 9 - top)

“When I take my children to the doctor for checkups, the doctor will not talk to me. He insists on talking to my nine year old daughter and expects her to translate for me. I am the mother!”

This is a TTY call that came into the office last week. This young deaf woman is very concerned with her role as a mother. What services are available to her? Better awareness on the part of the doctor would help a lot here.

(Overhead 9 - bottom)

“I hoped that my daughter would grow up and become a teacher — just as I had followed in my mother’s footsteps. Then I went to a PTA meeting at her school and there were *no deaf* teachers . . . What careers are open to deaf adults? I want realistic advice!”

This letter shows several different concerns we have already discussed. This lady is concerned about the schools, the teachers, and her child’s future.

One last story before I finish. It is a story about a young mother. She is very exceptional. I think her background as a college French teacher gives her a different perspective than most parents of two year old kids.

As soon as she found out her son was deaf she began reading everything she could find on deafness. She wrote to many different experts across the country asking their opinions. She quickly realized that total communication is the best way to get language into a child. She does not believe any student should leave school reading on a third or fourth grade level. And she is convinced this will not happen with her son.

The entire family is learning sign language and the son already has a large vocabulary. She is beginning to explore possible schools for her son.

Her concern is that she won’t be able to find a school that can continue the work she and her family have so laboriously begun. She has not seen any schools she feels are qualified to teach deaf students. Why does she feel that way? Because the teachers she has seen cannot communicate fluently with the students. She emphasizes that before she was certified to teach French she had to live in France and communicate fluently with French people. She does not see a similar requirement for teachers of deaf children. And she sees very few deaf teachers or professionals. She is scared. A lot of parents are scared. They are concerned with their children’s future.

I think it is realistic to say that the family of a deaf child will remain the one constant in his or her life. Teachers change, administrators change, schools change, and sometimes because of transfers, neighborhoods and towns and states change. IAPD wants the family to be strong, supportive, and able to communicate fully. We need to spread the word — we need to give parents a reliable, realistic picture of how they can assist their children become happy, useful citizens. We need to “get there firstest with the mostest”.

As I said before parents are hungry for information. We even have requests from parents who can’t read or write. I wish we could develop films and/or slide and sound

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presentations to reach these parents.

Many parents live in the country areas and are far from any library or other service agency. They still want and need information and advice. One of my dreams is to establish an IAPD mail lending library of films and books especially for parents. I know you can't learn everything from books — however it would be a start for these parents who are so isolated.

(Overhead 10) Illustration of how printed instructions can be misconstrued.

Books can certainly start some interesting conversations!

I've shared some parental concerns with you, and I've also let you have a glimpse of some of our services and dreams for the future. I hope I've given you some things to think about and I hope you will help spread the word about IAPD. I've talked enough now, you must have some questions and concerns of your own. Let's talk about them.

Discussion: There was a great deal of open and frank discussion of the continuing debate between groups which advocate a purely oral approach and those which advocate a total communication method — especially in the area of early childhood education. Several parents in the audience shared their current feelings of frustration and bitterness over the years they felt had been "wasted" while their children were in oral programs. Emphasis was made that they must not give up but continue to share their feelings with parents of younger children so that the same mistakes can be avoided.

A question was raised concerning teacher training programs and national trends with regard to instruction in sign language throughout the country, and even those pro-

grams with sign language gave only a brief session of sign language instruction for future teachers of deaf children.

Dr. Mervin D. Garretson shared some of his experiences from his travels with an evaluation team from the National Education Association. The team visited several schools across the country and took testimony from teachers, parents, and students. In every school where deaf students were mainstreamed the teachers and hearing students were using total communication. He expressed the feeling that change is happening, and that we must continue to let people know about these changes.

It was pointed out that IAPD, in an effort to cooperate with other parents, has formed a Coalition with the International Parents Organization (IPO), the parent section of the Alexander Graham Bell Association. The Coalition of parents hopes to work together on areas of mutual concern, and it has been agreed that there will be no debate over methodology in Coalition meetings.

In addition, IAPD membership has voted to begin working in Alliance with the National Association of the Deaf, and will become a section of the NAD if the Alliance is ratified by NAD members at their Convention in July.

The *ENDEAVOR*, the IAPD newsletter, was cited as an excellent way of getting information to parents. Also mentioned as a rich source of information was "The Exceptional Parent" magazine.

For more information, please write or call:
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