



Pediatric Complex Care Resource Centers (PCCRCs)



Journey Map for Milestones

A guide for navigating Home-Based Care for Children and Youth with Medical Complexities through the lens of life milestones caregivers may experience in their caregiving journey.

Keep Reading!



About this Journey Map: The Pediatric Complex Care Resource Centers (PCCRCs) equip, empower, and educate caregiver teams through education, training, and holistic support, helping them build relationships and confidently navigate resources and systems together. **The Pediatric Coach and Family Facilitator are two roles within the PCCRC that support families provide care at home.**



Asher



The Purpose and People of the Pediatric Complex Care Resource Centers (PCCRCs)

Equip
families and caregivers and offer essential non-clinical resources

Empower
Families, nurses, and caregivers to support children and their families

Educate
families, caregivers, and providers with the training needed to care for children

Hi, I'm your **Family Facilitator**. I can help you talk to the hospital or facility and make plans for taking care of your child at home. My goal is to make sure you and your child can transition to living together happily in your home.



Hi, I'm your **Pediatric Coach**. I can help caregiver teams by giving advice on how to get different kinds of support, solving conflicts, and organizing helpful meetings for everyone involved in taking care of children at home.



Keep Reading!

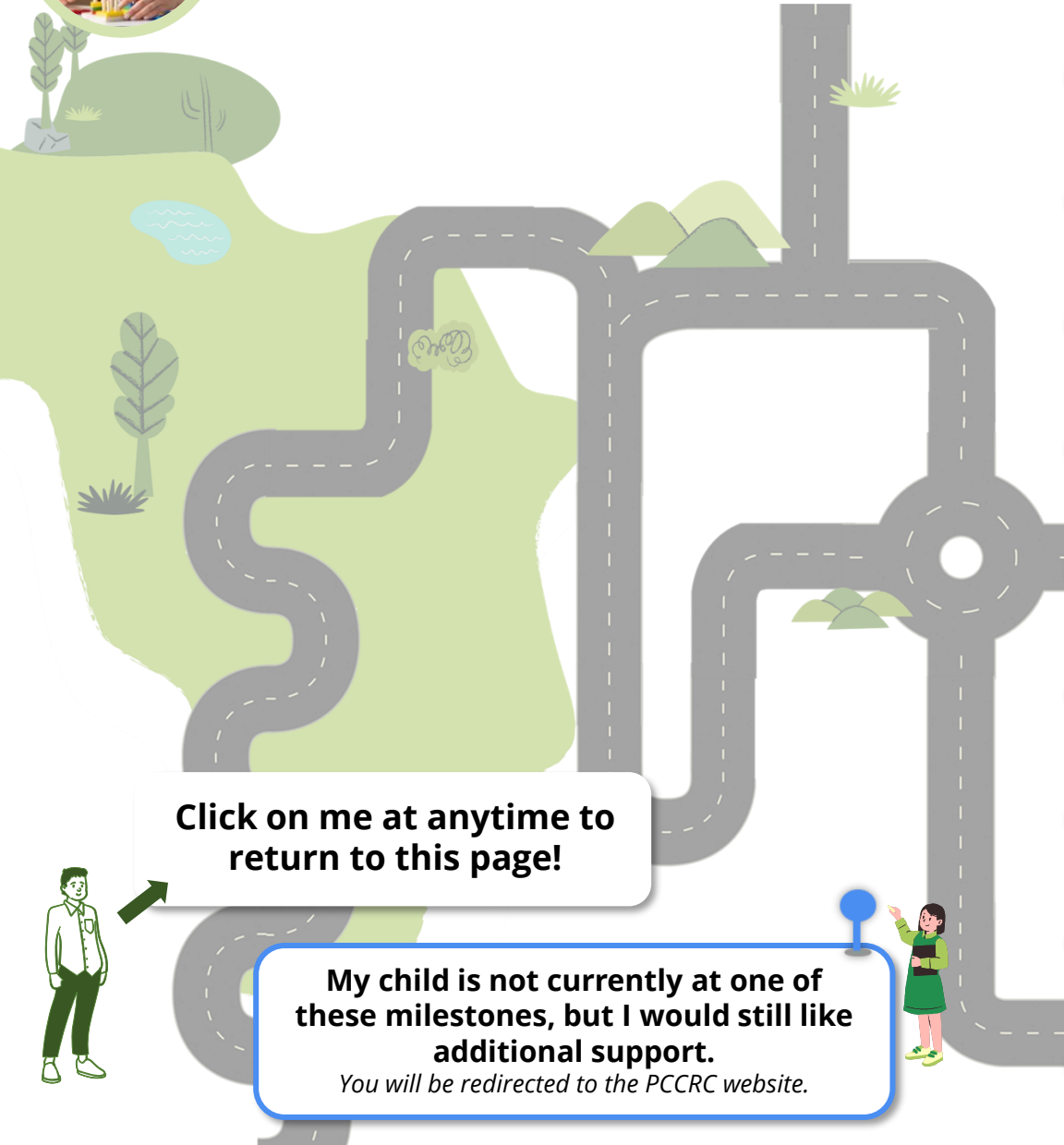


Homepage



Caregiving Journey Milestones

Click on a box that represents where you are in your caregiver journey.



 **I'm new to Pediatrics Complex Caregiving.**

 **I need initial or additional training to help care for my child.**

 **My child's living situation is changing.**

 **I think my child is eligible for different or additional services.**

 **My child's hospitalization needs are changing.**

 **My child's in home support needs are changing.**

 **I am looking for a new medical provider in my community for my child.**

 **My child is entering or leaving school.**

 **I need end of life support for my child.**

Click on me at anytime to return to this page!



My child is not currently at one of these milestones, but I would still like additional support.

You will be redirected to the PCCRC website.





Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

I'm new to Pediatrics Complex Caregiving.

Your **Family Facilitator** or **Pediatric Coach** can help:

- Find the appropriate [Medicaid](#) coverage for your child, [register your child with the county](#), and connect you to additional supports for your child and your family.
- Explain what pediatric complex caregiving entails, what resources are available, navigate new and difficult home healthcare situations, and communicate with your child's healthcare team.
- Educate you and your family on the best way to communicate with your child's healthcare team, advocate for your child, and get connected with community resources.
- Discover how to possibly get compensated for caring for your child as a Paid Family Caregiver.
- Understand your child's [individualized care map](#).

