SUMMER 2025

Pass it On

Information to use and share with families and professionals caring for children with special healthcare and education needs from birth to 26

THE EARLY CHILDHOOD YEARS

New Hampshire FAMILY VOICES®

603-271-4525 NHFV.org

PARENT INFORMATION Center

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INSIDE PASS IT ON

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About this Edition

Dear Readers,

We're excited to share this special early childhood edition of our newsletter with you. Whether you're a parent, grandparent, caregiver, or professional, we know how important the early years are—and how overwhelming it can sometimes feel when you're just starting your journey. There's a lot of information coming your way, and we hope this issue helps make things a little easier to navigate.

Inside, you'll find helpful tools, inspiring stories, and opportunities to connect. We're highlighting two exciting ways that families can get involved in shaping how early childhood programs and systems work in New Hampshire. When families participate, they not only help improve services for everyone, but they also build stronger networks of support and learn more about how to navigate the systems that all families encounter along the way. We're proud to share real stories from NH families about their unique early childhood experiences and a wonderful list of early childhood books, including many new titles you might not have seen yet. We recently launched our Early Childhood Hub, a new online space filled with easy-to-use tools designed to help you understand and support your child's development from day one. These resources align with New Hampshire's Early Learning Standards and include activity sheets that were created in partnership with Vroom®, a leader in brain-building science.

At the heart of all we do is a deep commitment to supporting families, children, and the professionals who work with them. If you ever have a question, need help finding resources, or just want to talk something through, please remember that you can call us anytime. Our support is always free and confidential. We're here for you—every step of the way.

Michelle Lewis,
Executive Director, Parent Information Center (PIC)

Sylvia Pelletier
Director, NH Family Voices (NHFV)

Ways for NH Families with Young Children to Get Involved and Strengthen Early Childhood Supports in the Granite State

Your Voice Matters: Join the Movement for NH Families

In New Hampshire, families are powerful partners in shaping the systems that support young children. That's where the NH early Childhood Family Network comes in — not as a formal program, but as a space where parents and caregivers of children birth to age eight can be heard, valued, and involved in real change.

The NH early Childhood Family Network welcomes all kinds of family voices — whether you're raising a newborn, supporting a preschooler, or guiding a second grader through their early school years. Your lived experience is expertise. By sharing what's working and what's not, you help improve the programs, policies, and services that support families across the state.

One important way families are already making an impact is through our Birth to Eight Family and Community Advisory Team **https://nhfv.org/b8/**. This group brings together parents, caregivers, and community members to advise early childhood leaders and influence decisions that affect everything from childcare and preschool to health care and family support systems. The team meets regularly and helps ensure that family voices are not only included — they're elevated.

You don't need special training to get involved — just your experience, your perspective, and a willingness to speak up. Ready to use your voice to make a difference? Join the NH early Childhood Family Network or apply to be part of the Birth to Eight Family and Community Advisory Team. Whether you're giving quick feedback or attending a meeting, your voice matters.Learn more and get involved here: **https://bit.ly/3ZuHCEc**. Together, we can build a stronger future for New Hampshire's children.

NH Interagency Coordinating Council (ICC)

The ICC is a passionate group of parents, caregivers, and professionals who advise the state's NH Birth to 3: Family-Centered Early Supports and Services program. In partnership with the NH Office of Special Education Programs and under Part C of the Individuals with Disabilities Education Act (IDEA), the ICC works to improve the quality and accessibility of services for infants and toddlers with developmental delays or disabilities.

If your child is currently receiving or has previously received Early Supports and Services, your voice belongs here. Parents and caregivers offer lived experience that is critical to shaping the future of early intervention in our state. As a member of the ICC, you'll help guide how services are delivered, how funds are prioritized, and how to better meet the needs of families across our communities.

The ICC gathers virtually on the first Friday of February, April, June, August, and December. Each October, the group hosts an in-person, all-day retreat to dive deeper into planning and collaboration.

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Jess B., a parent member said, "Parents and caregivers are such an important part of the NH ICC—we are the ones receiving the services and living the experience. Over the years, I've been part of honest conversations about what's working and what needs to change. I've seen ideas turn into action. Our voices matter. By joining, you help make New Hampshire a better place for all children and families."

Whether you're raising a young child or supporting families in your work, the ICC is a meaningful way to shape the future of early childhood services in New Hampshire. Join us and be a voice for our youngest children. For more information, contact **Nicole.M.Bushaw@dhhs.nh.gov**

Learning & Growing Along with Our Children During the Early Years: *NH Families Share Their Stories*

Tongue Tie, Tension, and Trusting My Instincts

Leona, my sweet 8-month-old baby girl, struggled to establish a latch for breastfeeding when she was born. I also noticed that she would stiffen and arch her body in discomfort when being held. When I brought these concerns to her doctor, I was referred to a pediatric dentist to assess tongue and lip ties and was also advised to explore different bodywork modalities to help relieve some of the tension we were seeing in her neck and core. At the dentist, I was informed that Leona was indeed tongue-tied. A tongue tie occurs when the frenulum, a small piece of tissue located under the tongue, is too short or tight, restricting the tongue's movement[1].

