Strengthening open disclosure in maternity services in the English NHS: the DISCERN realist evaluation study

Mary Adams,[1*] Natalie Sanford,[2] Charlotte Bevan,[3] Maria Booker,[4] Julie Hartley,[1,3] Alexander Heazell,[5] Elsa Montgomery,[2] Maureen Treadwell[6] and Jane Sandall[1]

[1]Department of Women and Children's Health, School of Life Course and Population Sciences, King's College London, London, UK
[2]The Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, UK
[3]The Stillbirth and Neonatal Death Charity (SANDS), London, UK
[4]BirthRights, London, UK
[5]School of Medical Sciences, University of Manchester, Manchester, UK
[6]The Birth Trauma Association, Derbyshire, UK

[*]Corresponding author Mary.Adams@kcl.ac.uk

Disclaimer: This report contains transcripts of interviews conducted during research that contain language that some readers may find offensive and contains descriptions of events that some readers may find distressing.

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Plain language summary

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Plain language summary

This study describes the experiences of families and healthcare professionals involved in incidents in NHS maternity care. The incidents caused harm-like injury or death to the baby or woman. We wanted to know whether services involved families in investigations and reviews and how this was done, what worked well, what did not work well and why.

To do this, we first looked at what had already been written about 'open disclosure' or OD. Open disclosure is when the NHS admits to families that the care they provided has directly caused harm. After open disclosure occurs, families should be involved in making sure that the NHS learns so it can deliver better care for families in the future. In our reading, we found that families want a meaningful apology, to be involved in reviews or investigations, to know what happened to their loved one, to be cared for by knowledgeable doctors and midwives who are supported in providing open disclosure and to know things have changed because of what happened. Recommendations for involving families in open disclosure have improved, but there is still work to be done to make sure families are involved.

Next, we talked to over 100 healthcare professionals involved in government policy for open disclosure in maternity services and 27 families who experienced harm. We spent 9 months observing the work of clinicians at three maternity services to watch open disclosure. We shared early findings with families, doctors, midwives and managers, and included their views. We found that services need to provide dedicated time, education and emotional support for staff who provide open disclosure. Services need to ensure that families have ongoing support and better communication about incidents. Finally, families must be involved in the review process if they want to be with their experiences reflected in reports and kept informed of ongoing improvements.

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