

Priscilla Alderson 1998

Living with spina bifida: the views of people aged between 18 and 33,
LINKS, 178: 18-20.

Introduction

To redress the imbalance of the usual current prenatal information on screened for conditions, 40 adults with serious congenital conditions were interviewed, informally at home, about their daily life, enjoyments as well as problems, and their hopes and plans. The convenience pilot sample was contacted through self-help and social, rather than medical, networks. The four women and one man with spina bifida were aged from 18 to 33. (All the names are changed.)

Social life

All the five interviewees had been in mainstream schools, though Richard changed from special school when he was 12 "so that I could get a proper education". A few other pupils at his mainstream school used wheelchairs, and they were taught wheelchair maintenance, and to use escalators and stairs by pulling themselves up and down in their chair, and to tip back in order to go up kerbs. Now aged 18, Richard drives, and uses the underground though he sometimes has to argue his way through officials. He does not want an electric chair because they are heavy, hard to maintain, and a manual chair keeps him active.

Richard enjoys many sports from basketball to archery, weightlifting to Aikido, a martial art. He is training to be a sports instructor and works with many people who have been injured in accidents, he plans to work in a public sports centre with good access for disabled people - already installed or he will work to improve it so that "everyone can mix together that is much better than disabled people being cordoned off". Richard hopes to enter the paralympics and works hard to improve his fitness still more. He likes going out with his friends to clubs and wishes he had more time for all that he wants to do. He hopes to get his own home soon but is happy to live with his parents who encourage him to be independent. Through his interview Richard mentioned how he prefers to try to do things before asking for help, and how he tries to adapt and find ways round problems. I asked him if he felt disabled and he replied: "No I don't, I think I'm as able as other people it's just that I don't walk." This could be interpreted as unrealistic denial, or as a realistic expansion of what it means to be normal. Many young people would envy Richard's physical strength, sports skills and social life.

Jackie and Angela are both in their 30s and live with their parents, Jackie mother works in the same office with her, Jackie says she has lost touch with her friends and only sees her family including her sister, and young niece and nephew, when not at work. She drives her family around and likes holidays and abroad and going to the cinema expect that both are expensive. Jackie can walk with sticks and lives in a block of flats for disabled people. She enjoys watching medical programmes on television and reads the *Mirror* and agrees with that newspaper's campaigns to increase spending on hospitals.

Vivian had to fight through the courts to be able to go to mainstream school and felt she had to defend her right to be there at her annual medical check. Cristel said that doctors and teachers refused to accept that he back was painful and that she could walk only very slowly. She was often in trouble at school for being late for lessons when there was some distance between the classrooms.

Four went on to further education, doing courses in retail, leisure and tourism, sport, health and social care, IT and office skills; Vivian did a-levels and an honours degree in languages which included one year living abroad. Later she learned she had stayed near a former German concentration camp which was for disabled people. All of them are now employed except Cristel, a single mother with a three year old son who is now at college. The others are a secretary, a

recreation assistant, a sales assistant and Vivian has done a range of jobs: promoter of festivals and events, arts administrator, journal editor, marketing manager, journalist, playwright, a consultant on access for disabled people in the arts world, educating professionals about disability, and she is a member of the Direct Action Network of disabled people campaigning to have access on public transport.

Households

Three people live with their parents, Vivian lives on her own and Cristel lives with her son. She is determined to prove that she can be independent and care fully for her son, although she gets on well with her parents and her son's father she prefers to live in her own flat. They all stress how much they value their independence. Angela feels that the authorities should provide better housing for young people, as she can't afford to leave her parents' home.

Main likes

Talking about daily life moves beyond medical viewpoints and helps to show how the interviewees value the quality of their lives. The wide range of activities covered dispels myths about disabled people leading boring restricted lives. Richard loves sports including; archery, basket ball, aikido and weight lifting and hopes to train for the Olympics. He thinks keeping fit is very important and he can pull himself up and down stairs in his wheel chair. Vivian was the only other person to use a wheel chair and is also very active. Four of the interviewees like travelling abroad. Spending time with friends and family was often mentioned, especially for two of the women who enjoyed being with their nieces. Other activities included; helping at Brownies and Rainbows, going to restaurants and the cinema, dancing, reading, computers, music, art and decorating, disability activity days, relaxing at home, watching TV. Vivian very much enjoys working.

