



Left holding the baby **By Debbie Andalo and Alison Benjamin**

Discriminatory attitudes mean people with learning disabilities get a raw deal at the hands of the NHS, says a new report.

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Frances Affleck worried that if she ever became a parent, there was no guarantee that the doctor would have the skills or the patience to explain to her clearly how her baby was developing and what to do if it had colic or a common cold. Affleck, 29, knew the NHS had neither the time nor the skills to help adults who, like her, are diagnosed with learning disabilities.

But now she hopes new parents will be able to help themselves with the publication of her book, *You and Your Baby 0-1*, which will steer parents through the first year of their baby's life. Using pictures with simple words, there is advice about common baby health problems, child development and how to breast feed, as well as pictures which help explain the roles of different health professionals.

Affleck, who is a project worker for the disability rights organisation Change, says: "This is the book I would want to read if I ever had a baby. If parents with learning disabilities don't have access to health information like this, they feel frustrated and upset."

The book, funded by the Department for Education and Skills, is due to be published next month. At the same time, Change is producing a "health picture bank" CD aimed at health professionals that includes 500 pictures they can use to help explain clinical issues to patients with learning disabilities.

Philipa Bragman, Change director, says: "We are trying to provide the tools to make the health service more accessible to people with learning difficulties. The pictures tell the story, and because they have been compiled by people who have learning disabilities, they should be able to get over a sense of what is going on."

The exclusion that people with learning difficulties feel from the health service is highlighted this week by disability charity Mencap, which commissioned a survey that showed 70% of GP surgeries have no information that those with learning disabilities can easily understand. Moreover, 75% of family doctors

say they have received no training to help them treat people with a learning disability, and 80% thought the Department of Health should provide medical students and practitioners with more training. Nine in 10 admitted a patient's learning disability had made it more difficult to give a diagnosis.

A GP with a list of 2,000 patients is estimated to have about 40 patients with a learning disability, of which about eight will have severe problems. Epilepsy, dementia, schizophrenia, and thyroid problems are some of the medical conditions that people with a learning disability are more at risk from than the rest of the population.

The survey of 215 GPs is contained in a report by Mencap that highlights how assumptions and value judgments made by healthcare professionals are a barrier to people with learning disabilities receiving a correct diagnosis and accessing appropriate care. Hospital practice fares as badly as primary care. While hospitals have a statutory duty to care for all patients, the report, *Treat Me Right!*, raises concerns about how negative or discriminatory attitudes and poor communication skills among healthcare staff can contribute to people with learning disabilities being much more likely to die before the age of 50 - often from respiratory problems or coronary heart disease.

Katherine was only 30 when she went into hospital suffering from chest problems. When she was put on an intravenous drip, the hospital staff forgot to include her epilepsy medication in the drip feed. As a result, she had a violent and prolonged fit and died.

Max, was 30 when he fell and broke his hip. What should have been a routine operation resulted in his death a few weeks later because no one noticed he had developed a kidney problem and become malnourished.

"We were really shocked by the number of premature deaths we uncovered," says David Congdon, Mencap's head of external relations. "While everyone understands that anyone can get cancer or have a major heart attack, people like Max should never have died. There are many stories of parents feeling obliged to stay with their child in hospital because of fears that they will be neglected or denied treatment. When something goes wrong we don't know if it's because of poor care that anyone could have received, or if it is discriminatory. We have suspicions but it is very difficult to prove."

In 2001, a report published into allegations made against the Royal Brompton and Harefield Hospitals, that children were refused heart surgery because they had Down's syndrome, upheld claims that doctors had failed to provide a "balanced view" of the treatment options available.

The Mencap report calls on government to set up a confidential inquiry into mortality among people with learning difficulties. "It is the only way to discover whether there is a systemic problem in the service," says Congdon. "It would also answer questions such as 'how many people a year with a learning disability die prematurely?' No figures exist." The report recommends that the government should fund GPs to carry out voluntary annual health checks for people with a learning disability, so that signs and symptoms of ill health can be diagnosed earlier.

The Department of Health did recognise in its learning disability white paper, Valuing People, 2001, that the quality of healthcare was "too variable". It points to good practice guidance issued in July 2002 on two key elements of its strategy to improve the health of people with learning disabilities: health action plans and health facilitation.

Later this year, it expects to bring forward proposals to offer disabled people the option of an annual health check, but has no plans to launch a confidential inquiry into premature deaths. "At present we aim to use funds to concentrate on health action planning and other related activity, that will help to bring better health to people with learning disabilities in the short term," says a DoH spokeswoman.

Earlier this month, it also set up a disability access working group, with the Disability Rights Commission, to develop initiatives to improve access to information and services for people with any disability, as well as raising awareness of disability issues among healthcare professionals.

But Mencap accuses the government of "ducking the issue". "They'll only get to the root of the problem by investigating if there is a systemic problem," says Congdon. "Mencap will have no option but to back parents of children with a learning disability who want to take individual legal action when they suspect there has been discrimination in the health service."

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