Leona would need to undergo occupational therapy (OT) before a frenotomy could be performed. A frenotomy is a simple surgical procedure that can be performed either with or without anesthesia in a hospital nursery, a doctor's office, or a pediatric dentist's office. During the procedure, the provider examines the lingual frenulum and uses sterile scissors or cautery to cut it free. The entire process is quick, and discomfort is minimal because the lingual frenulum has very few nerve endings and blood vessels. If any bleeding occurs, it is usually just a drop or two. After the procedure, a baby can be breastfed immediately [2].

In OT, we did lots of targeted play and exercises to help reduce tension and relax the floor of her mouth, improving her tongue elevation and overall oral function. I was surprised to learn that the tongue is directly connected to the entire nervous system and how issues such as tongue tie can affect other parts of the body, thereby contributing to other developmental difficulties (e.g., breathing, speech, muscle tension, gross motor skills, and more). It began to make sense that my baby's oral dysfunction was contributing to the other things that were "off" in her body.

After a couple of months of weekly sessions and "homework" (aka exercises at home), Leona's tongue was finally movin' and groovin', and at the point where she could safely have the release performed. We went back to the dentist, and the procedure took two minutes! Once she had her release, we continued with OT and bodywork for a few more weeks. Before we knew it, her latch had improved immensely, and her body had relaxed as well.

It took a lot of persistence, scheduling, and driving around to appointments, but I was determined to breastfeed my girl, and we finally got there! Now, at 8 months old, you would never have known she had these services in the first 6 months of her life. One thing I learned from this experience is that when something is off within your baby's body, it can often lead to other things being off as well. I am glad that I advocated for my baby by voicing my concerns to her PCP early on. I clearly described what I was seeing and outlined my goals. These conversations led us to find the proper support needed to address and treat the root cause.

Giving Alexander a Voice—and a Village

Alexander is a bright, joyful, and affectionate four-year-old boy. Our journey began when he was around 18 months old, after I started noticing several developmental concerns. Alexander was not engaging in typical behaviors such as pointing to objects, responding to his name, or making eye contact. He experienced significant challenges with emotional regulation and exhibited frequent elopement (running away).

Additionally, he was nonverbal for an extended period, which made communication especially difficult—he wasn't babbling or saying simple words like "mama" which concerned us.

We initially pursued a hearing evaluation to rule out auditory issues, but those concerns were quickly dismissed. After that, we consulted with his pediatrician, who referred us to a child development clinic for a comprehensive assessment.

Despite these early challenges, Alexander is a remarkably sweet and thoughtful child. He demonstrates a genuine sensitivity to the emotions of those around him and often goes out of his way to show kindness—for example, he loves picking flowers to give to others. His caring nature and determination to connect with the world in his own way are just a few of the many qualities that make him truly special.

Our family benefited from a variety of supports and interventions that have truly transformed our journey. Initially, we were connected with Early Intervention services through the Child Development Clinic, which then led us to work closely with Easter Seals. At first, these services were delivered in our home, which provided comfort during what was an overwhelming and unfamiliar time. These services included speech therapy and occupational therapy, both of which played a significant role in supporting Alexander's early development.

Because Alexander was nonverbal at the time, he was evaluated for an AAC (Augmentative and Alternative Communication) device, which turned out to be a major breakthrough. Once integrated into daily therapy sessions—and eventually into our home life—we began to see exciting progress. He started babbling, then saying his first words like "mama" and "papa." This device gave him a voice, and with that, his confidence began to grow.

When Alexander turned 3, he transitioned out of NHB-3 and into a specialized preschool for children with disabilities, which we were connected to through the school district. At this point, we also began services with Applied ABA in Manchester, NH. I was initially hesitant due to the negative things I had heard about ABA therapy, but after further research and seeing the approach used by Applied ABA, I decided to move forward. That decision has made a lasting impact. Alexander is now thriving—using abstract language and engaging more meaningfully with others. Some of the therapy even included practical life skills, such as support during grocery shopping trips, which had previously been very challenging for us. These real-world applications made a big difference in helping us navigate daily life more smoothly.

Some services were provided in person, such as therapy sessions and preschool support, while others, including parent education and community resource navigation, were offered virtually. I also got connected to The Moore Center and began participating in programs offered by PIC (Parent Information Center). These helped me understand the special education system in NH and equipped me to advocate more effectively for Alexander in educational settings and IEP meetings.

In addition, we took advantage of community sensory events, support groups, and parent training courses, which helped both Alexander and our family learn to navigate this new journey together.

