New Hampshire FAMILY VOICES®

Fall 2015

Empowering and informing families and professionals caring for children with special health care needs and disabilities from birth to adulthood for over 20 years.

In this issue:

2016 Conference Keynote
Upcoming Events
Book & App Reviews
Special Ed Law Forums
New Tools & Resources
Communicating with your Child's School Nurse
New Managed Care Guide
And More!

Back to School

Middle School Transition: Lots of Love and a Little Luck

By: Lee Laughlin

My son Timmy is entering the 6th grade. Ugh, how did that happen? Who gave him permission to grow up? Like the rest of the family, Timmy has albinism, a genetic condition that causes lack of pigment in the skin hair and eyes.

Because my husband and I have the same type of albinism, we knew our kids would be born with the same condition. So like his older sister, Timmy has difficulty seeing details at a distance (i.e. writing on the board) and reading small print. Unlike his sister, he also has some sensory and fine motor issues as well as a diagnosis of ADHD. These conditions may identify him, but they do not define him. He is an enthusiastic learner and teachers have always commented that he is a cheerful and active participant in class. We've had an amazing six years at our elementary school, but the time has come to move on to middle school.

We are big believers in raising independent kids. Middle school is just another transition into a more independent stage of life. We believe in building solid foundations and putting supports in place, then encouraging the kids to use the resources at their disposal. We are there to help, but we know to be truly successful in life, the kids will need to work hard and learn when and how to advocate for themselves.

It helps that we have an older child who has already successfully trod this path and is now a sophomore in high school. There have been changes at the middle school, but the key players that contributed to my daughter's success, are still there.

My son will have the same case manager my daughter had. This was a special request and I was thrilled it was granted. The case manager and I had a great relationship throughout my daughter's tenure. Her personality is a good match for my son and she already has a strong working relationship with the other key player on my son's IEP team, the teacher for the visually impaired (TVI).

As luck would have it, the TVI that serves the middle school worked with my son from birth to three then left that position to work with school aged kids. She's had my daughter for the last 5 years and will now take over my son's case. This is great news for us.

My son's ADHD manifests as a lack of focus and

Continued on page 15

(800) 852-3345 X 4525 (In NH) or (603) 271-4525

nhfamilyvoices@nhfv.org ♥ www.nhfv.org

Letter from our NHFV Team

Sylvia Pelletier, Project Coordinator

It's that time of year again! The days get shorter, the weather a bit cooler and for many families, the kids are heading back to school.

As parents ourselves, our entire staff shares in your sense of excitement, wonder and perhaps concern. This time of transition has many parents wondering what will this year bring. We hope it brings a sense of new beginnings and opportunities for success on many levels for you and your child. For some, certain goals will require a great deal of work, on an individual level and with the team at school.

Believe it or not, our staff has over 100 years of combined experience as professionals in the field of children with chronic conditions and disabilities and most importantly as parents of these children.

Here are some tips we would like to share to make this school year a successful one;

- Educate yourself & those around you. You are your child's best advocate. What are your school policies about homework and attendance? Do you understand the full protections of a 504 or IEP? What information about your child's diagnosis can you share with those working to ensure his/her success?
- Review your child's IEP and/or IHP at the start of the year to make sure everyone is on the same page. Involve your child in this process.
- Reach out in a friendly manner to open the lines of communication and keep them open. Put any concerns you have in writing. Remember that everyone is doing their best, but we are all working within different constraints.
- Minds are like parachutes, they only function when open. Don't let the experiences of others color your view. Whether you are listening to your child or those working with him/her, form your own opinions.
- Make sure the schedule allows for some down time - for everyone.
- Remember that you are only human - super parenting is for comic books and TV shows.

- Be present. As parents of children with special needs, it's easy to get wrapped up in all that we have to do and miss out on the precious moments we have with our kids.
- Ask yourself, will this matter in an hour, a week, a year or even 10 years? It helps to put what might seem like a crisis into perspective.
- Above all, be patient and keep a sense of humor.

If you find yourself in need of support, or to brainstorm a challenge with another parent, don't hesitate to contact us at NH Family Voices. With a trained staff, a large lending library, resources on our website and Pinterest page, and the support of hundreds of other parents via our private Facebook group, there is no need to ever feel alone.

Online Subscription

NHFV is striving to deliver valuable information and resources to families and the professionals that work with them through a variety of outreach tools. The paper copy of *Pass It On* serves many purposes and is one of our most valued resources. But reality is… many do their reading and sharing online. The electronic version of *Pass It On* contains live links so that readers may click and get to more in depth information in seconds. We would like to encourage those who are receiving a hard copy to think about this new feature and feel free to switch to the electronic newsletter version.