What do you find most useful in your life?

The main answer was "independence". Three people said that they knew that their families were there for them when they need them which was helpful, but that they didn't like asking for help unless they really needed it. Vivian said that a great help to her was knowing when to ask. Other helpful thing were; cars, a wheel chair, reflexology, going out with friends, and for Cristel, her son and her flat with no stairs.

Is there anything you would like to change or improve in your life?

Two people said that there was nothing that they would like to change. Angela said that she would like to be taller, partly for the convenience of being able to reach things and partly because people's attitude towards her would be different, because as she is she looks very young. She would also like bigger feet because it is hard to find fashionable shoes with such small feet. Vivian wished that she didn't get depressed and Cristel would like to go to college and sort out an education and a good job, she finds it hard to find suitable work as she can't stand up, sit or move for long periods of time.

Is there anything you would like to change about society?

Access was often mentioned in answer to this question. Two people said that they would change everything' about society; New Labour, the NHS, education and social attitudes. Richard thinks that more integration is very important. He is keen to expand opportunities for disabled people at the sports centre where he works. Angela said more should be done to improve housing and Cristel said she would rather work than live on benefits and she feels that more jobs should be accessible to disabled people.

What are your main hopes for the future?

Jackie and Angela both like to take one day at a time although Angela mentioned saving for a holiday, and hopes to get her own flat. The other three all want to advance their careers, Richard wants to continue getting fitter, and maybe take part in the Olympics. Vivian would like to earn more money so that she can save and will be able to support herself when she is more disabled. She would also like to have children and has consulted an obstetrician about this as she has a curved spine. Cristel very much wants a career and would like to find a way of working helping people. "My friends say I'm like a psychiatrist, they phone me up when they have problems."

What are your views on becoming a partner?

This question also led to answers which stressed independence. Cristel no longer lives with her boyfriend because she felt that he was looking after her and she couldn't stand that. The others say they feel happy on their own and would only want to have a long-term relationship if they met the right person. No one mentioned spina bifida as a problem with relationships.

Richard says he doesn't want to rush into he wants to enjoy life now and he might like to marry and have children later.

Richard: In some respects (tests) it is a good idea because then you can see if the child will have a disability then you can make a decision before it's too late if you decide you won't be able to cope with a child that has a disability I know it's a horrible thing to say but it can be aborted. I mean I am totally against abortion I don't think it is the right thing to do if you're old enough to decide you want the child you should be old enough to handle the child no matter what disability or ability. In some ways it is good but in some respects I don't agree with screening because some people will have a screen see they've got a child with a disability and decide no I can't cope I'm going to have it aborted or I'm going to have it adopted. Adoption isn't too bad but abortion I don't agree with at all.

It depends what sort of life the child will have if it is born. If it's going to have parents that care for it then I don't think that it should need screening or that the testing should have come about, but there are some people who will get rid of the child once it's born. One way or another whether it be adopting or actually physically getting rid of the child by killing it or just leaving it to die, whatever.

I think the counselling is partly driven by ignorance, someone with spina bifida still has a lot of movement they can care for themselves once they're ten, eleven years old, like any other child they start doing more things for themselves then, ion that respect they are just like an able bodied person but without the use of their legs.

Int: And indeed many people with spina bifida do walk

Richard: Yes, and if not they learn to adapt.

Int: If you met a woman who had been told the baby she is expecting has spina bifida what would you say?

Richard: I would say keep the baby, try and make the most of it because there are ways round things. Just because a child has a disability it doesn't mean the mother's life ends there, or the father's, or the child's for that matter. There are certain things they can do and they can't do but they learn to live with their limitations and get used to it. They're not very big problems, they are ones you can live with, you just change your life style to suit what you can actually do....I think the money [spent on screening] could be put to a better use on rehabilitation.

Int: Do you see yourself as disabled?

Richard; No I see my self as able bodied as anyone else. I've been given this label "disabled" because I'm in a wheelchair and I've learnt to live with it.

What are your views on becoming a parent?