One of the biggest lessons I've learned on this journey is the power of knowledge and community. In the beginning, coming from a Hispanic background and having no prior experience with autism or developmental disabilities, everything felt incredibly overwhelming. The unknown was frightening, and online research

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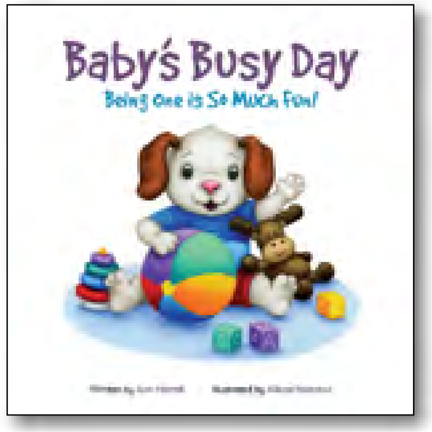
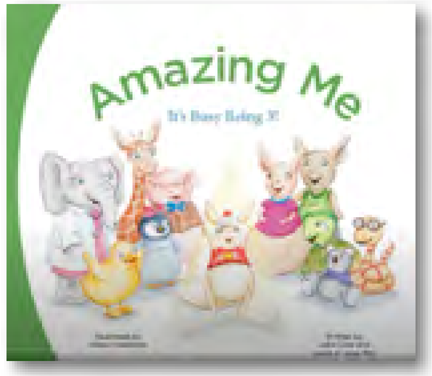




Baby's Busy Day
By Ann Harrell

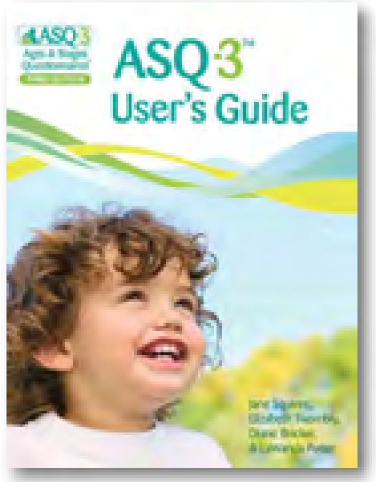
Meet Baby, a one-year-old puppy who is having a very busy day! Follow along as Mom, Dad, and Sis engage Baby throughout his day while encouraging his development along the way! As you read this fun story with your little one, keep an eye out for the paw prints to learn what one-year-old milestones to look for in your baby's development and the hearts for tips on how you can help!

Where is Bear?
By Libby Martinez

"Where is Bear?" is a terrific tale for 2-year-old children and their parents! This interactive book encourages children to help Tiger and his forest friends in their search to find Bear. Parents, with each turn of the page, your child will get closer to finding him, and you will learn about many important milestones to look for in your child. Look for the leaf at the bottom of each page and your own 2-year-old's milestone moments!

Amazing Me
By Allison Valentine

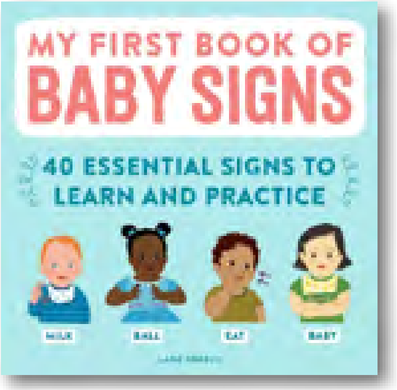
Meet Joey, an amazing 3-year-old kangaroo who is very excited about all he can do now that he is three. Joey doesn't know it, but these amazing things are called developmental milestones, and they're a very important part of each child's growth. Parents, this book for children ages 2-3 will show you what to look for as your child grows and develops. Whether you read this story to your child online or have a hard copy of the book, ask your child to find the koala bears. Each page with a koala bear also has a star and milestone at the bottom just for you. See if your 3-year-old is able to do some of the same things as Joey.



ASQ3 User's Guide

Absolutely essential to using ASQ-3®, this revised and redesigned guide provides step-by-step guidance on administering and scoring the questionnaires, setting up a screening system, working with families effectively, and using ASQ-3® across a wide range of settings. The ASQ-3 User's Guide is part of ASQ-3, the bestselling screener trusted for more than 20 years to pinpoint delays as early as possible during the crucial first 5 years of life. ASQ-3 questionnaires are reliable and valid, parent-completed, cost-effective, recommended by top organizations, and easy to administer and score. The 21 age-appropriate questionnaires effectively screen five key developmental areas: communication, gross motor, fine motor, problem-solving, and personal-social.

My First Book of Baby Signs: 40 Essential Signs to Learn and Practice
By Lane Rebelo



Storytime is the perfect time to practice sign language with your child. My First Book of Baby Signs is part storybook and part sign language guide, designed to encourage you and your baby to learn new words and signs as you read together. This baby sign language book starts with signs for basics like "eat," "milk," and "mommy" and then moves on to more advanced ideas like "help," "potty," and "I love you."

Hi! I'm Sam Collyar, a Resource Specialist at NH Family Voices.

Outside of work, I'm a wife, mom, and pet mom to 3 dogs, a cat, and 21 chickens. I keep busy in my garden and love books. My passion for books really kicked off when my then-eight-year-old was diagnosed with cancer, and we saw just how much hope could hide in the pages of a book. We turned to books for knowledge and stories from others in our shoes a lot, and I'm so excited to be in a position to connect people with books from our FREE Lending Library that could provide that same level of knowledge and comfort.

