Day for Life 2006

baby which tests positive for Down's syndrome, are by no means infallible.

Initial checks involve a scan of the baby's neck in a nuchal fold test, and blood tests on the mother to establish the risk of a Down's pregnancy: those mothers diagnosed with a higher than 1 in 250 chance are then offered amniocentesis where fluid is drawn from the womb with a fine needle.

But the amniocentesis itself carries a one per cent risk of miscarriage, and five per cent of high risk women test 'false positive' and may then find themselves pressured into aborting perfectly healthy babies.

Babies born with Down's have an extra chromosome which is associated with learning difficulties, heart problems and a susceptibility to leukaemia.

But the advances in prenatal screening have not been matched with an updating in the minds of medical professionals about what life will actually be like for a disabled child.

As a result parents are frequently misinformed by health professionals about the degree to which their children may be handicapped, and, if they choose to go ahead with their pregnancy, unsupported afterwards.

According to a newly released survey by the DSA:

- 37% of parents who found out at birth that their child has Down's syndrome were given no written information about the condition
- 40% were given no practical support such as the details of a local parent support group
- 22% of the parents who decided to go ahead with the pregnancy despite knowing their baby had Down's syndrome felt that their decision had not been supported by health professionals
- Two thirds of parents were given their test results over the phone, many of them on their own and some when they were at work.

Parents also reported that many health professionals had outdated or prejudiced views about people with Down's syndrome, and felt they had been pushed towards termination or adoption when they received a positive diagnosis.

Johanne Walters, one of the mums who responded to the DSA survey, said:

"The phone rang and I was told that my baby had Down's syndrome. I was immediately offered a termination and 'genetic counselling'."

Attitudes

At that point Johanne, who had already researched the condition on the internet, "knew the science behind the condition" and felt that what she really needed was "balanced, thoughtful advice".

"Unfortunately this was not forthcoming and I felt that I was being led towards the termination option. All the information that doctors gave me was negative and seemed to question why anybody in their right mind would have a child with special needs."

Carol Boys, the chief executive of the DSA, deplored the report's findings.

"Although attitudes and procedures have undoubtedly improved over the years, it is shocking to hear that so many parents are still not receiving the support and information that they require from health professionals.

"It is vital that parents are given the diagnosis in a sensitive and decent way, and also provided with a balanced and informed view to enable them to make a decision on the future that is right for them."

Dr Helen Watt of the Linacre Centre for Healthcare Ethics agrees.

"It is deeply sad and alarming that so many women are being induced to abort children with Down's and other disabilities.

"Abortion is a very damaging experience for the woman, which goes directly counter to the basic human instinct to protect and nurture one's child. No disability can justify the deliberate killing of an innocent baby; disabled children have a right to live their lives, no less than any other human being."

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