

Priscilla Alderson 2001 **Some unanswered questions**, Ward L (ed) *Considered choices? The new genetics, prenatal testing and people with learning difficulties*. Kidderminster: British Institute of Learning Disabilities, pages 63-71. ISBN: 1902519620.

Prenatal screening raises many questions. This paper is about questions which have few answers, or which are hardly ever asked. I hope that the paper is clear enough to be useful to a wide range of people

Why do we have prenatal screening?

Prenatal screening costs a lot of money. It does not save lives or treat illness. Could we be doing better things with this money? Yet instead of asking **why** do we have prenatal screening, people usually talk about **how** can we do it better. Some important research looks at how anxious women become when they are screened (1,2). This work raises such questions as “If screening makes some people so anxious, is it worth doing?” Or at least it asks, “How can we help people to be less anxious?” The work is fairly unusual, in raising critical questions about screening. Yet in an odd way, it implies that of course we must have screening **because** women are very anxious. There must therefore be a very serious danger which they are anxious about and which screening is meant to rescue them from. It is assumed we need to have screening to help people to cope with the dangers they are so anxious about. Before looking at the reasons for anxiety, the next question looks at what anxiety means.

What is anxiety?

The anxiety is hardly ever explained. It is called “distress”, “clinical anxiety” or “need for emotional support”. Doctors and nurses tend to see anxiety as a dis-ease which they ought to treat, with reassurance, or support, or by removing the problem. Medicine, psychology, law and ethics all tend to split thinking from feeling, and to see feelings like anxiety as purely feeling. We talk about “feeling anxious” but not about “thinking anxious”. Yet no one can think without feeling or feel without thinking. Anxiety is partly thinking. You cannot simply “be anxious”, you can only be anxious **about** something. If anxiety is seen as a vague feeling, an uncomfortable state, then if someone is worried, you might try to help them by cheering them up. So one aim of the screening staff is to say: “Your baby is all right, you don’t need to worry.” Another aim is to try to get rid of uncomfortable feelings. So if the staff say, “Your baby is not all right,” they add, “So would you rather not have it?” - and then you can feel all right again.

Anxiety, which was often started by the screening in the first place, becomes the main problem. Suppose a test shows that the baby has Down’s syndrome. Then screening staff say, “If you are worried, then we can get rid of your anxiety by getting rid of the fetus, of both the problems hidden inside you. But if you are not worried about having the baby, that is all right, we don’t need to do anything”. (Not doing anything means going through pregnancy and birth and bringing up the child.)

What are screened women anxious about?

Some women worry that they might have a late abortion, what will it be like? Some worry that they cannot understand all the medical details, or that they will not be able to make the “right decision”, or that they might have rows with their family about what they ought to do. Many women are horrified about having to decide whether to get rid of a baby they want to have, the most serious life-death decisions they are ever likely to make. But the more serious these worries are, and the more unhappy a woman is about deciding on an abortion, then the two main reasons

behind these worries are felt to be even more awful.

One main reason is that women fear that having a child with learning difficulties will mean endless hard work, sadness and no fun. It will be a burden for the whole family. The other main reason (and I am guessing here) is so awful that hardly anyone talks about it, but (I think) it is fear of carrying and giving birth to a monster. A baby too unlike you to feel like your own child. An alien that you will never be able to talk and laugh with. Someone who looks so different that other people will point and stare, nothing like the pretty little babies in Mothercare books.

One reason for thinking that screening staff as well as many pregnant women are scared of monster myths is the changing number of babies born with cleft lip and with talipes. Cleft lip involves a gap in the skin between the mouth and nose. After some operations this can hardly be noticed. With talipes, one or both feet are turned in. This too can be treated with surgery if it is severe enough, and it doesn't look ugly despite the awful name "clubfoot". Yet many fewer babies (per total births) are now born in the UK with these minor problems. From 1982/3 to 1992, the birthrate figures fell steadily to about half the number of babies with cleft lip (from 820 to 464), and to about one third of the number with talipes (from 2,041 to 747).(3)

Why were so many fewer babies born? It might be that screening staff suggest considering abortion when they see these conditions on the scanning screen. But these conditions need not involve any serious difficulties except ignorant fear about them. So how much "non-directive prenatal counselling" is based on incorrect views about disability, on fantasies rather than facts?

