

Answer Project

Transcript of edited interview with Catherine's parents (*Down's syndrome - age 26*)

Interviewer: Can you tell me how old Catherine is and who else is in your family?

Mother: Catherine's 26 and we've got two older sons. The first one, Andrew is 35, he lives in Manchester. He works in IT. And Martin is 32, he will be 33 in October and he's a chef.

Interviewer: So generally how would you describe Catherine's capabilities?

Father: Pretty good. She's capable of independent travel. She's very articulate, can hold a conversation with anybody on anything pretty well.

Mother: Usually she will start a conversation.

Father: Usually she will, yes. She needs to be doing something all the time, otherwise she gets bored and doesn't like being bored. She's not content with just watching the television. She will do that but it doesn't satisfy her for very long. So she does college courses. She does some work.

Interviewer: What does she like doing in her spare time?

Mother: She loves listening to music. She's forever, when she's at the shops, browsing through CD's and she buys the latest things but I think that's probably her favourite.

Father: I think she would go to a disco every night.

Mother: She would if she had the chance, yes. She swims. That's her favourite form of exercise. She writes doesn't she?

Father: She does, a lot, yes.

Mother: Not stories, it's generally um -

Father: About life.

Mother: Yes about life. Things I would like to do, things I have been doing and she uses the computer. She likes to put them on, print them out.

Interviewer: So what would you say her limitations are?

Mother: She's not very good at understanding money. She has improved quite a bit lately, but for instance if she has a £20 note, she's not sure if she

thinks something's going to cost say £2.35, she doesn't really understand how she can pay for that using a £20 note. We have to explain it over and over again.

Father: And it would take her a long time to work out how much change she needs so in that sense she's vulnerable.

Mother: And what else?

Father: Recently she has done a course at Newcastle and it wasn't the best of places to travel from by foot to get to the Central Station. And when we explained why we thought she should get a taxi it was because there are a series of underpasses. She wouldn't recognise when there are any hazards. She would recognise the route and she would walk along it, but it wouldn't occur to her that there might be something around the corner or if someone walked up to her they might be up to some sort of mischief or whatever.

Mother: She's not as trusting as she was.

Father: No she's not but she's still very innocent and naïve.

Mother: Yes, naïve.

Interviewer: So when did you know that Catherine was a downs baby and what was your reaction?

Mother: She was five weeks old. We weren't told straight away. We were told that she had a clicky hip or a suspected clicky hip as it was called and so we needed to go there to see the paediatrician when she was five weeks old. She was born in hospital and when you go to antenatal visits you have a card, a record card which is usually handed to you when you come out of hospital after you have had the baby to take to your own doctor, or health visitor, and they apparently lost this card. Whether they had or not I'm not sure, but it arrived here the morning that we were due to go back to hospital and on it in red it said "Query Downs Syndrome". Now then, in those days, the general term was mongolism and in fact I had never heard of Downs Syndrome. I knew mongolism because Ken has got a sister who's got a son with Downs Syndrome. He's ten or eleven years older than Catherine. So we went to see the paediatrician ostensibly about this clicky hip and while we were there I said, "By the way what's Downs Syndrome?" so he had to tell us and we learned later that he was near retirement and that he wouldn't have told us until she was about two if we hadn't had some suspicions which was absolutely ridiculous. Anyway, our reaction, well I just burst into tears straight away. And I suppose you were a bit shocked.

Father: Well, yes, shocked I suppose is as much as anything that can describe our reaction.

Mother: But what I felt mainly was nothing to do with my life but with Catherine's. I just felt, what sort of a life is she going to have. I mean she was

beautiful wasn't she, as a baby. I must say I had had a slight suspicion when I first saw her, but the members of the family said, 'no, no.'

Father: You were more concerned than me, as well, about what other people would think.

Mother: Was I? In what way?

Father: Yes, as to what would be their reaction.

Mother: Oh, towards Catherine? Oh yes, what sort of treatment would she receive from others, and what sort of life would she have, and I just cried and cried for days.

Father: I don't think it took us long before we more or less said that we had two options. We either sit in a corner and be sorry for ourselves or get on with life. And I think probably we had an advantage over a lot of other people because we had Andrew and Martin, so we knew everything was okay, and I suppose that helped us to also say that we would have to treat her as near as possible the same as we treated them.

Interviewer: Were there any particularly difficult care demands?