This is easy to do, just follow these steps!

1. go to www.nhfv.org and click on ***Membership*.**
2. Fill out the form as if you were a new member (please include address information).
3. Add nhfamilyvoices@nhfv.org to your email safe senders list, address book or contact list so that email newsletters are not blocked or filtered into your spam folder.

This free resource is intended for sharing so please continue to ***"Pass It On"*** to friends, family and professional you think might find it useful.

Partnering for Strength 2016

PIC & NHFV Announce Keynote Speaker, Rachel Adams

Save the date for the annual Partnering for Strength conference April 1-2, 2016. This is an event where families and professionals caring for children and youth with special healthcare needs and/or disabilities collaborate, learn and laugh together.

We are happy to announce our keynote speaker this year is Rachel Adams. Adams is a writer and Professor of English and American Studies at Columbia University. Her most recent book is *Raising Henry: A Memoir of Motherhood, Disability, and* Discovery. Parents, particularly those of young children and professionals that work with them will not want to miss her presentation of *Making Time for Our Children: Challenges and Opportunities for the Special Needs Family.* Recognizing that children with disabilities develop, move, and think at a different pace than typical peers, Professor Adams explores how in a busy and often hectic world, parents can make time to enjoy their children with special needs and allow them to operate at their own pace. She will talk about her experiences as the parent of a child with Down syndrome and use the lens of time to focus on how doctors, therapists, and educators think about issues such as slowness, regression, and developmental delays and the importance of allowing individual families to come up with alternate understandings of time that are appropriate to their beliefs, values, and circumstances.

In addition, Adams will be running a workshop later in the day about writing and advocacy for attendees.

To learn more about Rachel Adams, visit her website at http://racheladams.net/.

New Hampshire FAMILY VOICES®

Pass It On is a free quarterly newsletter for parents of children with special health care needs and the professionals that support them.

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This publication is not intended to provide medical advice on personal health matters. All health concerns should be discussed directly with your physician.

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How Big is My Problem?

A tool developed for children could benefit us all

About halfway through the summer I noticed something about one of my kids. His reactions to situations that he found "unfavorable" seemed far larger than the problem at hand. Many times it had to do with a sibling, and this is common because siblings often have the power to push our buttons like no one else. But I also noticed it with other situations too, like not getting something right on the first try.

After experimenting with just about every solution I could find on Pinterest, we finally found a technique that worked. It's a chart entitled, "How Big is my Problem?" There were many different versions of this chart available online, all are adapted from the *Incredible 5 Point Scale* by Kari Dunn Buron and Mitzi Curtis. This book is available through the NHFV Lending Library. The 5 point scale is widely used all over the world to help children develop and improve self-management and self-regulation, two evidence-based practices.

Many of us parents and professionals are acutely aware of the terms self-management and self-regulation, as they have become part of our everyday lives caring for children and youth with special healthcare needs and/or disabilities. All children need these skills to be successful. In fact, all adults do to and these are learned skills, they are not instinctual. I put the "How Big is My Problem?" chart in a place where I could pull it out whenever my son seemed to have an over the top reaction. His sister took his spot on the couch, he exploded, I pulled out the chart and asked, "Are you in danger?" and pointed to the crazed #5 face on our customized chart. He admits that neither the couch, nor his sister has put his life in danger today and we decide this is probably a #2 on the scale which means he's disappointed. We asked these questions all summer long.

The funny thing is, the "How Big is My Problem?" is a tool all of us could use! How many times do we as adults find ourselves reflecting on a frustrating situation and thinking, "I probably overreacted a little on that one"? As humans, we all struggle with this when under stress. It is a conflict between our primitive brain and our modern mind. Our primitive brain is our most powerful and oldest function of the brain. It has helped us survive thousands of years and survival is the brain's main priority. When we perceive ourselves to be under stress (threat), it is what provides us with the options of fight, flight, or freeze. These reactions are instinctual and have been part of our biology for thousands of years. And for all those years it served us well. When we were hunters and gatherers, if we saw a huge tiger, our brain would instinctually drive our reaction to fight, run away or freeze.

Now fast forward to modern day life, there's no tiger stalking us in our backyard (although in NH there could be a bear or two) and we still have these instincts. Our brains haven't caught up to our modern lives. For example, the IEP meeting. Here we find ourselves in a situation where we are advocating for our children's education, and because education is a major factor in determining our child's trajectory for success (modern world), our protective mama/papa bear instincts become activated (primitive brain). This is natural and in fact, biological. We see any roadblock to our child's wellbeing as a threat. In the modern world, the threat of our child not having every opportunity that every other child has

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Know someone who could use this info? Well then, just Pass It On! This newsletter is called *Pass it On* for a reason, we want you to share it with friends, families and co-workers!

