

That's all we wanted – to be heard, listened to, validated and believed

## Family Experiences of Advocacy Support in Maternity & Neonatal Services

### Authors:

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### What we already knew

Following serious failings in maternity and neonatal care the independent Ockenden Review of maternity services (2022) recommended the creation of Maternity and Neonatal Independent Senior Advocates (MNISAs) as an Immediate and Essential Action.

The MNISA role was piloted at 16 Integrated Care Boards (ICBs) in England between 2023 and 2025 with the aim of making sure bereaved and harmed families felt listened to and supported, and that their experiences lead to learning and improvement. To understand families' experiences of the MNISA service, we conducted research as part of a mixed-methods evaluation led by the NIHR Rapid Service Evaluation Team (RSET), in partnership with Sands, between October 2024 and June 2025.

### What we did

We spoke to 34 bereaved and harmed parents and families to find out what they thought about the service.

These conversations were analysed using Rapid Assessment Procedure (RAP) sheets and inductive thematic analysis. We looked for common themes in what families told us about their experiences.

### What we found

We found that families overwhelmingly valued the support provided by the MNISAs such as:

- Explaining hospital investigation purposes and timelines
- Helping families prepare information for meetings with the hospital
- Documenting discussions with hospitals
- Explaining medical language especially for families where English is a second language

### Impact and next steps






This research aligns with UK government priorities to place family voices at the centre of maternity and neonatal care, as reflected in recent policy commitments following national reviews. The findings suggest that MNISAs helped families have a meaningful voice in mortality reviews and hospital investigations. By helping families navigate hospital systems and understand medical terminology, advocates enabled more effective participation in these processes during an incredibly difficult time. The research also highlights an urgent gap in hospital-led support – whether due to limited resources or families' lack of trust in the hospital – underscoring the need for an advocacy service that works for parent.



This is all an absolute minefield for anyone to understand that's not involved in healthcare. We don't know what we don't know - what's meant to be happening from start to finish and all of the middle. [Our MNISA's] been able to be that person to explain information in a way that we understand, to know the correct questions to ask of the right people so that we're getting the answers that we want.

Mother whose baby died in the neonatal period, INT22

MNISAs were referred to as the "golden thread" in a fragmented system. MNISA support:

-  Reduced emotional overwhelm
-  Allowed families to focus on grieving
-  Reduced guilt about not advocating enough
-  Kept families engaged with hospital investigations
-  Made families feel listened to and believed








Families stated they valued the MNISAs independence, which differentiated them from other hospital staff.



Although bereavement midwives are there, they're still very much associated with the hospital. They're still protecting the reputation of that hospital, whereas with the advocate I was able to have open, honest, transparent conversations with her.

Mother who was admitted to intensive care and whose baby was stillborn, INT30

For many families, working with their MNISA was the first time they truly felt listened to. MNISAs

-  Took their concerns seriously
-  Ensured family voices were heard at Trust and regional level
-  Helped families influence change at local level
-  Made sure concerns were addressed within hospital reviews
-  Escalated issues to the appropriate senior leaders
-  Connected families with decision-makers they could not otherwise access
-  Held services accountable on families' behalf

### Conclusions

Families overwhelmingly felt that MNISAs ensured their voices were heard by the right people, and that the service supported them to influence meaningful change and service improvements. Families highlighted that MNISAs filled a critical gap in helping them understand their care and navigate investigations. Every family believed the service should continue – and those who had not received MNISA support said they wished they had received MNISA support.

...because people that are going to become me and my partner in the days, years to come; if they don't have an advocate and they've been treated as we feel we've been treated, then there is serious trouble, very serious, mental, physical, I honestly don't know how they'd do it.

Father whose baby died in the neonatal period, INT27