Mother: Funnily enough yes, she had been very difficult to feed. She was bottle fed but we found she didn't take very much milk at a time. She took a long time to feed and she was sick quite a bit. I have never been the most patient of people and I was getting to the end of my tether, but funnily enough, once when we knew that she had Downs Syndrome, she was this special baby, my attitude just changed altogether and she still was difficult to feed, but I could excuse that and get on with it. But other than that it wasn't until she was mobile and she started trying to escape, she ran off a couple of times but was brought home by the police.

Father: That was when she was only about 4 or 5 as well.

Mother: Yes it must have been, well she was younger than that the first time.

Physically caring for her, she was toilet trained at about the normal time for any other child. As you say, I think the two boys, they just treated her like a younger sibling, not even a sister.

Father: Well I think our expectations of her were higher because of having Andrew and Martin than maybe they would otherwise have been. I'm not saying that we put high demands on what she should achieve, but we just decided that we would aim for these things.

Mother: Yes just expected -

Father: At the normal time - If there's such a thing as a normal time. And a lot of it fell into place didn't it?

Mother: And how old was she when we got in touch with the Downs Syndrome Association? Nine months?

Father: Yes, she wasn't a year old.

Mother: And so we got information from them on stimulating exercises and that, so we worked, well you more than me, worked on her.

Father: We did, yes.

Interviewer: Did you get much support from Social Services?

Mother: No, but we didn't seek it either. I think we were lucky, we didn't need it really. I'm sure a lot of people needed it a lot more than we did.

Interviewer: Then when she started school, how did she cope?

Mother: Well she started nursery first, a special needs nursery. But she was only there about a year and then she went to Houghton-le-Spring, a mainstream nursery.

Father: She was only about three when she went there.

Mother: She was three, yes. I found it a bit difficult at first watching her because she didn't know how really to interact with the other children. When they were playing outside for instance on the slide, all the others knew that they had to go and queue and take their turn. But she didn't know that. It took her a long time to learn how to play with them.

Father: Well, I mean that probably reinforced what we already suspected, and that was that she was going to have to be taught young a lot of things that Andrew and Martin had just picked up for themselves naturally as part of their development, but she had to have a lot of these things reinforced before she understood what they meant to her. I think for a long time she didn't play with the other children - she played alongside them.

Mother: Which other children do, I know that, but generally by the time they are three, three and a half they do play together more, but she got over that

And then she started school and she was just four and a bit, - the local special school, which we were happy for her to go to, because we knew she needed special education.

Father: We also knew that the headteacher at the local primary didn't want to know. She just saw her as a problem.

Mother: So she went there and I think she coped better than I did there. The age range was four to nineteen at this school and there was a school bus that came and took her there and it was nearly Christmas when I stopped going on

the bus with her and waiting in the school yard until it was time to go in, because I thought that she was only this big and there were these huge nineteen year old boys running around. But the headmistress gently said one day, 'you know you don't really need to come' and I think she coped very well and she got on well didn't she?

Father: Yes, that's probably another one of her strengths, that she has always been very sociable and can get on with anybody and everybody. It might take her a little while to accept some people. She's a bit wary of people who are boisterous. But that's probably the only thing. Apart from that she will talk to people before they talk to her.

Interviewer: So was she ever bullied?

Father: Not as far as we know. I think, intimidation by other behaviour was the more accurate way of describing it. I think probably bullying is the wrong word. She suffered some name calling etc. but not from her peers, it tends to be younger people, younger boys and girls who are at the mainstream school at the moment for example. And they need to learn something more than Catherine. She doesn't go home in tears about it.

Mother: Oh no.

Interviewer: How has she managed since she left school?

Mother: Well it's only a year since she finished education because she went on to college, at City of Sunderland College, special needs courses, and the last of those that were available to her finished just a year ago. At that point she had got this part time job in Gap, through the college really. Not that they got the job for her but it was because one of the modules she did was retail and part of that was being located at different shops. One of those she visited was Gap and the manageress was so impressed with the group that she asked her head office if she could take one of them on completely, on the same terms as any other, not a special job, and three of them went for interview and Catherine got it. So she works Friday mornings in Sunderland and also it started before that. We are involved with our local church and Catherine has come to church since she was born and she has gone through youth club and then the older young people's clubs, but then she ended up being a lot older than any of the others. So the director said, we need to find something else for her to do, and we have an office with an administrator, part time, and he said she could work with Elizabeth one half day a week so she does that. It's unpaid; she helps in the church office doing photocopying. Sometimes she has to polish the silver if there's nothing else to do, but she likes that.