Local Event Highlights

Education and entertainment for families & professionals

September 15

Workshop

Evaluations: What's in it for your child?
Parent Information Center
54 Suncook Rd., Concord, NH
Pre Registration Required.
Call PIC at 603-224-7005.

September 18

Conference & Expo

Abilities Expo Boston
Workshops, Exhibitors & Events
The Boston Convention Center
Admission is Free
http://www.abilities.com/boston/visitors.html

September 25

Annual Conference

From Risk to Resilience
NH Association for Infant Mental Health
Annual Conference
The Mountain Club on Loon in Lincoln, NH.
For more info:
www.nh4youth.org/news/events/risk-resilience

October 4

Entertainment

Autism Friendly Performance of Cinderella
The Boston Opera House
For more info:
https://www.autismspeaks.org/cinderella

October 9

Conference

Mental Health & Schools Conference
SERESC 29 Commerce Drive Bedford, NH
For more info contact:
Liz Hodgkins lhodgkins@naminh.org

For even more happenings visit our events calendar at www.NHFV.org, just click on the events tab. Our calendar is updated weekly. To submit an event, email ebd@nhfv.org.

Find us on Facebook

Join our community!

We post the latest events, opportunities and news. This online community is a great way to connect with other families like yours!

Be sure to click the "get notifications" option so that you receive all updated information.

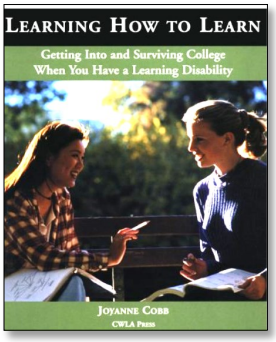
We also host a private Facebook group so that our families can connect with one another in a more private setting. Our staff and group members exchange information, resources and support around the clock.

http://www.facebook.com/groups/nhfamilyvoices/

♥ Do you receive this ♥ newsletter by email? Be sure to add nhfamilyvoices@nhfv.org to your safe email list - otherwise you could miss out on this and other great news from NH Family Voices!

New Hampshire FAMILY VOICES® Lending Library

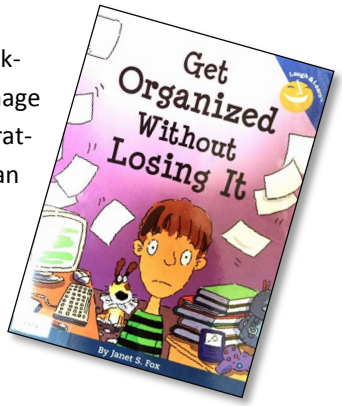
Back to School Books for Families & Professionals



Learning How to Learn: Getting Into and Surviving College When You Have a Learning Disorder
By Joyanne Cobb

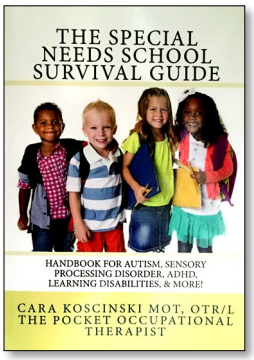
Written for high school and college students with learning disabilities, this thorough, down-to-earth manual, designed in an LD-friendly format, gently steers students through the process of applying to college, selecting the right classes, and succeeding academically. The author offers concrete, step-by-step advice on how students with LD can discover their learning strengths; take standardized entry tests in a form best suited to their needs; obtain special services; find and select a college program that will best support them and their goals; take advantage of a wide range of supports; and learn about and advocate for their rights under the Americans with Disabilities Act. The author also gives lots of personal tips and strategies for doing course work, writing papers, and taking tests.

Get Oraganized Without Losing It!
By Janet S. Fox



Kids today have a lot to keep track of—and keep organized. Schoolwork, friends, activities, chores…rooms, backpacks, lockers, desks…and what about fun? Here's friendly, practical, humorous help for kids who want to manage their tasks, their time, and their stuff—without going overboard or being totally obsessed. Tips, techniques, strategies, and examples empower kids to conquer clutter, prioritize tasks, handle homework, prepare for tests, plan projects, stop procrastinating, and start enjoying the benefits of being organized: less stress and more success. Lists and steps make it doable; jokes and cartoons make it enjoyable. Recommended for any kid who's frustrated, overwhelmed, and sick of hearing "Clean your room!" "Where's your homework?" and "You're going to be late AGAIN!"

