Living with a congenital condition: the views of adults who have cystic fibrosis, sickle cell anaemia, Down's syndrome, spina bifida or thalassaemia

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Abstract

Chapter 11 is about `Living with a congenital condition: the views of adults who have cystic fibrosis, Down's syndrome, sickle cell anaemia, spina bifida or thalassaemia'. The chapter reports interviews with 40 adults who have four conditions which are screened for prenatally; screening for cystic fibrosis is also proposed in some areas. The medical model of disability identifies people's problems mainly with their impairments. In this chapter, the medical model is contrasted with the social model, which attributes the problems people experience mainly to disabling social barriers and negative attitudes that unnecessarily exclude them from mainstream society. Examples of tendencies in the medical model and the medical literature towards pessimism about congenital conditions, and the possible influence of these views on prenatal screening policies and counselling are reviewed. The 40 people were interviewed to see whether they fitted with the medical model. This descriptive study used social research methods, with open questions about interviewees' education and employment, relationships, the rewards and problems they experienced, their hopes, and their views about prenatal screening. The aim was to obtain a general impression about their sense of the value and quality of their lives. Qualitative research cannot support general conclusions but it may discover exceptions which challenge general assumptions. In each of the five groups, people narrated how they enjoyed life and achievements, and contributed to their family life and to society, as well as contending with serious problems. They mainly attributed their difficulties to social conditions rather than to their own bodies or minds. Their reported satisfactions and activities did not correlate with the type or severity of their condition. More social research is urgently needed to investigate how typical or exceptional people like these interviewees are, if the influence of medical and social models of disability on prenatal policies and counselling are to be more clearly understood, and if the services are to be evidence based.

Introduction

Prenatal screening is offered increasingly routinely (Lowther and Whittle, 1997). As discussed in other chapters, the intended benefits of prenatal screening are to prevent disability and suffering, and to offer to prospective parents the opportunity of making informed choices if fetal anomalies are detected, including the option of termination of pregnancy (Wald *et al.,* 1998). Screening is calculated to be cost-effective when it helps to reduce the numbers of disabled people who require `life-long costs of care' (Wald et al, 1992) and expensive medical treatments (Cuckle *et al.*, 1995).

Screening policies are influenced by the medical model of disability which identifies disability with the individual's physical or intellectual impairment, and correlates levels of impairment with the quality of life which that person will experience. The aims of this model are to make precise diagnoses and prognoses, and to provide effective cure or relief. These therapeutic aims are inestimably beneficial to people with conditions which can be treated effectively, but they raise problems for people with conditions which cannot be corrected or

alleviated medically.

An alternative is the social model, which identifies disability with the disabling attitudes and barriers that unnecessarily exclude impaired people from mainstream employment and education, transport, buildings and leisure activities (Oliver, 1996; Bailey, 1996; Asch, 2000). This model holds that there is no clear correlation between degrees of impairment and quality of life, because severely impaired people can live very fulfilled lives when they have adequate aids, support and opportunities, and plenty of non-disabled people lead unhappy lives. Precise medical prognoses are seldom possible when people's quality of life and achievements depend so much on numerous unpredictable social factors and opportunities throughout life. Medical intentions to benefit may turn into harms, if ineffective attempts to treat conditions which cannot be cured or alleviated do more harm than good, or if effective treatment is not thought to be worthwhile offering to disabled people (Julian-Reynier *et al.*, 1995). According to the social model, funding diverted into social and political measures to make communities more accessible and welcoming for everyone would do far more to counteract disability than prenatal screening because far more people become impaired through illness, injury and old age than from congenital conditions.

The medical and social models have both been criticised as too extreme, one for exaggerating impairments and their effects, the other for denying these (Crow, 1996; Shakespeare, 1999). There is growing interest in a middle course which is neither morbidly pathological nor unrealistically optimistic, a course which examines how people actually live with a serious condition, and where they position themselves between the medical and social models of disability (Lippman, 1994). Although the views of health professionals and experts, of the general public and prospective parents on prenatal screening have been researched, as shown in this volume, little is known about the views of disabled people themselves.