Why is there this fear about aliens?

It is easier to be afraid of someone you have never met. Armies fight wars with people they do not know and can therefore see as very different and dangerous. The fetus is unseen and meeting a newborn baby, seeing and holding her, is quite unlike seeing a scan of a fetus with dark holes among the wriggling lines. When many disabled children go to special schools and grow up to be unemployed adults, most other people do not know disabled people, or have the chance to live and learn with them as friends. Doctors add to the fear of the unknown, the alien and monster myths when they casually talk of "serious risk, fear, suffering, danger of handicap, abnormal, faulty, negative genes, and even worse problems..."

Medical textbooks and research about prenatal screening can increase ignorance and prejudice. One survey asked screening professionals if they agreed with abortion for certain conditions. It explained that a child with spina bifida "will be unable to walk" (many can, and others can perfectly easily use wheel chairs), and that cystic fibrosis involves "an early death". Many people with CF live into their 30s and now their 40s; how early is an early death? People with Down's, the survey said, "could communicate but are unable to live alone". Quite a few people with Down's live on their own, but is anyone able to "live alone"? We all depend on one another.

Most people, including doctors, nurses and other screening staff, know very little about disabilities unless they happen to know a disabled person well. Medical books tend to give out of date information, based on people who lived for years in subnormality hospitals. The books confuse the effects of a lonely very boring life with the effects of having a learning difficulty. They hardly ever report how some people with Down's syndrome now take GCSE exams, are employed, or travel across the world to take part in the paralympics. Screening tests cannot tell how severe the condition might be or might become, and can say nothing about the kind of future

life the person might live, or about changes in society. So that prenatal screening tests can be as vague as reading tea leaves. The fear about aliens grows when disabled people are treated as if they are separate and different, and it disappears when disabled people are treated as ordinary members of society.

How could pregnant women get better information?

One idea is that they can visit a family with a child who has the same condition that their fetus has. Yet this falsely separates the condition from all other aspects of the life of the child and the whole family. Imagine that red hair is thought to be a big problem and a woman expecting a baby due to have red hair visits a family with a small boy with red hair. Suppose he has just kicked his football through the kitchen window and the woman arrives in the middle of a row about this. The boy's parents might try to hide their anger, or say that yes, their son demands a lot of hard work and patience, but maybe it is worth it - on the whole - and there are some good times.

How can any parents sum up their feelings about their child and "advise" when they know that every family is so different. Something which is a dreadful crisis in one household, is a laugh in another, or hardly noticed in a third. The idea of needing to visit to "find out how a family manages to live with a condition" falsely emphasises doubt or dread about the condition, and suggests that it can be separated from the person and family concerned and generalised to another family.

Many disabled people argue that people generally will only become well informed about disabilities when they live alongside disabled people in all aspects of daily life. They will then know them as very varied and in many ways very able individuals. Prenatal screening programmes, however, work against inclusion policies because their purpose is to offer the "choice" to expectant parents to exclude and reject an affected fetus. The programmes are built on negative assumptions about disability which make it impossible for the staff to be "nondirective".

What kinds of lives do people with inherited conditions actually live?

Life style depends much more on money and policies than on genes. If you can't walk, you can still have a busy social life if you have good transport. By 2,002, all the taxis in Bristol will have to be able to take wheel chair users. Things are changing quickly. Many more children with learning difficulties go to mainstream schools, and show how capable they can be. Yet, as I said earlier, there is much more publicity about disabled people's limits than about their achievements. And even when successes are published, these are usually in a "triumph or tragedy" format (4) which implies that it is hard and unusual to succeed if you are disabled. "Isn't it amazing that Tim has learning difficulties but he can win a gold medal!" We need much more research and publicity about the many positive sides of disabled people's lives.

How can research provide more information about life with learning difficulties?