The Special Needs SCHOOL Survival Guide:
Handbook for Autism, Sensory Processing Disorder, ADHD, Learning Disabilities, & More!
By Cara Koscinski



The Special Needs SCHOOL Survival Guide is a handbook for anyone teaching, living with, homeschooling, or working with students who have: autism, Sensory Processing Disorder, ADHD, learning disabilities, behavioral concerns, handwriting difficulty, fine motor delays, trouble with transitions, homework concerns, dyslexia, dysgraphia, and more! It contains an easy to read Q&A format. Every section answers common questions teachers, parents, and homeschoolers ask about teaching a student who has special needs. The "Out of the POCKET" activities are specially designed to be carried out easily in either a group setting or individually. Included are facts on Individual Education Plans, 504 plans, classroom modifications, and accommodations for many types of students and disabilities. This book is written by a pediatric occupational therapist who is also a mother to two children with autism and Sensory Processing Disorder. It will be an invaluable reference for parents, caregivers, teachers, students, classroom aides, school districts, therapists, occupational therapists, speech-language pathologists, physical therapists, special needs teachers, psychologists, physicians, principals, and teaching assistants. A "go-to" resource that you'll refer to time and time again!

Attention guidance counselors, educators, and school nurses! Our lending library is not just for families!

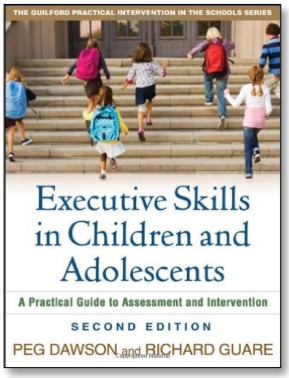
We have books and videos for professionals and children that you can use in your daily work. Looking for a specific subject? Give us a call!

Check out our lending library's topics list on our website www.nhfv.org

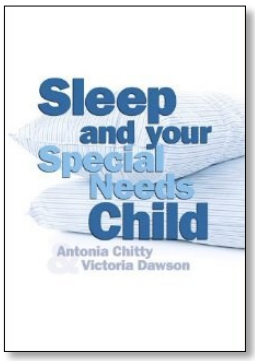
Books are sent free of charge through the mail with a postage paid return envelope.

To borrow a book call 603-271-4525 or visit www.nhfv.org

Executive Skills in Children and Adolescents, Second Edition: A Practical Guide to Assessment and Intervention
By Peg Dawson and Richard Guare



Concise and practitioner friendly, this bestselling guide has helped put executive skills on the map for school-based clinicians and educators. The book explains how these critical cognitive processes develop and why they play such a key role in children's behavior and school performance. Provided are step-by-step guidelines and many practical tools to promote executive skill development by implementing environmental modifications, individualized instruction, coaching, and whole-class interventions. In a large-size format with convenient lay-flat binding, the book includes more than two dozen reproducible assessment tools, checklists, and planning sheets.



Sleep and Your Special Needs Child
By Antonia Chitty

We know sleep is vital for children's health, mood, behavior, and learning ability. Without intervention, sleep problems can last into adolescence and beyond. Authors share a highly successful behavioral and cognitive approach to sleep management children with special needs. This practical advice is invaluable for parents who want to feel more in control and confident about tackling sleep issues in a way that is appropriate for their child.

1000 Books Before Kindergarten

Children's Librarians of NH Partner with NHFV on Early Literacy Initiative

NH 1000 Books Before Kindergarten is an early literacy initiative that encourages families and caregivers to provide positive, nurturing early experiences by reading aloud to children regularly and using the resources of their public libraries. The project is based on the national 1000 Books Before Kindergarten initiative. NH 1000 Books Before Kindergarten is sponsored by Children's Librarians of NH and supported by the NH State Library, Center for the Book at the NH State Library, the NH Academy of Family Physicians, and NH Family Voices.

Research shows that the most reliable predictor of school success is being read to at home during early childhood. The brain develops more rapidly during the first three years of a child's life than at any other time during the lifespan. Reading to children from an early age can help close the vocabulary gap and prepare children to enter kindergarten with the skills they need to succeed. Most important, sharing books with children promotes a lifelong love of books and reading.

Look for the program's canvas bags filled with resources for families at your local library. If this program is not currently running in your community, encourage your library staff to launch it by directing them to http://1000booksbeforekindergarten.org.

Call us or log on to www.nhfv.org and click on "how we can help, then choose Lending Library

Search thousands of books by subject

Add the book you like to your cart and fill out the delivery form

Books will be delivered to your home/office with a prepaid postage envelope for you to return them

Join the YEAH Council

Make an impact on your life and the lives of others

Zach Hastings is a Youth Correspondent and member of YEAH Council (Youth for Education, Advocacy and Healthcare) at NHFV. Hastings hosts a blog called Wheeling through life, the writings of a man and his wheelchair, Check out more at http://wheeledjustice.wordpress.com/

Hey everyone!

