

Module 4: Provider Support

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Getting Help Early

It is not uncommon for babies leaving the NICU to be discharged with orders for therapy, or for the need for therapy to arise in the first two to three years of life. Navigating this world may seem confusing and overwhelming. Remember that it never hurts to seek an evaluation if you have concerns. At best, the therapist can reassure you that your child is developing within typical ranges. If they do recommend services, be encouraged that you sought help quickly because the benefits of early intervention are numerous and can have an important impact on your child's later growth and development. The brain is the most adaptable to change during the first three years of life, benefits of early intervention are tremendous.

Learning disabilities aren't always obvious. However, there are some signs that could mean your child needs help. Keep in mind that children develop and learn at different rates – especially if they were born prematurely or spent time in the NICU. Because you know your child and their developmental history better than anyone else you are their best advocate. So trust your instincts. If you are concerned your child's development is out of sync with their siblings' or peers' talk to your doctor. And be sure to let your pediatrician know if your child shows any of the following signs:

- Delays in language development.
- Trouble with speech.
- Trouble with coordination and fine motor skills.
- Short attention spans.

To learn more about finding the right fit for therapy from other parents with preemies, visit [Hand to Hold](#). To review all of the services available for maternal and infant health in Illinois visit [Ever Thrive Illinois](#).



High Risk Infant Follow-Up Program

The Illinois Department of Human Services provides a program called the High Risk Infant Follow Up. The goals of the follow-up services are to promote optimal growth and development, teach the family care of the high risk infant, prevent complications, decrease morbidity and mortality, decrease stress and potential for abuse, and ensure early identification and referral for further treatment and evaluation.

High Risk Infant Follow-up serves infants who have any of the following conditions:

- a serious congenital infection;
- an endocrine, metabolic or immune disorder;
- a blood disorder;
- birth weight less than 1,500 grams;
- a positive urine toxicology for any drug or signs of drug toxicity or withdrawal;
- discharge from a neonatal intensive care unit; or
- a congenital anomaly or other conditions, such as intrauterine growth retardation

Your healthcare provider connects you with this program and you will receive a minimum of 6 visits by a follow-up nurse that will provide health monitoring teaching, counseling and/or referral for appropriate services your baby may need.



Illinois Early Intervention Program (EI)

The Illinois Early Intervention (EI) Program provides a variety of services for families of an infant or toddler with a disability or a developmental delay. In some cases, the program also helps families with very young children who are at risk of being delayed. The program is based on the idea that all families help their children learn and grow. Families with a child with special needs may need support to figure out the best ways to help their child develop. Families are partners with professionals in the EI Program to help their child have the best start in life.

If your child is eligible for the program, your provider may automatically refer them to the program. If you believe your child may be eligible for Illinois Early Intervention Program services and have not been already referred, you can directly call your local Child and Family Connections (CFC) office to arrange for an initial “intake” visit by a service coordinator at your home. He or she will schedule free evaluations of your child’s development. After your child is determined to be eligible, the service coordinator will serve as your personal contact through the entire time your child receives Illinois Early Intervention Program services.



Maternal, Infant, and Early Childhood Home Visiting

If you live in Cicero Township, Englewood, West-Englewood or Greater Grand Crossing, you may be eligible for the MIECHV program that offers extra support for you at home.

Through evidence-based home visiting programs, parent coaches provide child-development and parenting information to help teen parents create safe, stimulating home environments; model positive and language-rich relationships; and ensure families are connected to medical, dental, mental-health, and other supports.

Research has shown that home visiting programs increase children's literacy and high school graduation rates, as well as how much parents read to their children. In addition, such programs have been shown to increase positive birth outcomes for children, improve the likelihood that families have a medical home, and decrease rates of child abuse and neglect.



Healthy Families Illinois

The Healthy Families Illinois (HFI) program is a voluntary home visitation program that works with expectant and new parents who may be at risk for problems in parenting, including child abuse/neglect. Through intensive home visiting, HFI works to strengthen the parent/child relationship, promote positive parenting and healthy child growth and development. Home visits are offered weekly for the first six months and may continue for up to five years, with the length and frequency determined by the needs of the family. Home visitors model positive parenting skills and provide information on child growth, development and safety.

To find a Healthy Families Illinois location, visit the [Healthy Families Illinois Provider List](#).