A small exploratory study was conducted with 40 adults who have either conditions which are screened for prenatally (five each with Down's syndrome or spina bifida), or conditions which are screened for in some areas (ten each sickle cell, thalassaemia, or cystic fibrosis). During in-depth interviews, adults with these conditions talked about the rewards and problems in their lives and about prenatal screening policies. The research was intended to investigate and report their views, in order to expand the information available to people who plan, provide and use screening services. The rest of this chapter reports and discusses the interviews, after a brief section on the related medical literature.

Medical literature on conditions which are screened for prenatally

The extensive literature on the five conditions tends to emphasise difficulty and disability and seldom cites families' more positive experiences (reported, for example, in Goodey, 1991; Alderson and Goodey, 1998; and regularly in the newsletters of the self-help societies for each of the conditions). For example: `Spina bifida occurs in one of 2,000 births and leads to life long and devastating physical disabilities including paraplegia, hydrocephalus, incontinence, sexual dysfunction, skeletal deformities and mental impairment'(Scott *et al.*, 1998). `Including' could imply that all cases with spina bifida have these and other defects. The accurate phrasing would be `may include' because some people with spina bifida do not have these problems. The great advances in the medical care of people with cystic fibrosis, which have resulted in a life expectancy for adults is of 40 years and rising, are not clearly reflected in prenatal screening policies (Cuckle et al., 1995). Low standards of information and support given to couples making prenatal decisions is criticised (Green et al., 1994;

Marteau, 1995) and there are calls to end racist discrimination and to provide universal screening for the haemoglobinopathies which mainly affect ethnic minorities (Atkin *et al.*, 1998). If prenatal services and the counselling and support offered are to be improved and also expanded, they will become more expensive. Then the current cost-benefit calculations in terms of financial savings on disabled lives prevented (Wald *et al.*, 1992; Modell and Kuliev, 1993; Cuckle *et al.*,1995) will have to be revised considerably. The critical research about under-informed prenatal counselling is concerned with practitioners' knowledge about the tests, but seldom reviews knowledge, or lack of it, about the congenital conditions being tested for. The literature also says little about how prenatal prognoses are further complicated by uncertainty about the severity of each case and the unknown future life-style and opportunities of each potential person.

Cost benefit calculations appear to assume that everyone with Down's syndrome leads the limited kind of life described in `natural histories' (Brookes and Albermarle, 1996; Noble, 1998). In these, behavioural difficulties tend to be attributed solely to the syndrome (Taylor, 1997) without considering other possible causes such as unduly low expectations which are unlikely to encourage positive behaviour. Susceptibility to infections and a shorter life span are also emphasised as integral to Down's syndrome. This is in spite of research which finds that these characteristics are influenced by `lack of necessary care' by parents and health professionals, and that `the influence of prenatal diagnosis of chromosome disorders as a determining factor of the social acceptance of Down's syndrome is still questionable' and may partly account for sub-standard health care of affected children (Julian-Reynier *et al.*, 1995). One educational study reported an IQ range from 10 up to 92 (Lorenz, 1984) among people with Down's syndrome, and Noble (1998) found a range up to only 67 but literacy levels of 40% among people with Down's syndrome, even though many of them attend schools where they are not taught to read. Instead of recognising this variety, medical texts tend to refer to Down's as `the commonest form of severe mental retardation', and as `untreatable' (Goodman and Scott, 1997), or they mention Down's only in reference to prenatal screening (Cade *et al.*, 1995).

Generally in this literature, routine use of the terms `patient', `disease' and `suffering' misleadingly imply that with these conditions people are unremittingly ill, and are passive and dependent, and not also possibly contributors. Such assumptions influence the design of standardised questionnaires about quality of life, which enquire mainly into negative aspects of life (Muldroon *et al*., 1998) and offer little scope for people to talk about the possibly rich variety of their activities and relationships. This selectiveness, which serves the well-intentioned purpose of discovering and diagnosing problems that health care professionals might alleviate, can have negative effects when the findings are taken by health professionals and then by the mass media and general public to be comprehensive accounts of life with these conditions. Questions such as `how does your problem affect your life?' may exaggerate the effects of the syndrome by excluding other strong influences such as income or friends.