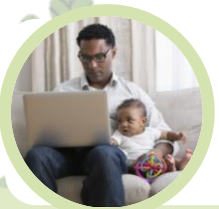
Your **Family Facilitator** helps connect you to transition services to get your child home.



Your **Pediatric Coach** helps connect you to home health care services to care for your child.



Homepage



Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

I need initial or additional training to help care for my child.

Your **Family Facilitator** or **Pediatric Coach** can help:

- Provide an overview of relevant trainings for your child's complex care needs, outlining the format, duration, and purpose of each to help you identify the best options for your family.
- Share information on becoming a Paid Family Caregiver.
- Connect you with ongoing support and resources and share testimonials from other families.
- Provide access to community services to assist you and your family.

Your **Family Facilitator** helps connect you to new health care trainings to facilitate your child's transition home.



Your **Pediatric Coach** helps connect you to new home health care online trainings to equip you to care for your child's needs at home.



Homepage



Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

My child's living situation is changing.

Your **Family Facilitator** or **Pediatric Coach** can help:

- Show you the steps to assess your child's needs, advocate effectively for your child's needs within the healthcare system and ensure they receive the best possible care.
- Connect you with resources in a new location, how to change providers, where to report your change of address and how to [reregister my child for ODP supports](#).
- Support continuity of care and facilitate communication with your child's new healthcare team during provider transitions.
- Connect you with other families who care for a child going through reunification, foster care, or adoption, and other relevant resources and community support services.

Your **Family Facilitator** helps when your child is living in a hospital or facility and you're looking for new contacts and services in your area.



Your **Pediatric Coach** helps when your child is living in the community and you're looking for new contacts and services in your area.



Homepage



Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

I think my child is eligible for different or additional services.

Your **Family Facilitator** or **Pediatric Coach** can help:

- Explain and determine which services your child meets the criteria for and which is most suitable for your child.
- Determine if your child is eligible to enroll in MH/ID, supports coordination, or [Intellectual Disability/Developmental Disability, or Autism services](#).
- Discuss the process of transitioning out of Pediatric Care (at 21) and explain what different types of waivers available and help supports will be available during and after this transition.
- Determine how often your child's needs should be reassessed to see if they are eligible for new or additional services, like assistance from the [Office of Vocational Rehabilitation](#).
- Outline the additional resources or support programs that are available for families navigating waiver and service processes.