If you are looking for a specific book or resource on a particular topic, email me at snc@nhfv.org!

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Easing the Journey: Tips for a Smoother Transition from NH Birth to 3 to Preschool or Community Supports

Change can be challenging, especially when it comes to your child's early learning journey. If your family is part of NH Birth to 3: Family-Centered Early Supports and Services (NHB-3), you may be approaching an important milestone: the transition to preschool special education or other community-based supports when your child turns three.

While transitions can feel overwhelming, they also open the door to new opportunities for your child to grow, connect, and thrive. With open communication and thoughtful planning, this next step can feel less like a leap and more like a natural part of your child's path.

To better understand how families can experience a smoother transition, we spoke with Nicollette King, a Certified Early Intervention Specialist at Pathways of the River Valley. Nicollette has helped many families navigate this process and believes that collaboration and clarity are key. She shared her top tips with us to help families feel more confident and informed during the transition.

Transitions are about more than just services—they're about relationships, trust, and building a foundation for lifelong learning. With the right support, families can feel confident and connected during this exciting new stage.

For more information about the transition process in New Hampshire, visit https://www.dhhs.nh.gov or reach out to your FCESS provider.

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1

Start the Conversation Early and Keep It Going
Communicate, communicate, communicate – early and often. While there are specific timelines for certain steps in the early childhood transition process, nothing prevents conversations from happening at any time about what is available to support children and families after age 3.

2

Ask Questions—Any and All
It can be difficult to know what to ask to get the information you need. NHB-3 Providers can help families brainstorm questions to ask or their concerns about the special education process and community program options.

3

You are an Essential Member of this Team
Families should feel empowered to ask any questions, no matter how small they may seem. Things like "Can I meet the teacher?" or "How will I know what my child is working on?" may be things you want to know about. Sharing your perspectives on what your child needs and what your goals are for them is also important.

4

Understand the Language
The jargon and acronyms used can be confusing for families new to this process. If you don't understand something, ask for clarification. The professionals are there to help you understand the process and make informed decisions regarding what is best for your child.

5

Provide Clear and Detailed Information
Community programs should share specific information about eligibility and program options, including the supports available to meet the specific needs of the child and/or family. When you understand your options, you can make choices that feel right for family.

6

Check in Often
One of the most effective tools during this transition is a simple check-in. Professionals and families should check in with each other, ask how they are doing, whether they have the information they need, and if the meetings and next steps are clear. Feel confident in speaking up at any time to prevent confusion and strengthen the partnership.

What is NH Birth to 3: Family Centered Early Supports & Services?

Every child learns and grows at their own pace. Most infants and toddlers will learn the same skills in a predictable pattern called developmental milestones. Some children need extra time and support to get there. Skills like smiling for the first time, taking a few steps, and even saying their first words are easier for some than others. NH Birth to 3: Family Centered Early Supports and Services can help you and your family determine what help, if any, your child needs to stay on track.

What NH Birth to 3: Family-Centered Early Supports and Services Look Like?
Providers bring the support to you! Utilizing natural settings like your home, childcare or places in your community, your Service Provider will help you integrate developmental activities into your everyday routines. We strive for our services to be natural and fun to encourage your child to enjoy practicing new skills.

How to Make a Referral
Anyone can make a referral to NH Birth to 3! You do not need a referral from your doctor. Trust your instincts and contact us. We can help you tease out what is typical, or not, for your child. New Hampshire programs are located in 10 regions across the state, to best serve families in their own communities. To find your local Area Agency or call 603-271-3770.

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Developmental Screening: An Empowering Tool for Families

The first five years of a child's life are crucial for their growth and development. Healthy development ensures that children of all abilities, including those with special healthcare needs, can thrive in an environment that meets their social-emotional and educational needs. One key way for parents to support their child's healthy development is by understanding developmental milestones.

Developmental milestones differ by age, and children typically grow at their own individual pace. As a result, it can be difficult to predict the exact moment a child will acquire a specific skill. However, understanding these milestones provides a general overview of the developmental changes to expect as a child matures. This knowledge can help parents support and encourage growth in various areas of development.

Milestones Moments checklists and the Milestones Tracker App, are two great resources to learn about milestones, monitor your child's progress in meeting milestones, and what to look for next. These resources and others can be found by going to nhfv.org/ec0-8/ and scrolling down to the "additional early childhood resources" section.

