

## INTERVIEW WITH THE PARENTS OF A DOWN SYNDROME CHILD

David: How many children do you have?

Mother: We just have the one. Tracy.

David: And how old is Tracy?

Mother: Tracy is two and a half now.

David: Tracy has Down Syndrome. When did you first find out that she had Down Syndrome?

Mother: We found out maybe three hours after she was born.

David: They can tell that quickly! How did you feel when you found out?

Mother: Like I'd been hit with a sledge hammer. It was a big shock. It was just very numbing. I really didn't think too much. The numbness set in.

David: How did you feel?

Father: Well I was quite shocked. I knew it before Jackie did, because when I went in to see the baby I recognized it instantly. So I knew it quite a time before she did. And then when the doctor called us into the office to explain it to us, I knew why he wanted us in the office. And what he wanted to explain. So, I wasn't too surprised when he was telling us about it.

David: Was the doctor, and the other staff of the hospital, supportive?

Mother: Not at all. As far as I was concerned the doctor just told us, "The child has Down Syndrome." That was it. Go home and that was the end of it. I didn't even know what Down Syndrome was. Then he said it was mental retardation. That I could grasp. But Down Syndrome? I had really no idea it was a chromosome problem, or the other things that went with being a Down Syndrome child. I knew nothing. The nurses were very nice. They knew what was going on, but there was no follow through. Nothing!

David: So they left it up to you to get information?

Father: Entirely.

David: Where were you able to get some advice?

Mother: Finally we went to the state Bureau of Retardation. We went to the state and we asked them. "We have a child with Down Syndrome. What do we do?" We'd no idea. We didn't know whether she'd have to have special medications. Nothing! When we were first told, I really didn't have these questions in my mind then. It was such a thing to happen.

Father: We did go talk to the doctor, too. He was very cold. He said, "Put her away." Just like that. And we couldn't see doing that.

David: He advised you to put the child in an institution?

Father: Right!

Mother: Yes. We knew there had to be different answers than that. We couldn't accept that. So we kept going to different doctors and seeing what we could find. But it seemed as if they didn't know too much about Down Syndrome or anything else. And they really couldn't tell me anything. But finally the Bureau of Retardation did tell us some facts. What Down Syndrome was, and what to expect.

David: In the two and a half years since then, have you found a source of support and advice?

Father: Very much so. The schools have been very, very cooperative, and they have given us quite a good outlook on it. What can be done with the child and how far she can go. As long as you realize her potential is limited, very limited, and accept it, that's the main thing. I think first to accept it and then to work from there.

Mother: I think we were very lucky in finding a school which is in Camden, and this school is kind of a follow-through. You take your child there from two weeks on. They work with the parents, counseling the parents intensively for six to eight weeks, while the child is being worked with for muscular problems and, when they get older, fine motor skills. But the parents are really given a lot of support and explanation. This is what it is and this is how you can help yourself. Not just "Take the child home. This is it. This is your problem."

David: So you take her there now, to this school?

Mother: Yes. She goes three days a week, and she loves it.

David: What kinds of things do they do with a two and a half year old?

Mother: Right now they break it up into segments. For twenty minutes she will be doing fine motor skills, beads and buttons, a lot of fine motor skills; and the other half hour they do self-help skills. Shoes, taking your socks off, putting a sweater on. And teaching them to eat correctly, sitting at a table, how to eat. Things that they would

get at home, but they get them in school also. And they do finger-painting, bathroom skills, lots of very good things.

David: And is there a program for you, or do you just have to leave the child there?

Mother: No, not any more. After the initial eight weeks, they figure, if you can function, fine! After the eight weeks, then you're on your own.

David: But you have to go all the way to Camden for this?

Mother: Yes, I go to Camden.

David: How retarded is Tracy at two and a half?

Mother: She hasn't had an evaluation since she was nine months, but she's in the trainable class.

David: Are Down Syndrome children rather homogeneous, or do they differ a lot?

Mother: They differ quite a lot. You can walk into a class of Down Syndrome children and you can tell they're all Down Syndrome children. But there is a wide range there. A few of them are acting their chronological age, and they're doing very well.

David: Do you know how retarded Tracy is?

Mother: Not really. But they don't have a complete evaluation till after five years?

Mother: They suggest that we have a complete evaluation of her at four and a half years.

David: She's two and a half. How far behind do you think she is now?

Mother: I think she is functioning at a one and half year level.

David: How retarded can Down Syndrome children be?

Mother: To severely retarded, where they're just lying. They never walk; they don't feed themselves.

David: A lot of people say that Down Syndrome children are very easy children. They're happy and cheerful.

Mother: They are very happy, cheerful people. But they're also very stubborn. Very stubborn! You do better with them by trying to coax them, rather than trying to be too strict or stern with them, because then they just stiffen up and that's it! They won't move.

David: In what ways is Tracy stubborn? How does this show up?

Mother: If you want Tracy to follow commands, which is the big thing right now, Tracy would just like to turn around and do something that she's not supposed to be doing. You call her. She will go the other way. But I think this is also true with a lot of children. She's at the stubborn age.

David: That seems to be the terrible twos.

Father: Right!

Mother: Yes. She's running true to form.

Father: But, if you speak softly to her, you'll get a lot more out of her than you would if you yelled or were very harsh.