You may have read a few of my columns in past editions of this newsletter. This time, I would like to tell you about a great opportunity.

I'm a member of the YEAH Council, a group of differently abled individuals who meet once a month in order to try and make a difference in the lives of others. We do this by teaching people about transitioning from school life to work life, how to take care of their own medical needs and about independence in general.

YEAH Council is a youth driven and directed group of individuals with disabilities and/or special health care needs. We are focused on developing and strengthening the skills and resources needed to achieve the unique independent life that we each desire. YEAH does this by empowering, educating and supporting individuals and professionals in the areas of education, advocacy and health care.

The work that YEAH council does across the state has had a direct impact on the quality of life young people with disabilities and/or chronic health conditions experience in New Hampshire.

We are currently looking for new members. If you're between the ages of 14 and 26 and have a disability or special health care need of any sort, message us at yeahcouncil@nhfv.com. We'll find you a place in our family!

YEAH COUNCIL

There's an App for That!

Organizing information and brainstorming

Popplet By Notion

Popplet is a very easy to use mind-mapping tool to capture and organize ideas. This can be especially helpful for students who struggle with organization and visual memory. By using Popplet, students can quickly jot down ideas and sort them visually.

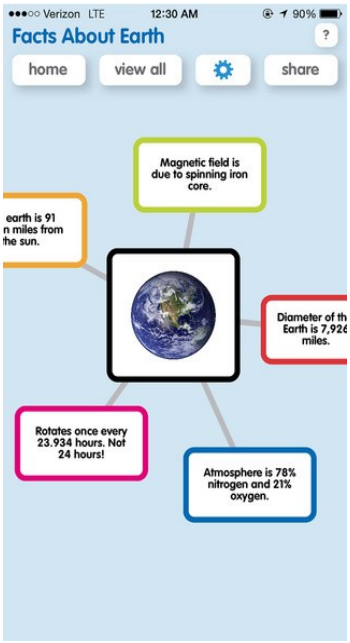
This app has appealing graphics and an intuitive, neatly organized interface. It produces immediate results with its ability to manipulate "nodes" or ideas on the screen easily for those with fine motor difficulties or for younger users.

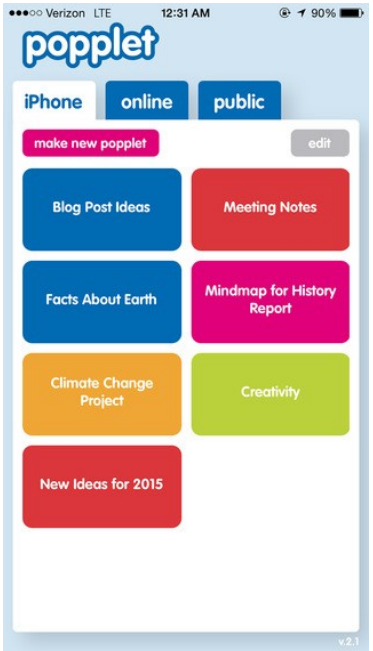
Popplet is great for learning in the classroom and at home. By capturing facts, thoughts, and images, students learn to create relationships between them and generate new ideas.

At the middle and high school levels, Popplet is great for organizing information before writing a paper or starting a project. The user can add pictures, text and video to combine all resources and information in one place.

ADDitude Magazine editors listed Popplet as one of the best homework and study apps for children with ADHD.

Popplet can be used online for free or by downloading Popplet Lite on to your iPhone or iPad. It's always a good idea to try the free version before purchasing the full blown app for $4.99. You can also see how this app is used in different ways by visiting www.popplet.com





NH Special Education Regulations Reauthorization

Family is Crucial to Having Functional IEPs

By Bonnie Dunham, Parent Information Center

The current ***NH Rules for the Education of Children with Disabilities*** (NH's special education regulations) are due to be reauthorized by June 30, 2016, and the NH Bureau of Special Education wants to hear from you to help them decide what to include in their proposed reauthorized *NH Rules*. Some changes will be needed in the *NH Rules* to ensure that they continue to comply with Federal and State law. Other changes may be proposed based on needs identified by the Bureau and/or the public. You get to tell the Bureau what you believe is important to ensure that the *NH Rules* continue to meet the needs of NH children with disabilities. Your involvement truly is important!

During the last major reauthorization of the NH Rules, hundreds of parents and others gave input – and the Bureau listened, which is why NH still requires short-term objectives as part of every child's IEP, begins planning to prepare a child for life after high school (transition planning) by age 14, requires parental consent at each step in the special education process, and includes clear timelines and other components that encourage parent involvement in the special education process.