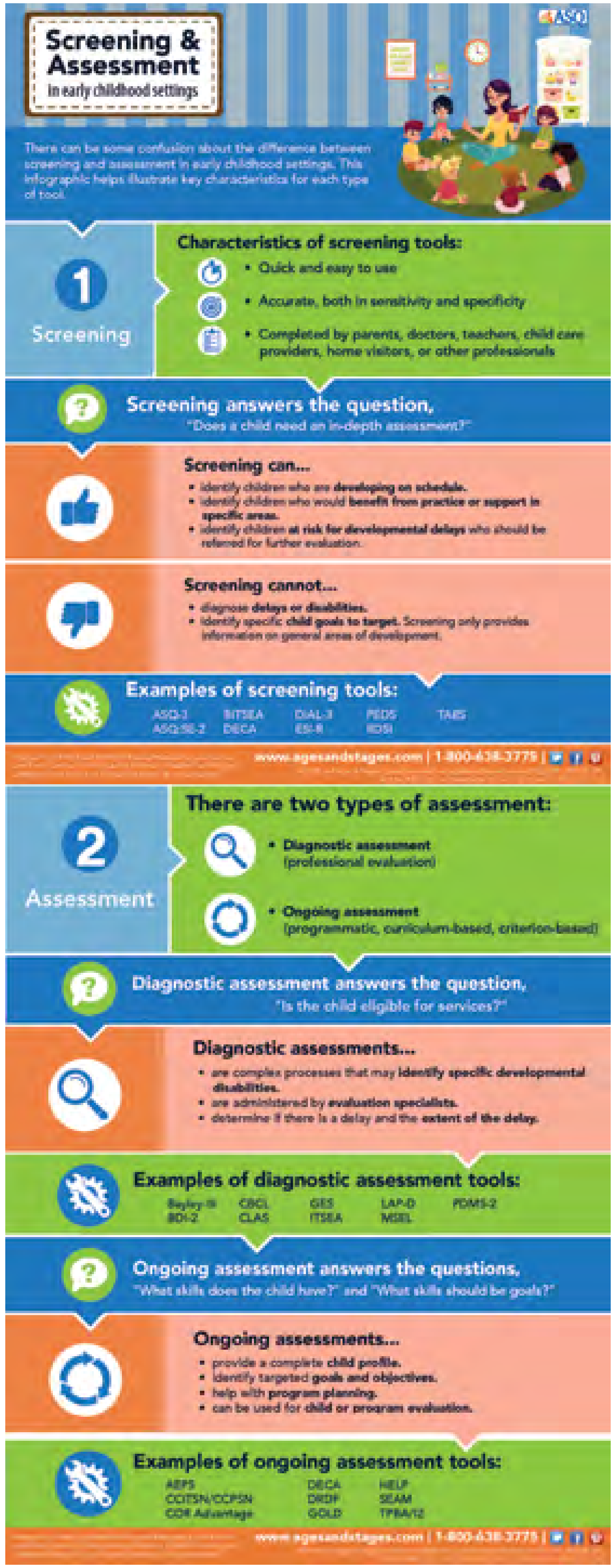
While learning milestones can help families understand general child development, a developmental screening takes an even closer look. Using a screening tool like the Ages & Stages Questionnaire (ASQ) has proven valuable in enriching parents' knowledge about their child's developmental progress, as well as helping families with early detection and identifying when a child might need additional support.

An ASQ is a quick and helpful assessment of how your child is performing in key areas, including communication, social skills, motor skills, and problem-solving skills. The ASQ is designed to be an interactive and positive experience for both child and caregiver by using activity-based questions and only taking 10-20 minutes to complete! The results help identify your child's strengths, uncover new milestones to celebrate, and reveal any areas where your child may need more practice or additional support. A completed screening is also an empowering tool for parents to use when advocating for their child with doctors and/or educators. Having your child's ASQ results on hand to look over together can help bridge communication between you and your child's provider, and effectively assist in planning next steps, with your child at the heart of the conversation.

If you're interested in understanding your child's development better and would like to complete an ASQ screening, there are several ways to access one.

- NH Family Voices: Contact our Developmental Screening Coordinator, Carly Ireland, at cri@nhfv.org. She can walk you through the process and send you an ASQ via mail or email.
- Check with your child's pediatrician, many practices use the ASQ and offer them at certain well-child visits. If you have concerns and would like to do a screening at a different time, see if they can accommodate your request.
- If your child attends preschool or childcare, ask the school if they administer or have access to ASQ. If so, you can request to take one home to do on your own.
- Reach out to your local Family Resource Center (FRC). FRCs provide family support, parenting programs, child development screenings, and information and referrals to community resources that help families thrive. Visit www.fsnh.org to find your local FRC for more information.
- At Easterseals.com you can complete an ASQ screening online, and they will send you the screening results and summary information via email.

Learn more about your child's growth and development at nhfv.org/education/early-childhood-2/



Screening & Assessment
in early childhood settings

There can be some confusion about the difference between screening and assessment in early childhood settings. This infographic helps illustrate key characteristics for each type of tool.

1 Screening

Characteristics of screening tools:

- Quick and easy to use
- Accurate, both in sensitivity and specificity
- Completed by parents, doctors, teachers, child care providers, home visitors, or other professionals

Screening answers the question,
"Does a child need an in-depth assessment?"

Screening can...

- identify children who are **developing on schedule.**
- identify children who would **benefit from practice or support in specific areas.**
- identify children **at risk for developmental delays** who should be referred for further evaluation.

