



Care Coordination Programs for Infants with Complex Conditions

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Family Connections with Pediatrics

Thanks to advances in technology and medicine, babies who are born very early are surviving and going home from the hospital. Many will have long-term, complex needs that throw their families into a fragmented healthcare system. In this month's *Pediatrics*, the article, "Care Coordination Programs for Infants with Complex Conditions: A Systematic Review," summarizes what kinds of care coordination programs exist for infants with complexity and how they work ([10.1542/peds.2022-061083](https://doi.org/10.1542/peds.2022-061083)).

What is a systematic review?

A systematic review is a formal process of looking at all the articles on a topic.

What are care coordination programs and how do they work?

Programs are set up to help families with all types of services and supports. Many of the programs studied helped families with insurance issues, parent coaching, and scheduling medical appointments. Some of the programs also participated in medical rounds, monthly care meetings, and meetings to plan for discharge from the hospital. Some programs also offered 24/7 communication services to help with emergency care

issues and care management. Other services included help with transportation and follow-up phone calls. Programs may be located in a hospital or in the community at a primary care clinic. Staff can include physicians, nurse practitioners, registered nurses, social workers, nutritionists, community health workers, and parent advocates.

Who qualifies for a care coordination program?

Each program has different guidelines for acceptance, but most help infants who have chronic illness, 2 or more conditions, and who will need many healthcare services.

What were the findings?

The research team looked at 3 areas to see how these programs were working: the infant, the parent, and healthcare use and cost. Here are the effects care coordination programs had on each area:

Infants

- Experienced less serious or life-threatening illnesses, including death
- Improved quality of life, including healthy weight and less reliance on mechanical ventilation

Parents

- Improved mental and emotional health
- Increased satisfaction with child's care

Healthcare use and cost

- Fewer days in the hospital, hospital readmissions, and emergency department visits
- Mostly cost-neutral or cost saving for insurers, health systems, and families

What is not included in this systematic review?

- Outcomes for families like family management, wellbeing, and ability to manage a complex condition
- Outcomes for minority and vulnerable communities

We know that supporting families and their children with complex care needs is one way to shape future health. This systematic review shows that these programs can help infants, families, and the healthcare systems. The cost to build such a program can be high, and more research is needed to find creative ways to build and keep these programs going.

What can I do with this information?

1. If you're a family member caring for an infant with complex needs, ask your child's care team if there is a care coordination program to help support you.
2. If you're a healthcare professional or researcher, consider looking at long-term infant health outcomes to see the impact of these programs on early life experiences.