The list of scheduled regional early input forums is included below. More information can be obtained from the Bureau of Special Education. The Parent Information Center is another helpful resource. Contact Bonnie Dunham at bdunham@picnh.org. with any questions.

Individuals wishing to provide written input should email Bridget.Brown@doe.nh.gov by October 2, 2015. Please include "written input" in the subject line.

The Bureau has scheduled the regional early input forums and webinars(**) listed below to present the current rules and hear from the public. To accommodate the needs of parents and others, forums have been scheduled at a variety of times. Participants can join the webinars from their computer, tablet or smartphone by using the access link/conference code number provided.

Date	Time	Location
9/4/2015	1 pm - 3 pm	Laconia Public Library 695 Main Street, Laconia , NH
9/8/2015 **	9:30 am - 11:30 am	Webinar NH Special Education Rules Meeting #1 Access link: https://global.gotomeeting.com/join/429881605 To join the call dial 1-800-240-3895 guest code: 600113#
9/14/2015	1 pm - 3 pm	North Country Ed Services 300 Gorham Hill Rd, Gorham, NH
9/15/2015	10 am - 12 pm	Claremont Savings Bank, Community Room 145 Broad St., Claremont , NH
9/16/2015	9:30 am - 11:30 am	Lane Memorial Library, Lane Room 2 Academy Ave, Hampton, NH
9/21/2015	5 pm - 7 pm	Londergan Building Room 15 101 Pleasant Street, Concord, NH
9/23/2015**	1 pm - 3 pm	Webinar NH Special Education Rules Meeting #1 Access link: https://global.gotomeeting.com/join/429881605 To join the call, dial 1-800-240-3895, guest code: 600113#
9/28/2015	6 pm - 8 pm	Linwood Public School, All Purpose Room 72 Linwood Drive, Lincoln, NH

Education and Your Medical Home

Back to school time is an opportunity to improve your partnership

Partnership in Practice: What Does This Mean?

Primary care practices are increasingly asked to work in partnership with patients and families, both in meeting individual care needs and in quality improvement efforts for the practice. Much of this work happens as a result of the commitment to a concept of *how* care should be delivered, known as "medical home". This is not a new concept, but for many, the term is unfamiliar, and confusing. It is important that patients and families understand what it *feels* like to receive care within a practice committed to this concept.

In a medical home model, a primary care practice acts as the center or hub of a patient's care team. In this model, the practice is responsible for addressing the medical *and* non-medical needs of the patient. This is a whole patient approach. This doesn't mean the practice has to provide non-medical services, but it is supposed to work together with a patient / family to address identified needs and refers to resources that will help meet those needs. In the case of a child, a parent works in partnership with a child's primary care physician to identify goals and priorities. The practice actively communicates and exchanges necessary information with all participants to achieve these goals. Participants vary based on the needs of the child. They could be specialists, educators, family members, or childcare providers. The key is that a primary care physician is at the center, looking at the child as a whole.

As children head back to school, this is a great time to consider what role your child's provider plays, or could play, as your partner in insuring your child's needs are met at school. Do you have concerns about your child's learning, development, or behavior at school? Have you discussed these concerns with your child's provider? Does your school have questions about how to best meet your child's health needs? Have you asked your child's primary care provider how they can help to support school staff to understand and meet your child's needs during the school day?

If you want more information about partnering with your provider, or need help to get started, please contact us at NH Family Voices.

Medical Home Principles

Patient/Family Centered: A partnership among practitioners, patients, and their families ensures that decisions respect patients' wants, needs, and preferences, and that patients have the education and support they need to make decisions and participate in their own care.

Accessible: Patients are able to access services with shorter waiting times, "after hours" care, 24/7 electronic or telephone access.

Compassionate: The provider exhibits empathy when listening to patients with full attention and communicates with families effectively in a way that is easily understood.

Comprehensive: The team of care providers takes a "whole person approach" for a patient's physical and mental health care needs, including prevention and wellness, acute care, and chronic care.

Coordinated: Care is organized across all elements of the health care system, including specialty care, hospitals, home health care, community services and supports.

Continuous: The patient's relationship with the primary care doctor is developed and strengthened over time by seeing the same provider at each visit and communicating with this person when questions or concerns arise outside of the medical office.

Culturally Effective: The team is aware of and values the patient's culture and religious beliefs and considers these when prescribing treatment and care.

Talking With Your Child's School Nurse

School nurses are doing more for children with special healthcare needs than ever before

School nurses play a big role in the overall wellbeing of a child with special healthcare needs and/or disabilities. Keeping your child's school nurse in the loop and letting them know about your concerns could really make a difference in your child's educational experience.