Screening cannot...

- diagnose **delays or disabilities.**
- identify specific **child goals to target.** Screening only provides information on general areas of development.

Examples of screening tools:

ASQ-3
ASQ:SE-2
BITSEA
DECA
DIAL-3
ESI-R
PEDS
IDSI
TABS

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2 Assessment

There are two types of assessment:

- **Diagnostic assessment** (professional evaluation)
- **Ongoing assessment** (programmatic, curriculum-based, criterion-based)

Diagnostic assessment answers the question,
"Is the child eligible for services?"

Diagnostic assessments...

- are complex processes that may **identify specific developmental disabilities.**
- are administered by **evaluation specialists.**
- determine if there is a delay and the **extent of the delay.**

Examples of diagnostic assessment tools:

Bayley-III
BDI-2
CBCL
CLAS
GES
ITSEA
LAP-D
MSEL
PDMS-2

Ongoing assessment answers the questions,
"What skills does the child have?" and "What skills should be goals?"

Ongoing assessments...

- provide a complete **child profile.**
- identify targeted **goals and objectives.**
- help with **program planning.**
- can be used for **child or program evaluation.**

Examples of ongoing assessment tools:

AEPS
COTSN/CCPSN
COR Advantage
DECA
DRDP
GOLD
HELP
SEAM
TPBA/2

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Understanding Family Support During and After NH Birth to 3: Family-Centered Early Supports and Services

If your child is receiving NH Birth to 3: Family-Centered Early Supports and Services (NHB-3), you may also be eligible for Family Support through your local Area Agency. Each Area Agency has a Family Support Council (FSC) that helps guide how support is provided and has funds set aside to help families.

Your Service Coordinator can explain how Family Support and FSC funds work and what your family might qualify for. Each FSC has its own guidelines, but the goal is the same: to help families connect with their communities, find the resources they need, and get the information and support that fits their situation.

Some examples of Family Support include:

- Opportunities to connect with other families through events
- Help attending workshops or conferences
- Respite care
- Home or vehicle modifications

As your child gets ready to transition out of NHB-3 around age 3, your Service Coordinator will help you plan for the next steps, whether that's preschool or other community services. This is also a good time to ask:

- Will we still qualify for Family Support after NHB-3?
- What other services can the Area Agency offer our family?

For more details about what to expect, check out the Transition from NHB-3 Guide for Families and Staff here: https://bit.ly/4kWnt22.

From Baby Steps to Big Leaps: Explore Our New Early Childhood Hub

Your Child's Development Birth – 6 Months

Birth – 6 Months Development Details

Physical Development

Activities to Support Your Child's Development

The early years of a child's life are full of growth, change, and discovery. From a baby's first coo to a preschooler's imaginative play, every moment offers an opportunity to support your child's healthy development. Our new Early Childhood Hub is an online resource for families of young children, including those with special health care needs.

Explore a wide range of easy-to-use tools that help you understand and support your child's development, right from the start. These resources are aligned with New Hampshire's Early Learning Standards and created in collaboration with Vroom®, a trusted name in brain-building science.

In each section, you'll find age-appropriate developmental milestones, engaging activities, videos, and podcasts that support five key areas of growth: physical development, language and literacy, social-emotional development, cognitive skills, and number sense (early math). Whether you have five minutes or an afternoon, you'll discover fun, simple ways to turn everyday moments into powerful learning opportunities.

Keep in mind that the milestones shared for each age group are intended as a general guide, every child develops at their own unique pace. We've also included information and resources to help you know what to do if you have questions or concerns about your child's development. Visit https://nhfv.org/education/early-childhood-2/ and start building brighter beginnings together.

Easing the Journey continued from page 11

What happens after making a referral?

Intake
An Intake Coordinator will provide introductory information, gather some initial information about you and your child, and answer your initial questions.

Evaluation
Evaluations are play-based which include a multidisciplinary team of at least two providers who will interact with your child and ask you questions to get a deeper understanding of your child's current developmental level.

Individualized Family Support Plan (IFSP)
If your child is determined eligible, you will work with your team to identify services and develop goals to assist in achieving your child's optimal growth. You and your family are a KEY partner in this process!

Transitions
NH Birth to 3: Family-Centered Early Supports and Services will support you and your child until your child is no longer eligible or the day before their 3rd birthday. Your Service Coordinator will work with you to develop a plan for what to do next. Some children reach age-appropriate skills, some transition to preschool special education, and others move on to other local programs that best suit their needs and those of their families. We will do everything we can to make this transition smooth and supportive.