Bias towards low expectations of disabled people's wellbeing and abilities also affects the methods of research with them. Frequently, parents and carers are questioned, instead of the disabled people themselves, especially if they are children or have learning difficulties. Possible conflicts of views and interests between carers and cared-for people may not be adequately recognised in the analyses. Costs and dependency are liable to be over-estimated when carers emphasise these in interviews with practitioners in order to gain more support and resources for the affected person and the family. Normative surveys are valuable in

measuring needs and planning services but, especially if conducted by practitioners involved in their care (Silverman, 1985), they are liable to make interviewees anxiously try to select "correct" answers to appear normal. Standardised questionnaires and structured interviews with a firm order of closed questions, necessary for most quantitative analysis, limit the responses and so may make respondents appear to be dull and stupid. Researchers may use confusing technical terms or talk down to interviewees, interrupt detailed replies as irrelevant or be too authoritative or pitying - styles which discourage any interviewee. Disabled people who are used to being questioned in this way tend to be cautious (Ward 1997). There are notable exceptions in the medical literature which take greater account of social perspectives. (Santalahti, 1998; Clarke, 1997). Yet for all the above reasons, the texts which influence prenatal counselling may not enable the staff to give balanced, nondirective information about congenital conditions to prospective parents.

Methods

The above literature review was intended partly to explain the methods we chose to use and to avoid, in order to elicit detailed replies about the different kind of life each person lived. We also aimed to respect people's feelings when talking with them about such sensitive topics. In this qualitative research, we did not aim to assess people, or measure frequencies, or produce standardised results. The descriptive study begins to explore and map the individual and shared views of people with a range of disabilities connected to prenatal screening.

The study was approved by the Institute of Education ethics committee. A leaflet, explaining the project, its topics and aims, and interviewees' rights (such as to refuse to take part in the research, to withdraw, and say 'pass' to questions, to have their names changed in our reports to protect anonymity) was sent via intermediaries mainly self-help organisations, to prospective interviewees with an opt-in reply form. The informal networks for contacting the interviewees and respectful opt-in methods prevent us from knowing the response rates, but there were varying responses. Eight of the 30 people with cystic fibrosis contacted by post agreed to take part. Everyone with thalassaemia who was directly asked by a contact in their self-help group agreed, but several attempts to reach people with Down's syndrome through three organisations, a newsletter and other intermediaries eventually found only five people. This may have been more to do with the relative isolation in which they live, or their lack of confidence, or their carers' lack of conviction that it was worth interviewing them, than with their actual ability. Our aim, in using informal networks and respectful opt-in methods, was to stress that these were to be social not clinical interviews, with no pressure to agree to take part.

Informal tape-recorded interviews in people's own homes lasted from 30 to 150 minutes. They chose who else, if anyone, would be present. My first interview was with a young man with cystic fibrosis who showed me into the living room where his girl friend and sister were sitting. I was very worried that the interview would be constrained by their presence, but he seemed to use it as a chance to raise topics with them. When he started to talk about his shorter life expectancy, they told him to stop and he replied that they always said that, and he wanted to talk to them about it, and he continued with this theme. Two men with Down's syndrome were interviewed together in the house where they had lived for 14 years independently with two women who also had learning difficulties. Such background details increase understanding of the interviewees and their responses.

We asked the interviewees open questions about their daily life, encouraging narrative responses, in order to gain an impression of each person's sense of the value and quality of

their life. For terms such as `disease, patient and coping' we substituted the more neutral words `condition, person and experience'. When problems were mentioned, possible social factors such as income or transport were discussed, besides possible physiological factors. Two women (with thalassaemia and spina bifida) became distressed and one wanted to stop talking though later she sent some notes. One man with sickle cell was in such pain that his interview was held over three short sessions because he was so keen to continue. Three people (with Down's) firmly replied 'pass' to some questions, and a few others seemed reluctant to talk at times, so that we moved to other topics. Most people appeared to enjoy their session and said that they did.

Towards the end of most interviews, we said we would like to use all their discussions in our reports but we would have to select and summarise their comments for published papers. We asked interviewees to help us to complete their summary sheet, noting their key responses to each main topic in a few sentences. This worked well, as the previous discussion had helped to clarify their views, and the sheets gave them some editorial control over how we would use their views. The notes and transcripts were analysed by hand, mainly according to the topic headings. Interviewees were sent a short end-of-project report, and reports were also written for four of the newsletters of the self-help organisations through which we had contacted them.

