

Interview with Vinura's parents (Downs-9years)

Interviewer: Tell me how old Vinura is and who else is in your family.

Mother: Now Vinura is 9 years old and I have another one daughter, and with my husband we are four members.

Interviewer: And how old is your daughter?

Mother: 11 years.

Interviewer: And so how old was Vinura when you came here?

Mother: 10 years.

Interviewer: What does Vinura like doing?

Mother: Normal activities, so mostly he likes to play with his sister, or write or writing and reading.

Interviewer: What does he like playing at?

Mother: Many computer games and ball games or anything.

Interviewer: What is he particularly good at?

Mother: Actually he loves each other, he loves each others and he loves me and he loves his sister and father and what he likes ...

Interviewer: That's good.

Mother: Yes. He likes to go out for walks and he asks me to go along with him.

Interviewer: What is he not very good at?

Mother: Actually the main problem is that he cannot pronounce some words, proper pronunciation is the problem, he also has a speech problem. And sometimes he is a little bit naughty and he cannot understand some risk ... For example, sometimes he suddenly crosses the road or something similar. And he knows he shouldn't do that. Then sometimes immediately after this his mind changes he realises he can't do that.

Interviewer: Concentration?

Mother: Yes. He lacks concentration and sometimes gets angry. With normal activities he is okay but concentration is a problem and

mostly he doesn't like to study from the reading side or writing part.

He likes he can do only little few minutes only. Anything he can't do for a long time. He said that's enough.

Father: Vinura's main problem is his behaviour and his speech problems. He can do his speech. He can produce bad behaviour. The main thing is if he says something but anyone can't understand. No-one understands, and then he gets annoyed. That's the problem with Vinura. If he can be helped by giving speech therapy, it means that he could do some physical exercises, lips, tongues and all. Here he can get it properly I think that it is a good thing for Vinura.

Interviewer: Yes that will be good.
Does he speak any English?

Mother: He can understand, not 100 % but normal speaking he can understand and he can say some words, 'come', 'see', 'go', things like that, he can talk bit by bit.

Interviewer: What's your native language?

Mother: Sinhalese. it's a different language, yes.

Interviewer: How does he speak that?

Mother: He can ... in our language he can speak but not like us, but he can speak.

Interviewer: And physically how is he? Is he ok?

Mother: He is, he's okay.

Interviewer: Are there any particular difficulties in looking after him for you?

Mother: We always have to stay with him, or have somebody stay with him. I or my husband or any adults always have to stay with him because we have to look after him. That's the problem.

Interviewer: How does he get on with your daughter?

Mother: With my daughter, yes, he loves her and he can do things with her and he likes to play or write or do many things with his sister. She can look after him too. Actually she also can look after him, she can control him.

Interviewer: When you came here did you get much help with him from Social Services ?

Mother: Here? No. No we picked a special school for him from these schools through the Civic Centre.

Interviewer: Would you have liked more help?

Mother: Yes we like because we hoped to see something regarding his spiritual development.

Interviewer: And what sort of school does he go to?

Mother: It's a special school for children with Downs Syndrome.

Interviewer: Does he like it?

Mother: No, and we don't like to send him there to school but what can we do? The normal school is a bit risky. We'll like to send him to a normal school but he needs some special programmes, some special skills for his development.

Interviewer: So you can't send him to a normal school?

Mother: No. His behaviour is not like a normal child's. A class teacher cannot do that job because he needs a special attention.

Interviewer: How does it affect your family (life)?

Mother: Yes sometimes it's a little bit difficult if we have to meet the difficulties - both of us - my husband I are always involved with him. In my country we had another situation, we had some help from my husband's sister but here, the only ones involved with him is us. You know it's difficult because some one has always to stay at home with him. He cannot be left alone. We have to take turns, even for work, because one of us needs to stay home; if I stay, my husband can go out to work, if husband stays, I can go to my studies.

Interviewer: How does it affect your daughter's life do you think?

Mother: Yes we can think sometimes about that. It has some effect on her life but we always leave it at that. We are trying to get a better understanding about our son ... we tell her, your brother is like this, you have to help him. Now she is okay but we don't know what to think about the future.

Interviewer: What do you think Vinura's quality of life is for him?

Mother: I think it's alright but in comparison with other people, there are things he cannot achieve. He could if someone would help him.

Father: He is very happy. He knows how to talk to other people, how to behave with people and he knows that very well. Everyone loves him.

Interviewer: He's very sociable.

Mother: Yes, nice, smiling and ...sociable. ...

Interviewer: What are the best things about Vinura?

Father: The thing is if we can educate him to behave properly. At the time we are facing his behavioural problems. He can't stay a long time in one place. He wants to go around and do something only for a limited amount of time. After doing one thing, he likes to go into doing other things. That's the problem. If we can teach him how to behave... that's the only thing we need. That's enough for him.

Mother: We have to do something for his future, any organisation, or any service... I don't know if my country can do that or this country can do that, in my country... you know, is a very developing country.

Interviewer: What would you say to people who thought they were going to have a Downs baby.

Mother: Yes. I think any procedure to prevent this birth of baby ... I mean if somebody can check before getting the baby it's more helpful.

Interviewer: So did you know that Vinura was going to be a Downs Syndrome boy?

Mother: No, after his birth I think it's after two or three years we found out he had Down Syndrome. In my country there is not procedure of prior checking.

Interviewer: So if you had known, would you have had him or not had him, if you could have stopped it?

Mother: Yes. It should be stopped. Because it's a big problem ... I have no doubt.

Father: If we know what kind of baby we are going to have. If we know before that ... if you can check the baby what kind of baby we are going to have ... if we know in the early stage if you can stop it like this Downs Syndrome baby that is better because the parents of Down Syndrome babies are falling down mentally. They can't do anything properly. I mean, normal day to day work they cannot do because one of them

has to stay with him. You can't leave him alone. Actually we can't think what can that do to you, once cannot think what this is going to do to you, you know. One has no idea what one is doing. We have to look after him every time, each and every time we have to look after him... so, if we can stop something like this before birth then it's a good idea to stop it.