Source: NH DHHS https://bit.ly/3ZxLUdQ

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5 Resources to Use When Preparing for Kindergarten

1. NH Kindergarten Tool Kit bit.ly/4jLkt7y
2. Transition to kindergarten resources for families, including questions to ask about transitioning to kindergarten from the NH Department of Education bit.ly/45QbAX2
3. NH Preschool and K-12 Special Education Similarities and Differences bit.ly/4kBiC6t
4. Your Child is Going to Kindergarten: Making the Move Together bit.ly/4jMbAuk
5. Saying Goodbye at drop off: 11 Ways to Help Children Say Goodbye bit.ly/3ZskeHs

Learning and Growing continued from page 7

only made it feel scarier. Slowly, by connecting with professionals, asking questions, and becoming involved in my son's therapy, I started to feel more empowered. I learned that communication can take many forms—and that an AAC device can be life-changing for a child who is nonverbal. I learned that the tone and patience in how we speak to children matter greatly, and that celebrating small wins, such as a new word or a shared moment of eye contact, is incredibly meaningful.

I also learned that being informed—about services, your rights, and what your child is entitled to—can change everything. Taking classes through PIC helped me become an active participant in IEP meetings rather than feeling lost or unsure of what to say. Understanding how to advocate for Alexander's needs has been one of the most empowering things I've done as a parent.

Finally, I've learned that you're never alone, even if it feels that way at first. There are communities, groups, and other parents going through similar journeys, and their support can make all the difference. Whether it's a sensory-friendly play session or a support group chat, finding others who understand makes this path feel more manageable—and filled with hope.

Learning to See Differently, Together

Ellie is a joyful, curious 28-month-old who may seem quiet in new settings—but once she feels comfortable, her bright personality shines. That initial caution is partly due to Ellie's visual impairment, which is where her journey begins.

In the first few weeks after she was born, we noticed that Ellie didn't seem to open her left eye as much as her right. Occasionally, we saw what looked like a silvery spot in Ellie's pupil—but as first-time parents, we weren't sure what "normal" looked like for a newborn. At Ellie's two-week checkup, her pediatrician noticed that the eye lacked a red reflex. We were quickly referred to Boston Children's Hospital, where Ellie was diagnosed with a congenital cataract. She underwent surgery at 4 weeks old and was fitted with her first contact lens at 6 weeks. Around that time, we learned about NHB-3 services and the range of supports available to help Ellie explore and navigate the world in ways that worked for her.

After moving from Massachusetts to New Hampshire, we connected with Community Partners, where Ellie began receiving weekly visits from an occupational therapist and regular support from a teacher of the visually impaired (TVI). These services helped not only Ellie, but us as well.

I was getting frustrated when Ellie wasn't meeting milestones or couldn't do certain things—and I had no idea how to help her, but working with these providers completely shifted my mindset. Some blessings come with having a child with differences—such as learning to think about accessibility and remembering that there are many different ways to experience the world.

That shift in mindset opened the door to new tools and strategies. Ellie is incredibly tactile, so we found that introducing new objects and experiences through touch helps her feel grounded and engaged. She hated taking baths until we started letting her feel the water first—so she could 'see' what was happening. One of our favorite tools has been tactile books, which use different textures to bring stories to life through the senses. These sensory experiences have helped Ellie connect with her environment in ways that feel safe and meaningful. High-contrast colors have also made a difference in helping Ellie better distinguish objects. One challenge early on was that Ellie was born during the height of the 'sad beige' trend. That muted, neutral color palette might be popular in décor and baby toys, but it makes it really hard for someone with visual impairment to see anything. Our apartment was no exception. With guidance from our OT and TVI, we began using painter's tape to mark doorways and corners, making it easier for Ellie to navigate and learn the layout of their home.

Ellie also wears an eye patch part of the day to strengthen her vision, which has become trickier as she's entered toddlerhood. She's learned how to take it off, but we've found so much support in the visually impaired community—especially through online groups with other parents navigating similar journeys. We're so thankful to live in a time when, even though Ellie's condition is rare,

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Manage My Meds?!

By Keri Brand

The YEAH Council has been hard at work putting together a presentation about youth perspectives on medication management. The goal was for the presentation to help other youth, families, and professionals who work with youth to navigate this tricky milestone that is fundamental to healthcare transition.

To prepare for the presentation, members of the YEAH Council, along with six other youth, completed a short survey about their experiences with managing medications. The survey asked youth to identify their challenges and successes in learning to manage their medications, as well as to describe what motivated them to try to become more independent with medications. The presentation was given online on June 10th. Three members of the YEAH council presented their personal experiences, and the results of the survey were shared.

From learning to swallow medications to understanding insurance coverage of prescriptions, managing medications independently can seem overwhelming. What the youth shared is that managing medications on their own was the result of building different skills, many of which can be learned one at a time. Swallowing pills may be one of these. Another is knowing what medications one takes and what each medication looks like. Next might be knowing when to take each medication. Many of the youth reported that remembering to take medication on a schedule was one of the things they had struggled with. YEAH members have used calendars, timers, and pill organizers to support them in mastering this skill. Family members may need to help and back youth up for a while. Once this skill is solid, the youth can move on to other skills, like learning how to obtain their prescriptions and how to navigate the pharmacy. The process doesn't happen overnight, and it doesn't have to, especially if you start the learning process early. The American Academy of Pediatrics (AAP) recommends starting this process around age 12(1).