Interviewees' responses

Education and employment

Background details about the interviewees are summarised in table 1. Most of them had attended mainstream schools and all were literate and numerate. Three people with Down's mentioned the names of their schools but not the type. Some single people had lived with partners so that the number who have experienced live-in relationships is higher than the table implies. The cystic fibrosis (CF) group were the most highly educated, five had been to university and two planned to go there, but although most of them felt able to work, several could not find suitable employment.

The woman with Down's had worked in an office for 13 years. People with Down's worked, paid and unpaid, as actors, an artist, a caterer, some taught professionals about real life with Down's, and taught people with learning difficulties about independent living and safe sex. . Employment in all groups covered a wide range: computing, accountancy, administration, teaching, retail, counselling, journalism, sports. For example, a man with spina bifida worked in a sports centre, and was able to haul himself in his wheelchair up and down stairs. He hoped to enter the paralympics and said `I'm not disabled'. When he went clubbing in the city with his friends, he could manage the stairs to the underground trains and found arguing his way past officials who tried to keep him out was the main problem. This small group of people contributed considerably through unpaid work, at home caring for relatives and friends, and as parents, and in the wider community. For example, one woman with spina bifida was `the taxi driver' for her family, and another advised on disability access to famous public buildings. A woman with CF had done voluntary work in Argentina. Three people were writing books, including a novel about the good aspects of CF `because these are never publicised'. One man with Down's ran a small youth club with his brother, and one man with CF gave skilled learning support to disabled people in colleges; he relied on disability benefits to cover his high medication bills, and could not afford to start paid work on a low salary when he would have to pay for his medication. In contrast, one woman with CF had a prestigious job in a leading city company.

Rewards and problems

Quality of life links to their enjoyments, such as seeing friends and family, travel, eating out, cinema, clubbing, music, shopping, charity work, sports, faith in God, 'enjoying nature', reading, writing and painting. While reviewing their past and present they were asked `what did you find most helpful' in your life? To these deliberately open questions, people gave a range of replies and several went on to talk about being inter-dependent in relationships where neither person is much more dependent than the other. Some people with thalassaemia stressed their independence:which stemmed, for example, from 'my stubborn father who would not let me get away with anything'. Others found helpful, 'my wife/ husband/ partner/ friends,' 'knowing I'm not the only one with uncertainties,' 'people who accept me as normal,' 'my car, my mobile phone and my own flat,' 'my positive attitude and knowing it's okay to feel happy or sad.' The woman with Down's who lived partly on her own partly with her boy friend who had diabetes (she laughed saying that his diet was good for both of them) said she managed her housekeeping money 'except for the big things, my sister helps me with them.'

They had very varied hopes and plans. People with Down's would like to become a champion snooker player, a college art teacher, a family man, and the co-director of a play about the 20 year history of his theatre company for people with learning difficulties which performed on television and around Europe. We asked, 'Is there anything you would like to change or improve in your life or yourself?' Some wanted a better job, income and housing, or to find a partner, or have children. Few mentioned their condition, though some spoke of its effects, 'have better lungs', (CF) 'be taller', (thalassaemia) 'have less pain' (sickle cell). In each group, some people described loneliness and depression and others said they were happy as they were. We asked if they would like to change anything about society. Most had clear views. 'Where shall I begin?' 'Tear it down and start again!' They all spoke about injustice and discrimination, from the man with Down's who protested against being pushed about in the street, and who was depressed about having to have to attend a boring day centre when he was not acting, to the woman with spina bifida who said that buildings and buses should be more accessible for wheelchair users like her, to people with sickle cell who found racism, and taunts about being lazy added to their problems when they were too ill to work. Three people with Down's syndrome spoke about wanting more respect for their human rights. The interviewees saw prejudice against their conditions as very hurtful and wasteful, preventing them from living their lives fully. 'There is this sickly child image of CF. If I tell people at parties that I have CF they say, 'Why aren't you dead yet?' `How can we get jobs or mortgages or pensions when people have those attitudes?' People with CF saw a paradox in that medical research had raised their life expectancy to 40 years and over but, in order to raise pubic funds and support, still promoted the `sickly child' images which fed public prejudices that rejected and excluded them, thereby preventing them from living their extra years as fully as they wanted and were able to. They wanted to see a fairer society. The general stress on tolerance and equality provides an important context for understanding their later responses on prenatal choices.