Most research so far concentrates on the difficulties. Doctors and psychologists measure physical and mental problems. They interview parents and concentrate on their worries. Societies like Mencap, Scope, and ones for autism or fragile X, as their newsletters show, sponsor and report research which also tends to concentrate on problems and special needs. They emphasise the inherited condition as the central aspect of life, and work to raise funds for research to cure or relieve the condition. Many of the societies belong to the Genetic Interest Group which, as its

name shows, sees genes and biology as the key factors.

Another view is to see social conditions like transport, school, income and work as having more important effects than genetic ones. Some families join social or sports groups rather than disability groups. Many say they do not see their child as different or disabled or as having special needs.(5) Although professionals sometimes describe this as “denial”, it can be seen as the opposite, as acceptance and affirmation of all the ordinary aspects of life which their child can enjoy. Very few researchers interview people who have inherited conditions, although their views may differ from those of their parents who are assumed to speak for them.

The questions in our present research

The European Commission has sponsored a project in Finland, England, Greece and Holland on Prenatal Screening: Past, Present and Future, 1996-1999. We are asking doctors, nurses, experts, pregnant women and the general public for their views. As the most multiracial society involved, England is also having a “family survey”. We are interviewing 50 people aged between 16 and 35, 10 in each group of people who have Down’s syndrome, sickle cell, Thalassaemia, spina bifida or cystic fibrosis.

Prenatal screening is based on the view that the value and quality of life of people with these conditions may not be worthwhile. What do the people concerned think? The interviews look at their views about the value and quality of their own life, what they enjoy and find difficult, what are their aims and hopes, are there any aspects of their life they might like to change? What do they feel about being or becoming partners or parents themselves? The later questions ask for their views about screening and prenatal decisions. If they met someone who was expecting a baby with their condition, like Down’s syndrome, what might they say to her?

Some of these questions could be upsetting and painful. Should we ask them? If we do not, the ignorance about the views of the most affected people will continue. The silence will imply that they cannot cope with the questions, or even that they do not have any answers of their own. If someone does get upset, at least this will mean that they understand, and if so this could mean that they would like to talk even if it is upsetting. So far, nearly everyone in the study has said that they felt all right talking about these questions, some said they welcomed the chance to do so.

How is this research unusual?

- * Most research with people with learning difficulties sees them as patients or dependent in some way. This research sees them as people in their own right who contribute to society, and is about their views about their life.
- * We aim to work with them as partners, only tape recording if they agree, and only talking about topics they are happy to talk about. At the end of the session, we fill in a summary sheet with them, in their own words, to use in short reports.
- * A lot is known about doctors’ and nurses’ views and quite a lot about parents’, but very little about the young people’s own views.
- * Interviews with young people with spina bifida some years ago found that many were very unhappy and would rather not have lived. But the study did not take account of how their lives were made harder by education, social and medical policies at that time.
- * Emphasis on genes and the “blue-print for life” tends to stereotype disabled groups and emphasise potential problems and costs. Our research aims to redress the balance, by showing the

great variety and the happy aspects of their lives as well.

* Talk about choice in prenatal screening respects the rights of future parents and of able people. If the choice is to be informed, far more needs to be known about life with an inherited condition and the views of the people most directly concerned. One woman with Down's syndrome talked about attempts to exclude her, and the interviewer said, "So you had a row about it?" She answered, "No, not a row, a fight, a fight for my rights".

* The planners need to know more about the views of the people they want to help, if they are to plan useful health and screening services. From 1998, our work will be reported to planners, health staff, the general public and to people with the inherited conditions, to help everyone to be able to make more informed prenatal decisions.

References

- 1) Marteau, T., (1989) Psychological costs of screening. *British Medical Journal*, 299:527.
- 2) Green, J., & Statham, H. (1996) Psychological aspects of prenatal screening and diagnosis. In: Marteau, T., & Richards, M. (eds) *The troubled helix: social and psychological implications of the new human genetics*. Cambridge: Cambridge University Press.
- 3) Office of Population Censuses and Surveys. In: Department of Health. Health and personal social services statistics for England 1994 edition. London: HMSO, 1994, table 4.3, p24.
- 4) Oliver, M. (1990) *The politics of disablement*. Basingstoke: Macmillan.
- 5) Alderson, P., & Goodey, C. (in press) *Enabling education: disabled pupils' views about schools*. London: Institute of Education.