Father: It's another one of the things that she looks forward to.

Mother: Yes.

Father: It's a bit of responsibility. It's contact with other people, different people.

Mother: Something independent from us. That's her buzz word, 'independence'.

Interviewer: So does she have special friends?

Father: She's got a wide range of friends actually. Her contemporaries near here. She has obviously grown apart from them, or at least they have grown apart from her because they can do a lot more things independently than she can.

Mother: Some of them are married now anyway.

Father: Yes, that's right. But she doesn't recognise age so anybody's her friend. And she's got lots of friends of varying ages at the church. She's got a lot of friends through Downs Syndrome North East which we have been a member of since she was about a year. 25 plus years. I've been on the committee nearly all that time as well. And so she looks forward to seeing them. But they tend to be events. There's a regular monthly night-club in Newcastle in the Live Theatre near the Quayside and they go there. It doesn't go well into the early hours but it goes beyond eleven and that's something that they all look forward to and that's where she can meet not just the people that she knows through the Downs Syndrome but also from various establishments in Newcastle.

Mother: It's special needs.

Father: It's a special needs nightclub and above all one of the things that she and the others look forward to.

Interviewer: What about boyfriends?

Mother: Well, you'll have to ask her about that. She doesn't tell us much. But, yes I know that she would, she hasn't got a boyfriend, but she really would love to have a boyfriend wouldn't she?

Father: I think that's as much as anything based on what she hears the others talking about, especially the other people in the shop.

Mother: Well because she thinks it's normal you see. Why shouldn't she do the normal thing? But, it's not that easy.

Interviewer: So do you think about her living outside of your home?

Father: Yes, yes. I mean that's the next stage. She's been thinking about it. Well we thought she was going to be the first one to leave home. But she has been talking about it for a lot longer than we have. No I suppose not because we've held back, but I suppose we haven't done anything about it yet.

Mother: It's partly that. I mean I am perfectly happy for her to stay here and also, well we are not sure exactly whether we'll find the perfect place for her.

Father: Oh, well I know that. I think that what bothers me is that if she goes into some form of support accommodation, which is what she would need, she wouldn't be completely independent. She would probably still need us to find some of the outlets for her interest and her energy, because I'm not sure that she would get that opportunity. So Joan's right in that respect.

Mother: Obviously we aren't going to live for ever and so we need to get Catherine settled somewhere where we know that she will be able to carry on without us.

Interviewer: What has been the hardest thing do you think?

Father: I don't know. There have been a few challenges but mainly that's been with authority making assumptions, not doing what we want.

Interviewer: How has it affected your life then?

Mother: Well, it has enriched our lives and widened our horizons. We've made so many friends, mainly through the Downs Syndrome Association. I think it's because she has always been young for her age, for me I tend not to remember how old I really am, because I mix with younger parents or have done, because I was older when I had Catherine. Most of the other mothers with children the same age as her were a lot younger than me, so it's sort of kept us younger in that way hasn't it?

Father: Yes, I think it has.

Mother: But at the same time, now that we've got to this stage, our contemporary friends, their families are all totally independent and even if some of them are still living at home we see them just trotting off whenever they feel like it, but we've got these ties.

Father: We've got to think about other things.

Mother: It doesn't really worry me much, just very occasionally. We still do get the opportunity because she goes to a respite house in Sunderland, that's to give her respite from us really.

Father: That's certainly what she says.

Mother: Yes, she doesn't go very often, maybe two or three weekends a year. But we usually take that opportunity to have a weekend away on our own.

Father: Yes we usually go walking in the Lake District which is what she hates.

Mother: She professes to.

Interviewer: What would you say to prospective parents then?

Mother: Well, all being well, if the child doesn't have any health problems, which Catherine didn't, I mean that's a totally different thing really because obviously you have got to look at that sort of thing, but that apart to treat the child just as you would any other.

Father: Yes, really recognise that there is potential there. When Catherine was born nobody really gave us hope. There was quite a pessimistic outlook. It was through contact with other people and especially through contact with the Downs Syndrome Association that we realised that there was a lot more positive future than we had had painted and certainly it has worked out well for us.

Mother: Yes, so I would say contact the Downs Syndrome Association. You will get advice from them. The advice would be to treat the child normally as much as you can but to give a lot of stimulation, and also as you do with any other child, really praise any achievements and encourage them like that.