Being or becoming a partner or a parent

We asked for people's views on being or becoming a partner and a parent. Some people said they already enjoyed this, or looked forward to doing so. There was no obvious connection between severity of impairment and the answers on being or becoming a partner. A few

people referred to their condition, such as the woman who said she was unlikely to get married, because 'thalassaemia does rule your life because of other people's attitudes.' A few said they were very sad not to be married, or said they preferred to be independent. The woman who was most restricted by CF spoke of her unhappiness that she was unable to work, or to look forward to being married and having children. She had recently moved back into her parents' home as her health deteriorated, although she still enjoyed going out to pubs and clubs, despite the smoke which everyone with CF found a problem. She was composing, singing and recording music for a CD, and she had a boyfriend who helped her to do her daily physiotherapy. Another young woman was excited to be back at full time work after having a heart-lung transplant. Her husband had insisted on marrying her when she was very ill, and they were enjoying travel and other activities together, made possible by her unexpectedly regained good health. One woman said she had more problems with being gay than with having CF, and she hoped to have a woman partner and two children. The most disabled person interviewed hoped to be a mother, and she discussed how taking folic acid preconceptually complicated her strong sense of identity, 'I'm proud of having spina bifida.' She believed her experience with her condition had greatly increased her compassion and sense of justice. Other people said they considered that their condition 'has made me stronger/more determined/kinder,' `my friends tell me their problems,' and one woman with spina bifida felt that becoming a mother had changed her very much. `Having a baby wisens you up.' Though still close to her partner she preferred to live mainly on her own with her child. Several women said that if they had children, they would need a very supportive partner because of their poor health, and some were concerned about the strain on their health of childbearing and child care, especially if the child had a condition which needed extra care. The interviewees varied from wanting to have children, to saying 'maybe one day,' to not wishing to become parents.

Prenatal screening

The discussions led on to prenatal testing, and our question: 'If you met a woman who has been told the baby she is expecting has (your condition) what would you say to her?' The wide range of replies on screening, information, choice and advice is shown in table 2. The numbers of people supporting each view have not been given, to avoid suggesting a spurious representativeness in our exploratory convenience sample. However, people with Spina bifida or Down's tended to be sad, angry or appalled about terminations of pregnancy for their conditions, whereas the other three groups were more likely to discuss prenatal choices calmly as if they were used to talking about them and accepted that their relatives might want to have tests and terminations. As mentioned earlier, this view may reflect their support for tolerance and respect for individuals and their choices because they had found prejudice so hurtful. Everyone wanted prospective parents to have accurate, realistic information about their condition, and they tended to doubt that this was given. The two men with Down's syndrome who had been describing, very enthusiastically, the plays they helped to create about disability, discrimination, rejection and resilience, when asked `If you met a woman who had been told that the baby she is expecting has Down's syndrome, what would you say to her?' suddenly looked very sad.

> Peter: That is actually what we are doing in this play, for heaven=s sake. [A pause] I=m speechless. The productions we have done are just fantastic. [They look as if their reply is too profound to put into words.] Carry on [to the next question]. Pass.

Interviewer: Yes. You just think it is a completely out-of-order idea? It's not worth talking about, it's so dreadful?
Peter That's, that is what I was thinking of.
Int: Yes, thank you. I am sorry to ask you about these things. The reason is, people around the world are asking doctors, nurses, parents, experts, but they don't ask people with Down's syndrome, and surely you're the people who really know what you're talking about, that your lives are interesting and really worth living and good lives?
Peter and Philip: Yes.
Int: Yes, it's very good of you to talk to me. Was there anything else you wanted to say?
Philip: Well it's just about some of these things, they are too personal, I don't want to talk about them to you or anyone.

After Peter said `pass', as an exception, I carried on a little more with the question, because although their faces were so expressive I felt that their reply would only count as ambiguous silence unless I tried to describe it and give them the chance to agree or disagree with my interpretation.

Discussion

Qualitative research cannot provide conclusive evidence to validate generalisations, but if it discovers exceptions it can question the validity of generalisations and call for their re-evaluation. Even with only a very few examples it can investigate meanings and arrive at deeper understandings of concepts, such as informed prenatal choices, and the nature of the five congenital conditions, showing them to be more complex than is often assumed. The interviewees are not presented as typical, because no one knows what a typical person with one of these conditions might be like. The interviewees may be unusually confident, they almost all talked calmly and openly about potentially painful issues, although our sociological research about their self-reports may under-report their physical problems. In contrast, medical and psychometric research may over-emphasise these, as illustrated earlier and this chapter could be read as redressing the balance a little.