Greater Englewood Healthy Start Initiative

At UIC, the Chicago Department of Health Greater Englewood Healthy Start Initiative is a program funded by the [U.S. Health Resources and Service Administration \(HRSA\)](#). Greater Englewood Healthy Start was implemented 18 years ago to reduce the rate of infant mortality, low birth weight and other poor perinatal outcomes for women and infants living in Englewood and West Englewood communities. To achieve this goal, the program works closely with community residents, agencies, businesses, and schools, to improve the access to health care and social services. The identified population is high-risk pregnant women, infants, and fathers with young children.



Women, Infants, Children (WIC)

WIC is a food assistance program for Women, Infants, and Children. It helps pregnant women, new mothers and young children eat well and stay healthy.

WIC can provide:

- Special checks to buy healthy foods - like milk, juice, eggs, cheese, cereal, dry beans or peas, and peanut butter
- Information about nutrition and health to help you and your family eat well and be healthy
- Information and help about breastfeeding
- Help in finding health care and other services in your area

Use the [DHS Office Locator](#) to find your local Women, Infants and Children office near you. Make an appointment and find out what papers or documents you need to bring with you. At your appointment, WIC staff will check to see if you and your family qualify. If you need assistance, contact the State WIC Office at 217-782-2166.



Supplemental Security Income (SSI)

Children who are disabled may qualify for disability benefits through Supplemental Security Income (SSI). To be considered disabled, a child must have an impairment or group of impairments that cause marked and severe limitations in their functioning and is expected last at least twelve months (or cause death). There are both medical and income requirements that must be met to qualify for SSI benefits. To qualify medically for SSI, your child's condition must meet or equal the requirements of one of Social Security's impairment listings in its "Blue Book" or Social Security must agree that your child's condition "functionally equals the listings."

Children who have any of the following impairments may qualify for presumptive disability payments.

- Cerebral palsy with marked difficulty with walking, speaking, or hand and arm coordination
- Low birth weight
- Prematurity (with birth weight limit based on gestational age at birth)
- Total deafness, or
- Total blindness.

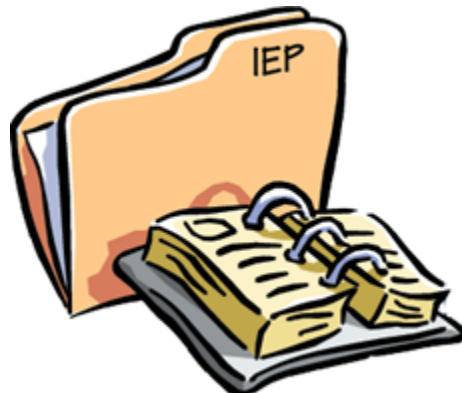
To sign up for this assistance, visit your local Social Security Administration (SSA) office. The [SSA's office locator](#) can help you find the location nearest to you. You can also call the SSA at (800)772-1213.



Individualized Learning Plan (IEP)

Every child has unique developmental needs, but some children's needs are greater than others. Most children who spend time in the NICU will experience a developmental delay of one kind or another. Because of this they will most likely be referred to receive services from the Illinois Early Intervention Program (mentioned previously). They then will need to be monitored and may even need special accommodations if they continue to have delays as they grow.

When your child reaches school age, they may need an individualized education program (IEP). An IEP is a written statement for a child with a disability that is developed, reviewed, and revised in a meeting to give information to teachers about how best to help your child learn. You can learn more information by contacting parent support centers such as the [Family Resource Center on Disabilities](#) and [Family Matters Parent Training and Information Center](#).



Speech and Language Pathologist

A family would see a Speech Therapist if they have any concerns for their child's development in any of the areas mentioned above. These can include:

- articulation disorders
- cognitive impairments or delays
- expressive and receptive language impairments or delays
- fluency/stuttering
- voice disorders
- auditory processing disorder
- oral motor and oral feeding issues
- Dysphagia (swallowing)

They will generally need a referral from their Primary Care Physician or from another healthcare provider that is overseeing their child's care. After the referral is received an evaluation is scheduled. During the evaluation the Speech Therapist will look into the parent's concerns and any other concerns that arise during this time. After the evaluation the Speech Therapist will determine whether or not the child will need ongoing services.

Parents play a significant role in the whole process of Speech Therapy. Although the Speech Therapist evaluates specific concerns, development, delays, etc. the parents ultimately know the most about their child. Parents play a role in the evaluation, interpretation of results, and development of a treatment plan. Speech Therapy is not successful without the involvement of the parents to carry out programs recommended at home and throughout their everyday lives.

