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Down's children received "less favourable" hospital treatment

Zosia Kmietowicz *London*

An inquiry into the way children with heart defects were treated at two "centres of excellence" in England has blamed poor communication between doctors and families and lack of resources for dissatisfaction among parents.

Doctors at the Royal Brompton Hospital in London and the Harefield Hospital in Middlesex failed to put patients first and offered parents a biased view of only some of the treatment options available for children with Down's syndrome, according to the independent inquiry panel's report.

Although it stopped short of accusing doctors of discrimination, the report stated that "children were less favoured in accessing treatment because of their Down's syndrome."

The inquiry was commissioned by the hospitals 18 months ago after parents whose children had been treated at the hospitals between 1987 and 1999 complained that the results after surgery were worse than elsewhere. An earlier review, however, had found no evidence that this was the case.

Ruth Evans, chairwoman of the inquiry's panel, described the process of collecting evidence from 49 parents, many of whose children died or were neurologically damaged as a result of surgery, as "extremely harrowing."

The report clears doctors of any negligence, however, although many are criticised for

poor communication and worrying about whether parents would be able to look after a child rather than whether surgery would be beneficial.

Among its 119 recommendations the report advises that, in future, consultations between doctors and parents should be taped so that parents can listen to them at home. In addition, parents should be given advice on seeking a second opinion if they wish.

The report also calls for a national service framework for paediatric cardiac services to be introduced within the next 12 months to set out standards of what parents should expect.

The report was welcomed by Sir Philip Otton, chairman of the Royal Brompton and Harefield NHS Trust. "We accept and intend to implement in full those of the inquiry team's recommendations which are within the trust's area of responsibility and have today set out a plan of how we will do so," he said.

Jeremy Rutter from the Down's Syndrome Association said that parents who complained about the service had been "absolutely vindicated." He said that they had to "fight hard to get the treatment for parents of the future."

However, Josephine Ocloo, chairwoman of the Brompton and Harefield Heart Children Action Group, whose daughter died while under the care of the Brompton Hospital in 1996 at the age of 17, called the inquiry a



A baby with Down's syndrome receives physiotherapy. Two London hospitals were criticised for their handling of children with Down's

"sham and a cover up."

She criticised the report for failing to demonstrate medical negligence among doctors despite plenty of evidence of poor clinical practice.

"As parents, we have been lied to and tricked into participating in this inquiry, which bypasses our concerns almost entirely. We believe the inquiry singularly failed to penetrate the secretive and unaccountable world of medical decision making or to identify processes of concealment which are triggered in hospitals whenever families demand answers," said Ms Ocloo. "Once again the rights of patients and their families have been fundamentally ignored. After 18 months we still do not know why our children died or why they were brain damaged. We want to know who was accountable."

The action group called for the resignation of Mark Taylor, chief executive of the Royal Brompton and Harefield Trust, and asked that another independent inquiry be commissioned—this time by the secretary of state for health. Ms Ocloo also pleaded for the disappearance of medical records to be made a criminal offence.

"How do families ever go on to get answers if medical records go missing. Why is it that there was such a systematic pattern with all of our families of crucial missing records? You cannot get justice by bringing a legal case if you don't have medical records," she said. □

The Report of the Independent Inquiries into Paediatric Cardiac Services and the trust's implementation plan are available at www.rbh.nthames.nhs.uk

Key findings of the inquiry

- The Royal Brompton Hospital and the Harefield Hospital had failed (a) to provide adequate support for parents, many of whom had new babies; (b) to communicate effectively with parents at all stages of the treatment process; and (c) to encourage partnership in care
- Some doctors at the Royal Brompton Hospital had failed to provide a balanced view of all treatment options available for children with Down's syndrome and congenital heart disease in the early 1990s
- Successive governments had not adequately funded the care and treatment of children who experience serious neurological injury as a result of cardiac surgery
- The Department of Health had also failed to provide adequate funding and resources for the development of paediatric cardiac services at Harefield Hospital