Health care researchers tend assume correlations between satisfaction in life with clinical measures of health, whereas our interviewees seemed to consider that their quality of life was more affected by attitudes, opportunities and social networks. The two most severely disabled people with spina bifida (one, Vivian, sat on the floor shifting her weight frequently because of pain from severe scoliosis) were among the most active, with full time demanding jobs and other interests, as well as a busy social life with their friends. Vivian said, `I'm a great one for socialising. You do feel low and in pain and angry with people, and it is important to have friends and to go out for a drink.' In contrast, another woman who cried during her interview about her loneliness (although she wanted to go on talking) was so slightly affected physically by spina bifida that her work colleagues did not know she was disabled. Others talked about the problems of coping with `invisible disability' such as CF or the haemoglobinopathies and of trying to obtain appropriate support. A few people like Vivian knew about the medical and social models of disability and firmly believed in the social model: that disability is constructed through negative social attitudes and barriers rather than from physical or intellectual impairments. In most interviews, the two models were not mentioned, but nearly everyone talked about experiencing social problems (with income, employment, housing,

transport, relationships, discrimination, problems getting pensions or mortgages and paying prescription bills, and problems experienced by people they cared for) more than about problems arising from their own body or mind, despite opportunities to talk about these if they wished. They often pointed out the difference between social and bodily influences, like the woman who said, ‘CF doesn't do any good, but people with CF do.‘

‘Is your life worthwhile, valuable?’ `Would you rather not have been born?’ These are inappropriate questions to ask directly, but they can be approached indirectly through questions about the aspects of life people most value or find hardest. Our descriptive interviews showed how at least some people with these conditions, including some who were severely affected, were active, competent and enjoyed many aspects of their lives. More social research is urgently needed to investigate how typical or exceptional people like our interviewees are, if the influence of medical and social models of disability on prenatal policies and counselling are to be more clearly understood and if the services are to be evidence based.

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Table 1. The 40 interviewees

Conditions	thal	CF	sickle cell	spina bifida	Down's
Interviewees	10	10	10	5	5
men	5	2	6	1	4
women	5	8	4	4	1
age range	26-39	17-30	21-33	18-33	20-43
median age	33	24	29	26	30
mainstream school	10	9.5	9	4.5	2?
special school	-	.5	-	.5	?
done college/ courses	6	4	8	3	5
university	4	5(7)	2	1	-
live with parents	6	3	4	3	2
with friend(s)	-	4	1	-	2
with partner	1	2	2	.5	.5
have children	1	1	3	1	-
live on own	3	1	3	1.5	.5
have done paid work	10	9	7	4	3
now do paid work	9	4	5	4	-
student	-	2	1	2	2

Table 2. Interviewees' views on prenatal screening, information and choice

Screening

* Screening should be compulsory.
* Screening should be offered to everyone.
" Screening is good in one way but in another it's not good because sometimes it makes us think for the worst but in the end it turns out for the best.
* It's too expensive and wasteful to screen everyone - and would anyone have babies?
* Prenatal tests should only be offered to individual people who ask for them if they might be carriers.
* There should not be any prenatal screening or tests.

Information

* The more information the better.
* Most people do not know enough about these conditions to decide what to do about screening results, and nor do most prenatal counsellors and doctors.
* Information about our conditions is too negative and biased.

Choice and advice

* I wouldn't put anyone through what I'm going through, but I'd give people the advantages and disadvantages of everything.
* I would draw the line at severe mental handicaps.
* I agree with abortion for some diseases, but not for my condition.
* I'm angry that abortion is advised for CF or Down's, but I respect everyone's right to choose.
* I wouldn’t advise anyone.
* I'd go ahead and take the risk of having the baby whatever it had, you don't know how bad it will be.
* Screening is good when it helps people to prepare, if their baby will be disabled. They can learn more, and feel they have chosen the baby and that it has not been forced on to them.

* I disagree with abortion for any reason.
* 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.
* I would advise them to have the child.
* It's quite easy [I would advise] everything, you know, the baby, it's a human being, feed it, look after it, give it lots of love, everything.

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