Your **Family Facilitator** helps you determine eligibility and provide a list of service options available to you as your child transitions home.



Your **Pediatric Coach** helps you determine eligibility and provide a list of service options available to you to assist your child.



Homepage



Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

My child's hospitalization needs are changing.

Your **Family Facilitator or Pediatric Coach** can help:

- Prepare for your child's hospital admission or discharge, including guidance on questions to ask about their care plan.
- Assist with care coordination and support you in advocating for your child's needs within the healthcare system.
- Provide guidance and assistance in creating and implementing a transition plan for hospital discharge.
- Connect you with parent support groups, networks, and community resources to assist you during this time.

Your **Family Facilitator** helps you coordinate with the hospital/facility, medical personnel, and social workers to prepare for the changes.



Your **Pediatric Coach** helps you coordinate with any nurses/aides involved in home-based care.



Homepage



Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

My child's in home support needs are changing.

Your **Family Facilitator** or **Pediatric Coach** can help:

- Assess your child's current care needs and adjust their care plan to reflect any new or changing requirements.
- Find qualified caregivers and connect you with specific programs or services that offer temporary relief or coverage for unstaffed hours using [PA Navigate](#).
- Monitor your child's progress during and after the transition to ensure ongoing support and well-being.
- Support you in coordinating with the hospital or facility, medical personnel, and social workers for comprehensive care.
- Connect you with community resources, support services, and parent networks to assist you and your family.

Your **Family Facilitator** helps you prepare for your child's move by coordinating with the hospital or facility, medical personnel, and social workers during transition times.



Your **Pediatric Coach** helps you prepare your home for your child's care by providing in-home visits, assessing accessibility needs, and advising on ramps, durable medical equipment, and home modifications.



Homepage



Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

I am looking for a new medical provider in my community for my child.

Your **Family Facilitator** or **Pediatric Coach** can help:

- Support you in ensuring a smooth transition for your child's care and connecting you with recommended healthcare providers or specialists, especially if you're having trouble finding options locally.
- Transfer your child's medical records and documentation to new healthcare providers.
- Provide information about specialized community-based services, such as physical, occupational, and speech therapies, as well as oral healthcare options.
- Guide you to appropriate providers and support contacts if your child needs care after leaving Early Intervention.
- Connect you with community resources and support services to help you through this journey.

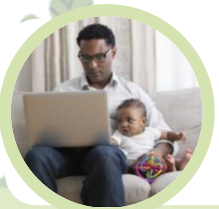
Your **Family Facilitator** helps connect you to health care services to care for your child as you transition your child home.



Your **Pediatric Coach** helps connect you to home health care services to care for your child in your home.



Homepage



Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

My child is entering or leaving school.

Your **Family Facilitator or Pediatric Coach** can help:

- Identify key steps and develop a personalized plan to support a smooth transition for your child into their new environment.
- Provide information about new and ongoing resources, services, and community supports available for your child and family.
- Support you with [Individualized Education Program \(IEP\)/504 Service Agreement](#) development and meeting preparation.
- Offer guidance on effective communication with new caregivers and teachers and help your child access social opportunities with peers.
- Assist you in finding new services and resources if your child needs support after graduation before age 21.

Your **Family Facilitator** helps connect you to available services and resources in school and the community as you transition your child home from a hospital or facility.



Your **Pediatric Coach** helps connect you to the full scope of services and resources available to you in and outside of the school from home.



Homepage



Caregiving Journey Milestones

The Pediatric Coach and Family Facilitator are here to help you navigate the caregiving journey and provide you with resources and support. Here are some examples of things they can help you with:

I need end of life support for my child.

Your **Family Facilitator** or **Pediatric Coach** can help:

Your **Family Facilitator** helps connect you to support and coordination of services if you choose to transition your child home during this difficult time.



Your **Pediatric Coach** helps connect you to support and coordination of services in your home during this difficult time.



- Find experienced healthcare providers for your child's current needs and coordinate care across providers and services, including hospice.
- Support you in making informed decisions, navigating important choices, and connecting you with relevant organizations like the [Pediatric Palliative Care Coalition](#).
- Prioritize your child's comfort and dignity are prioritized throughout this process.
- Provide guidance on necessary legal documents, such as advance directives or power of attorney.
- Connect your family to community resources and support networks for additional help during this time.



Homepage