Families should be sure to involve the school nurse in any conversation with school staff regarding a medical condition or diagnosis, but also for secondary concerns that could be related. For example, if a child has a diagnosis of Tourette's syndrome, he or she may have anxiety related to tics happening in school. This can be a cyclical situation as anxiety can also increase tics.

"It's always good for parents to inform the nurse and guidance staff of any emotional challenges a student may be dealing with. If a student has anxiety, many nurses are open to practicing relaxation techniques such as deep breathing, yoga or guided meditation. Parents should also share any techniques the student uses at home to help manage stress." said Denise Bailey, School Nurse at Salisbury Elementary School. Nurse Bailey has a degree in Alternative Healthcare in Nursing. She explained that having experienced anxiety throughout childhood and adolescence herself, she is passionate about teaching kids tools they can use in and out of school. "I do yoga classes with students who are interested and practice guided meditation with them quite often when they come into the health office feeling sick or upset. It has been really effective. The kids love it and parents thank me for working with their child. Many times, I loan out some of my resources, like yoga cards for kids and families bring them home to learn together", said Bailey.

Individual Health Plans

A school nurse can develop an individual health plan (IHP) with input from your family and your child's PCP (remember that a medical release form needs to be signed before any communication or release of records can occur). This is a document that explains a student's medical condition and how to address his/her needs throughout the school day. It will outline things like medication dosage, frequency and who is authorized to administer the medicine. In the case of a condition like diabetes, an IHP would explain how a child needs to be monitored and who will oversee that. An IHP should also address the steps to be taken in an emergency situation and include the family's authorization for the agreed upon plan to be executed.

"I do IHP's on all of my students with asthma. It is a way to let the teachers know that they have a student with a respiratory issue in class. It explains what symptoms to be aware of and what to do if symptoms occur", said Nurse Bailey.

Developing an IHP with your child's school nurse is a great opportunity to collaborate and expand a child's support system at school. The IHP format varies by district. It can be used alone or with a 504/IEP and should be reviewed annually to keep everyone up to date on changes that occur. It is important to remember that an IHP is not like an IEP or 504, as there are no federal or state protections provided. However, if a child has a chronic health condition or disability, it can be just as important.

Many organizations provide sample IHP formats to help families and professionals get started, but talk with your child's healthcare providers first to discuss his/her needs and ask for documentation outlining what their recommendations are. Then it's off to school!

Children with Special Health Care Needs and the Well-Child Visit

The American Academy of Pediatrics (AAP) recommends 13 well-child visits during the first three years of your child's life. Well-child visits are all about prevention and promotion of healthy habits. Recommended vaccinations are given during these visits, as well as routine screenings for such things as vision or hearing problems, anemia, autism, and other issues. It is the perfect time to share what your child is doing and learning, and to share any questions or concerns you might have.

If Your Child Has Special Health Care Needs, Does He or She Still Need These Additional Health Care Visits?

Yes! Every child needs well child visits! Even the child with the most severe special health care issues or disabilities still needs good information on healthy eating, oral health care, and safety precautions. The information can be tailored to fit the needs and abilities of the child, but it is still important.

The Well Visit Planner: A Tool to Help You Make the Most of Your Well Child Visits

A new tool can help you make those visits as meaningful as possible: the **Well Visit Planner.** The Well Visit Planner is an online tool to help families prepare for their children's upcoming well-child visits to the health care provider. It's free to use; is available in English and Spanish; takes 10-15 minutes to fill out before each visit; and can be printed and taken to a visit to help you and your child's doctor discuss your child. It helps families be better partners in their child's health care, and helps health care providers better serve the needs of the child and the family.

Using the Well Visit Planner for Children with Special Health Care Needs

You can adapt how you use the Planner depending on your child's special health care needs. For example, your child may have a developmental delay. If so, it may be more helpful to complete the questionnaire about your child's developmental age, not his or her actual age.

Use the Planner as a tool to help you think through the topics around promoting good health and preventing illness and accidents for your child.

The Well Visit Planner can also give you ideas of questions to ask your child's specialists or other health care providers.

To Learn More about the Well Visit Planner

To learn more about the Well Visit Planner, check out two videos:

The Well Visit Planner, Part 1—Making the Most of your Child's Health Care Checkups: An overview of the Well Visit Planner
The Well Visit Planner, Part 2—Using the Well Visit Planner: A Step-by Step Guide: A tour of the Planner—the steps involved and the kinds of questions it asks.