Youth shared tips and strategies for others who are learning. Here are some of their responses:

- If you are experiencing a symptom that you haven't talked with your doctor about while taking medicine, let them know so they can advise you.
- Know what you're taking, learn your condition, and stick up for yourself.
- Use an organizational system, such as a calendar or checklist.
- Ask yourself why remembering to take medication is difficult for you - is it the side effects or something else?
- Listen to your elders.
- Write things down for reference for next time.
- Think ahead because sometimes you can't get medications right away.
- Create a daily routine.
- Giving your pet a treat when you take your medications is helpful because even if you forget, your pet won't.
- Have grace. Try different things until you learn to manage your own medications.

Keri Brand is a Resource and Program Support Specialist at NHFV and a mom of two kids. She has an M.Ed in Science Education from Temple University and enjoys spending time in nature whenever she can.

Youth for Education, Advocacy, and Healthcare (YEAH)

Did you know there's a council led by and for youth with chronic/complex health conditions and disabilities in NH? It's free to join and only requires 3-5 hours of your time each month.

Youth voice can influence policies and how health and education professionals engage with young people while also empowering other young adults!

Visit **nhfv.org/get-involved/youth-involvement/** to learn more about the YEAH Council mission and check out our podcast while you are there.

The YEAH Council is supported by The Parent Information Center and NH Family Voices if you would like to chat with us, e-mail **yeahcouncil@nhfv.org**

YEAH COUNCIL

Managing My Meds in College

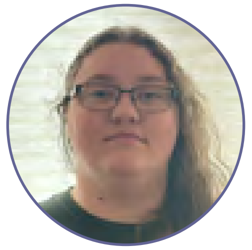
By C.J. Martin

As a member of YEAH, I wrote this account of my experience, which describes how managing medications successfully must also include advocating for yourself during appointments and ensuring that each of your providers has all the necessary information about you to choose the best course of treatment.

I had a generally smooth ride to medication independence, but only because I was willing to subject my doctors to a few friendly interrogations. I'm generally an independent spirit, so I started attending appointments alone at 18 and switched several of my doctors around that time since I had relocated for college. We went over my medical history, which, luckily, I had spent time studying, but when I said I was experiencing aura migraines, the new gynecologist stopped me mid-explanation. It turned out that I had been put on hormonal birth control, which can increase the frequency and severity of aura migraines! From then on, I was more thorough about telling doctors my medical history and careful to ask about any interactions new medications could have—either with other medications or preexisting conditions. The doctors can stand a few more minutes of questioning!

I took this same approach when I was prescribed a controlled medication. I interrogated the doctor about it. What possible interactions are there? Are there any lifestyle changes that could lower its known risks? How do I pick it up from the pharmacy? By the time I got my first prescription, I knew to have my ID ready. I had started watching my saturated fats to reduce the risk of high cholesterol associated with my med, and that it didn't interact with any of my other medications—or preexisting conditions.

Don't forget to come up with a list of questions before your appointment, or reach out through your patient portal afterward to make sure you receive all the information you need to know and you don't end up taking a med that hurts rather than helps.



C.J. Martin is a student at the University of New Hampshire and has been a member of the YEAH Council since 2019.

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it's possible to connect with families who are further along and generous with their tips and encouragement. Now, Ellie is preparing to transition out of NHB-3 and into the school system. It's a big change; there are a lot of new and sometimes scary things—but there are so many resources that are helping make the transition smoother. As part of the plan, Ellie's team visits her at home and daycare and even takes "field trips" to new places, such as unfamiliar playgrounds, to help her develop strategies for navigating new environments.

In the beginning, we really wrestled with the fear of what this diagnosis would mean for Ellie's future. It felt like the only story, and it was a story about loss. We worried about all the things she might not be able to do.

Over time, that changed. The support we received through NHB-3 helped us understand what Ellie could do and how to help her get there. Connecting with other families—especially online—helped us see that we weren't alone. But most of all, it just took time. Time to watch Ellie thrive in ways we never expected. She's brilliant with puzzles, loves to read, and is always finding new ways to adapt. We've been amazed to see her actively integrating her senses—if we're reading a book about baking and get to the page about mixing ingredients, she'll hop up and grab a whisk from her play kitchen. She surprises us every day. Time helped us see just how curious, funny, and full of personality she is—and taught me that her diagnosis doesn't define who she is or limit who she is becoming.

Let go of the expectations you thought you'd have—your child will grow in their own way, in their own time. At some point, we realized I needed to stop comparing and start trusting. Our mantra became: Ellie will do what Ellie will do, when Ellie is ready to do it. Parenting is a wild and weird adventure no matter what, and when your child has a visual impairment, there's just a little more 'wild' and 'weird' in the mix. Ellie's visual impairment is part of who she is and part of her story—but it's not the defining story, and it's certainly not the most interesting thing about her. Still, let's be real—when she is older, 'I've been wearing a contact lens since I was six weeks old' is going to be an epic fun-fact icebreaker!

Sources: [1] bit.ly/45Wn5My, [2] bit.ly/4l8IaYw

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