

A Guide to Getting Started with Systems of Care



Learning Objectives

After reviewing this Guide you will be able to:

- Recognize the complexity of systems of care
- Identify initial steps for engaging with systems of care
- Acknowledge that coordinating the systems of care can feel overwhelming or frustrating

Introduction

When your child has a serious medical condition, you must navigate many complicated systems. These can include the hospital or healthcare setting(s) where your child receives care; health insurance and medical supply systems; your local education system; and other networks of public support, like Medicaid or disability waiver programs.

The purpose of this guide is to help you get started as you learn how to navigate these systems. While there is no direct or easy way through the maze of complex caregiving, there are some common practices that can ease your path.

Things to Keep in Mind

It is normal to feel overwhelmed, frustrated, and confused by systems of care

Systems of care for children with a serious medical condition all have different rules and different leaders. They are rarely coordinated. In the US, type of support that is available to you/your child is often determined by the state where you live, and by the availability of funding within state programs.

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It is your job to make these systems work for your child.

The difficult reality is that, as a parent or caregiver, it is up to you to make the systems of care work as well as possible. This takes dedicated time and effort: making phone calls, filling out forms, and scheduling appointments. It takes confidence to ask questions, file appeals, and request help when you feel stuck. This administrative burden may exacerbate the physical, emotional, and spiritual feelings you may have about your child's condition.

There are resources to help you find your way

Remember: there is no such thing as a bad question or an inappropriate ask when your child is seriously ill. You are their best advocate. If you feel like you need better guidance or re-sources from anybody involved in your child's care, keep asking.

Where to Begin

Here are some tips to help you as you navigate your child's care

Identify existing sources of support from your child's healthcare provider(s)

- Ask if the clinic or hospital caring for your child has a social worker, case manager or resource coordinator.
- Ask about potential resources available from the healthcare setting, like meal vouchers, transportation assistance, housing assistance, translation services and financial aid. Ask for help to connect with resources outside the healthcare setting.
- Many children's hospitals or clinics also provide this information on their websites, under headings like "resources for patients and families."

Get familiar with your insurance benefits

- If you have health insurance, reach out to your insurance provider to understand if they provide case management or resource guidance for chronic or complex conditions.
- Spend time with your benefits booklet to understand your potential out-of-pocket spending liability and begin to learn about the types of providers in your network.
- If you do not have health insurance, explore options for your child's coverage through your state's Medicaid and Children's Health Insurance Program (CHIP). Learn about coverage options and how to access support at [InsureKidsNow.gov](https://www.insurekidsnow.gov) and [kidswaivers.org](https://www.kidswaivers.org).
- Many families must appeal insurance coverage denials, especially for things like medical equipment or ongoing therapies. Learn about the appeals process for your coverage, and anticipate needing to use it.
- [HealthyChildren.org](https://www.healthychildren.org) from the American Academy of Pediatrics has an overview of [health insurance considerations](#) if you'd like to explore more.

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Prepare to learn about multiple service options

There are many programs and services available for children and families impacted by serious illness. You may hear terms like home health care, long term care, medical home, personal care, private duty nursing, respite care, waiver services, etc. and not be entirely sure what they mean or how to access them. That's okay.

- [Neumors KidsHealth](#) has an excellent [Special Healthcare Needs Glossary](#) that may be helpful as you learn this new language. (Complement this with their great article on [Getting Support When Your Child Has Special Health Care Needs](#).)
- Family-to-Family Health Information Centers (F2F) help families of children and youth with special health care needs navigate local systems of care in individual states/territories. F2Fs are part of [Family Voices](#), a national family-led organization supporting children and youth with special health care needs. Consider contacting your F2F for guidance tailored to your unique situation.
 - [What are F2Fs?](#)
 - [How do F2Fs help families?](#)
 - [Find your F2F](#)

Connect with community

There are many patient advocacy organizations for children with serious medical conditions. You may benefit from connecting with families with similar lived experience.

- Review the National Organization of Rare Disorders (NORD) [Member List](#)
- Search organizations within the Global Genes [Global Advocacy Alliance](#)
- Browse by disease at the [Genetic and Rare Diseases Information Center](#)
- If your child is undiagnosed, you may consider connecting with the [Undiagnosed Diseases Network](#).

Conclusion

Caring for a child with a serious medical condition takes incredible stamina. It's almost impossible to tackle all of the daily tasks. Be kind to yourself. Identify what must happen to keep you, your child, and your family as safe and well as possible. Don't be afraid to say "no" to things that add to your stress. CPN [Core Concepts](#) are designed to help you advocate for yourself and your child at all points as you navigate systems of care.

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Referenced Resources with URLs

From the American Academy of Pediatrics, an overview of health insurance considerations: www.healthychildren.org/English/family-life/health-management/health-insurance/Pages/default.aspx.

To learn about your state's Medicaid and Children's Health Insurance Program (CHIP) options for coverage: InsureKidsNow.gov and www.kidswaivers.org.

A glossary of words and terms about special health care needs: kidshealth.org/en/parents/special-needs-glossary.html.

Network of family organizations across the United States that provide support to families of children with special health care needs: familyvoices.org.

A guide to Family-to-Family Health Information Centers: familyvoices.org/felsc/whataref2fs.

National Organization of Rare Disorders (NORD): rarediseases.org/nord-member-list.

Find organizations supporting rare disease patients and families: globalgenes.org/about-us/global-advocacy-alliance/global-advocacy-alliance-members/.

Browse by disease: rarediseases.info.nih.gov.

If you child is undiagnosed: undiagnosed.hms.harvard.edu.