David: What kinds of things can Tracy do?

Mother: She is almost potty-trained. She tells me when she wants to go. She feeds herself. She dresses herself, some. She sometimes puts her top on. She'll comb her hair. She'll wash her face. She really does an awful lot of things that a two and a half year old would do at this time.

Father: She eats very well by herself, too. She handles a spoon and a fork very well.

Mother: She's very well behaved in restaurants, which is more than a lot of two and half year olds are.

David: What's her vocabulary like?

Mother: She has maybe a vocabulary of 6 words, 6 or 7. Not much more.

David: But I'm sure she understands much more than that.

Mother: Oh yes. She understands a lot. She will try and say a lot, maybe the first two letters of a word. She will try, which is the main thing.

David: Do you have any idea of how she's going to progress as she gets older?

Father: Not really.

Mother: How do you know how your children are going to progress? It's hard to tell right now. We just take it from day to day and, when she does some things new, it's very nice. But we don't have any long range plans. When you have children, you usually

pick out the college and you pick out the profession. Tracy will be with us a long time, and we'll just enjoy her.

David: Do you know what the life expectancy of Down Syndrome children are? Is it less than ours?

Father: Quite a few of the children have a chronic heart condition, and some have weak chests. But, thank goodness, Tracy doesn't have either, so she seems to be a very healthy child.

David: So she should have long life?

Father: We think so. Yes.

Mother: The life expectancy of these children is just normal, if they don't have the heart problem.

Father: Or the chest problem.

Mother: They're very susceptible to colds and any kind of infections that are going around. But with antibiotics, that's almost mastered now. So she will probably live a normal life span.

David: What kinds of things can children with Down Syndrome do as adults?

Father: It varies. There's just such a wide range of what they're capable of doing. Some of them will proceed a lot faster and a lot further than others. Some will be limited to a mental age of 8, 10; some 16; some 18. some graduate from high school, and others grade 5, or grade 6. It's very varied. It's hard to say.

David: But a number do graduate from high school?

Father: Yes, definitely. I've heard of a few cases where they went to college.

Mother: You're talking than about a different kind of Down Syndrome.

Father: They're very rare. It's very rare for them to go to or beyond high school.

David: What do you mean a different kind of Down Syndrome?

Mother: There's three types of Down's children. There's the translocation, there's the 21st chromosome, which is Tracy, and then there's the mosaic kind of Down Syndrome which does not always affect the brain, so they have normal intelligence. They have the features and everything else, the lax muscles, but their brain is not affected. So

they lead very normal lives. Of course, they can get through college with no problems. Tracy is a 21st chromosome child. So she is affected in all areas.

David: You mention the physical features. What are the physical features of this syndrome?

Mother: All the children have a number of them. They don't all have all of them. There are quite a few, I think there are something like 23 different kinds of physical features that they may have. The flattening of the bridge of the nose, the almond shaped eyes, the ears very low on their head, the thickness of the neck, the extra folds of skin, the very lax muscles. This is why they have problems coordinating. The laxness of muscles.

Father: The weak neck muscles.

Mother: All the muscles are very floppy. You have to really work to get them toned up. And of course the retardation is in varying degrees. The fingers may be webbed and their toes webbed. Some of the children have extra joints in their fingers. They're all very double jointed. They can bend backwards and forwards. And the flatness of the head. The back of the head is usually very flat.

David: Tracy doesn't seem to have many of those.

Father: Not to any excessive degree. She does have a little flatness, and her nose is very snub.

Mother: You wouldn't be able to say she's not a Down Syndrome child. You can tell just by looking at her that she's a Down Syndrome child. And people of course, notice this. So at least in this respect we are lucky. We knew what we had to handle. In other children, with different kinds of retardation, maybe you don't find out, till much later.

David: How do other people react to Tracy?

Father: Well strangely enough, most people don't even realize that she's a Down Syndrome child. The few that do are usually the professional people.

David: Is there a societal reaction to Down Syndrome children?

Mother: Right now she is two and a half, and the people react to the child in her, more than that she is a Down Syndrome child. I think this is not going to always be like that. When she gets older, I think you're going to see more difference. And I think if society can be a little more tolerant of mental retardation, it will be much better. There will be quite a lot of soul-searching when she gets older.

David: For whom?

Mother: For us, as parents, when she is discriminated against and we have to watch this. Because I don't think by the time that Tracy is older the attitude will have changed that much. It's changing, but very slowly. Not fast enough as far as I'm concerned.

David: In what way might she be discriminated against?

Mother: For work. They can do much more than what is being done with them now in sheltered workshops. Or community centers. They're doing tasks. They're earning money, a little money, but they can do much more. They shouldn't be given just menial jobs. I think they should be given something worthwhile. Retarded adults right now are bringing in 6 billion dollars annually. And this is just in menial jobs. I think they can do much more. They are doing much more in Europe with the retarded people.

David: Many of the places where the retarded people work are special workshops, factories, offices for the retarded. Is it easy to integrate them into other working force?

Mother: No. I think this is probably the reason that things are going so slow. Employers are a little apprehensive in employing the retarded if they don't have any background with retarded people. And then again, retarded people are confused with the mentally ill, and this is one of the things that's going to take people a long time to get straight. I think we should have more education of the public, and show them what a mentally retarded person is like. They have so much to give to society.