The views about parenting are very mixed. Angela feels that she is a very motherly person and would love to adopt a child, but would not go through pregnancy and birth because of her condition. Jackie used to want children but looks after her two nieces and said "those two are enough, they come to stay, they're hard work, especially when they're naughty, you have to keep them busy." Richard is only 18, he would like to have children, but isn't too bothered at this time. Vivian is planning to have children now, and Cristel is "very pleased to be a Mum."

What do you think about genetic research and gene therapy?

There were some positive views on genetic research. Cristel is in favour of research about treatment but would prefer more knowledge about prevention, and better training for health staff about caring for people with spina bifida. It was not until her son was born that tests revealed the cause of her back pain. Jackie feels that screening is a good thing and that they "should test for everything". Richard feels that he does not know enough to comment. Angela and Vivian were more dubious about the benefits of genetic research. Vivian said "they should be testing for illnesses like Cancer and AIDS, not for disabilities." Angela isn't convinced of the value or promise of the research, she said "we are all here for a purpose, disabled or not."

The views on gene therapy were far more negative. Angela believes the money could be better spent on practical help and support for people. Richard cannot see it as being much use, however, he thinks that if he was asked to do research he would give it a try it once and then decide whether to continue rather than just dismissing it. When asked about gene therapy, Vivian replied "Uuurgh, perfect people are already here, cosmetic surgery, a load of rubbish." She is angry that any disabled people should be under-valued or their lives thought not worthwhile. Cristel said; "I think it's wrong. You shouldn't alter nature because it might make it worse for people in other ways, you don't know the side effects."

What do you think about prenatal screening or testing?

Three of the five felt that screening was a good idea because even if you are not considering an abortion at all, you can prepare for the child and find out properly about the condition. Cristel said that although she did not agree with abortion herself, she thought that everyone should be given the chance to make an informed decision. Angela said that screening should not be about the possibility of abortion, she believes that "parenting is unconditional", parents should accept their child on any terms, but still thinks that screening is a good idea so that the parents can prepare. Richard thinks the funds for screening could be spent on more useful things like rehabilitation. Vivian said that she wouldn't have screening tests, because she disagrees with abortion: "you can't decide for people who haven't had their lives yet".

Comments

How typical are these five people? They are likely to be unusually confident and outgoing to agree to be interviewed. They talked calmly and openly about personal and potentially painful issues. Some of them raised sensitive topics before the questions were asked about them. This group may be at the more positive end of the spectrum of people with spina bifida. Some have serious disabilities, but it seems that personality and attitudes, as well as health or ability, have a strong impact on quality of life. Whereas typical research, by centring on medical topics may over-emphasise illness, this study centres on social topics and may under-report health problems. We did not try to find a typical group, but have piloted a new more socially-based interview approach which we hope to follow up with a larger group, to see how typical the views of the 40

people in the five groups are. Questions raised by this study, and more details from the interviews, will be discussed in further reports.

Professional and public views of spina bifida are dominated by reports from health staff, who mainly see people with spina bifida when they are ill. Prenatal counsellors may not know anyone with spina bifida, and they can have over-negative views. The interviewees, even if they are unusual, are an important group, because they challenge general assumptions about spina bifida. They give a broader picture which balances the present negative one and could help people who plan, provide and use screening services to have more informed understanding. Apart from their direct answers on prenatal screening, the interviewees give indirect answers. When talking vividly about the quality and value of their lives, they question assumptions in prenatal screening that life with spina bifida is better prevented.

This group suggests that they held back by negative social attitudes rather than lack of medical care. They long to see progress in social attitudes, to overcome prejudices and discrimination. Knowing how hurtful discrimination can be may lead them to be more liberal and non-judgmental, as they would like other people to be. They are all in favour of prospective parents being informed, but want their choices to be properly informed by better understanding of positive sides of living with spina bifida.

Conclusions

Physical impairment is not the same as disability. Everyone valued mobility, achievements, fulfilment and enjoyment in life, and thought that all these are primarily social. These affect quality and value of life as much and more the anatomy. Vital support came from political parents who fight for integration and encourage independence, from accepting unavoidable limitations but also learning to manage and adapt to as active a life as possible, and from friends, and from all the things that encourage confidence. Accessible transport systems and the experience of mixing in society, with appropriate education and employment were all stressed. "They're what all young people need."