To learn more about speech and language pathologists and other specialty providers, visit [Hand to Hold](#).



Dietician

A dietitian figures out the nutritional status of a patient or client and provides recommendations and education to address any nutrition concerns or to promote general healthy eating habits. Nutrition is very important for your baby's overall growth and long-term health. The focus is making sure the child is gaining weight and growing like he should, his nutrient needs are met, and that we introduce healthy eating habits as early as possible so that those habits will follow them the rest of their life.

A family could see a dietitian any time they have nutrition questions or concerns. Referrals from a physician are not required. Because dietitians are involved in both the treatment and prevention of nutrition concerns, parents could see a dietitian to address a specific nutrition issue they are experiencing at home or just to receive general healthy eating information from a trusted and reliable source. Continued monitoring is needed for some children and a one-time visit is needed for others.

Especially with high-risk babies, addressing nutrition issues early is important to help the baby grow and develop to their greatest potential. Oftentimes parents receive conflicting information from the media, friends, and other health care professionals rather than when they are just seeking advice from a specialist whose focus is just nutrition.

Parents can visit the website for The Academy of Nutrition and Dietetics (www.eatright.org), which is the national organization for more information about Registered Dietitians. To learn more about dietitians and other specialty providers, visit [Hand to Hold](#).



Occupational and Physical Therapists

Occupational Therapy (OT) is a health profession that helps patients improve the way their nervous system functions. Physical Therapists (PT) can also help promote these skills. Both Occupational and Physical Therapists help clients develop skills that will lead to success in everyday life including motor, social, personal, academic and vocational pursuits. Occupational therapy helps children to develop skills necessary for learning and performing specific tasks, but it also deals with social and behavioral skills. Physical Therapists can help children improve their functional independence and gross motor skills. Both can help your baby with the following:

- coordination of movements between the two sides of the body (“crossing the midline”)
- fine motor control and organization (small movements like picking up something small with fingers)
- motor movements and coordination
- gross motor coordination (large movements like lifting a leg or waving a hand)
- ocular motor skills (eye movement)
- self-regulation
- sensory modulation (reaction to touch)

Therapists not only work directly with the child, but also with the family, parents, caregivers and teachers in order to educate and support specific skills and behaviors which will be used to improve and facilitate the child’s performance and functioning.

Any time a child is not functioning at an age appropriate level in any aspects of their life, they might see an OT or PT for an evaluation.

To learn more about occupational or physical therapists and other specialty providers, visit [Hand to Hold](#).

Pediatric Pulmonologist

Pediatric Pulmonologists will often assist the Neonatologist in the care of infants in the intensive care unit with respiratory problems. This can range from helping to diagnose and manage rare lung diseases, to performing procedures such as a bronchoscopy, to helping with ventilators and oxygen therapy in infants with the more expected complications of prematurity.

Once home from the NICU, infants may follow up in the Pediatric Pulmonology clinic to help manage weaning from supplemental oxygen, weaning from cardiopulmonary monitors (apnea monitors) and reinforcing the treatment plan. Infants with uncommon lung diseases will also be seen in outpatient follow up. Once a child is established in the Pediatric Pulmonology clinic, sick visits can be arranged to help manage respiratory issues. Depending on the disease process, this may involve breathing treatments, systemic steroids, antibiotics or additional supplemental oxygen.

To learn more about pediatric pulmonologists and other specialty providers, visit [Hand to Hold](#).



Support Groups

As a parent of a young child that was born premature, you are not alone in the issues you may face. There are several groups where you can meet with other parents to find support.

The first group for you to know about is the Parents are Great group (PAGes) at UIC. You should have received information about it when your child was in the NICU. Contact your doctor or community health worker to find out more.

The Neighborhood Parents Network offers a list of different support groups that meet up here in the Chicago area. You can find groups related to where you live, developmental disabilities or even preemies. Visit their [website](#) to explore.



Gigi's Playhouse is a center that offers several education and therapeutic classes for children with down syndrome. Visit their [website](#) to learn more.



Dads Appreciating Down Syndrome (D.A.D.S) is another group that focuses on children with down syndrome. They have a group specifically for dads in the Chicago area. Visit their [website](#) to learn more.



These are just a few examples of support groups. Talk to your community health worker (CHW) and see if there might be others that would work for you!

Great job! You're another step closer to finishing the CHECK Prematurity Online Program. Hopefully you now know more about all of the different providers that can help you and your baby.

Now you can move on to the next topic, which talks about different ways you can help soothe your baby.

