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## How can families beat the center in all components of health systems change for small and sick newborn care

<https://dx.doi.org/10.4314/jan.v3i4.13>

Received: 14th September 2025

Accepted: 14th September 2025

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*How can families beat the center in all components of health systems change for Small and Sick Newborn Care:*

As the parent of a premature child, who was thrust into a world where I knew nothing about it, the greatest gift I was given was that offi-Care.

You see, I had my preemie almost 8yearsago,andback then already, our neonatal team understood the importance of having us, the parents, at the centre of our child's care. They knew something (that at that time I did not), that even with the greatest doctors and technology, nothing can truly replace the bond that is shared through parents and their children, and more importantly the long-term positive out comes this provides.

I saw how being beside our child, daily, form any hours, how taking on the role of his caregivers and not being treated as visitors, propelled his growth and healing.

We were taught how to take care of our small, medically fragile child and it built upour confidence for when we were finally discharged. You see, what needs to be remembered is that (hopefully) at the end of the day, these babies get discharged home and back into communities. For our family, that day came sooner than expected, and whole heartedly believe it was due to FiCare.

Not only is the parental involvement crucial, (in all aspects of care), but so is receiving appropriate education (and some time straining) on their child's condition. The saying "knowledge is power" is there for a reason. This way parents are able to make informed decisions. The problem with this in the LMIC's setting is that facilities are usually at, or, over capacity and staff is over worked and therefore simply do not have the time or man power to take the time to explain in depth, and in layman's terms.

Post discharge is, (from my experience) where the issues tend to arise. Parents have left the safety net of the hospital and staff who were providing evidence based knowledge, and are now

left to their own devices. If they have received adequate training and support in hospital, then taking a stand fort he small, sick newborn outside of hospital is easier. However, our high mortality rate post discharge is happening because we are discharging small, sick newborns in to communities that do not know anything about small, sick newborns, and parents are therefore being influenced based on people's opinions in relation to full term newborns and not small, sick newborns. Awareness and involvement need to be extended beyond the NICU(1) Keeping track of these small newborns and their health outcomes (not only for the first 2years in life), but beyond is crucial for us to understand in depth the effect of being born too soon. Too often I have seen that parents end their follow-up appointments before 12 months. (unless the baby has been earlier diagnosed with having any issues). This is where data systems and QI is so important and needs to extend beyond NICU. (2)

It is so important and that all woman have easy access to antenatal and post natal care. We need to from schoollevelalreadybestressingtheimportanceofearlyantenatalcarebecausethisisthefirststepi n becoming aware of any issues that may arise or have arisen in the pregnancy, how to monitor them effectively and ensuring a safe delivery for both mother andbaby(3)



Again this is most effective through multi disciplinary collaboration and community engagement (4) Leadership and Governance:

I think that effective leadership and governance is at the top of the priority list when it comes to ensuring effective change that includes incorporating care-givers at into every aspect of their newborn care. If the top is in good working order, that trickles down into all aspects of care(5)

I feel like over the past decade Maternal and Newborn Health Care is on the right path and the best thing that could've been

done was to include community and stake holder engagement (4). The more

we engage and include parents (as these are the people directly impacted by having small and sick newborns) the better our outcomes for the babies to survive and thrive.



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