The Well Visit Planner (WVP) was developed and created by the Child and Adolescent Health Measurement Initiative (CAHMI) (www.cahmi.org). National experts, families, and pediatric providers worked together in the design, development, and testing of the WVP. The information contained in the WVP is based on the American Academy of Pediatrics *Bright Futures Guidelines for the Health Supervision of Infants, Children, and Adolescents* https://brightfutures.aap.org.
To use the Well Visit Planner, go to: www.WellVisitPlanner.org .

10 Reasons to contact NH Family Voices

1. My child was just diagnosed, I have all this information but no idea what to do next.
2. I am looking for books or DVDs on my child's diagnosis that I can use to help his teachers & classmates understand him better.
3. My spouse lost her job and now we won't have insurance to cover medical costs for our child with special needs and our family.
4. My child's school says she can't go on a field trip because they do not have a nurse available or anyone to administer meds.
5. I'm not sure how to begin looking for a qualified specialist, therapist, respite provider etc. in New Hampshire
6. I just found out Medicaid will pay for diapers. How does that work?
7. I need to pick a managed care organization or switch managed care organizations.
8. My child sees a specialist at Children's Hospital in Boston but they say they do not take Medicaid or our insurance.
9. Our doctor is recommending a medication, therapy, piece of equipment for my child that is not covered by our insurance.
10. I am working with a family and could use some help coming up with creative healthcare solutions for them.

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Empowering and informing families and professionals caring for children with special healthcare needs & disabilities for over 20 years.

Problem?... continued from page 4

in school is equivalent to the tiger drooling and smacking his lips while looking ravenously at our adorable son or daughter. And here is where the "How Big is My Problem?" tool comes in.

As adults, we probably don't need to carry the "How Big is My Problem?" chart around with us. We can quickly surmise how big the issue at the IEP table is and whether we need to stand our ground or save that energy for something that's more important. It's the pause it gives us that is so valuable. Just pausing for a moment before we get all riled up and asking ourselves, if this one thing will matter next week, next month or in 2 years, that's a powerful tool.

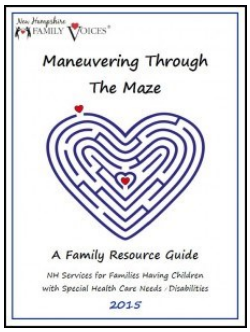
Life is a long journey of learning for all of us. My favorite tools are the ones everyone can use. Kids learn best by example rather than constantly being told what they should be doing, thinking, and feeling. We all do.

This tool can be found on the NHFV Pinterest page at https://www.pinterest.com/nhfamilyvoices/ under the behavioral health board.

By Robin deAlmeida, Mom, Mindfulness Instructor & Marketing Extraordinaire at NHFV

01

Maneuvering the Maze



This updated family resource guide provides over 100 pages of listings of state health and human services agencies, educational resources, private associations and organizations that serve children and youth with physical, developmental, mental health and chronic health conditions and their families. Resources, tips and best practices in this publication can be used by all state residents.

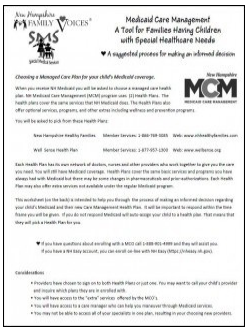
02

Medicaid Managed Care

Many families who have previously been able to "opt-out" will be receiving letters stating they must now enter the managed care system as it is no longer optional. Knowing that many within the specified categories are families with children who have special health care needs, NH Family Voices has put together this supplement to help you better understand NH Medicaid Managed Care.

03

Picking a Plan



A suggested process for making an informed decision. Picking a Medicaid Care Management Health Plan can be a bit overwhelming when your child has special needs. NH Family Voices and Special Medical Services collaborated on this tool in hopes it will help families look at the providers they are currently using and how they would fit into one of the MCO networks.

We have put together these FREE guides for families and professionals caring for children and young adults with special healthcare needs and disabilities.

Visit www.nhfv.org to download these resources and explore many more! You can also email nhfamilyvoices@nhfv.org to order hardcopies for your home or office.

New Hampshire FAMILY VOICES®

Middle School... continued from page 1

poor executive function skills. A low dose of daily medication helps him maintain focus. There isn't enough medication in the world to help with his poor executive function skills. This is where both the case manager and the TVI come in. Both have experience helping students build organization systems that work for them. Whew, we lucked out and I know it.

Fears and concerns

Our fears (both my son's and mine) for middle school are mostly social. He's a good kid, but he wears his heart on his sleeve. He often has strong opinions about how things "should" be and gets frustrated when things don't go his way.

He's concerned about being bullied because of his appearance. People with albinism have very fair skin and hair and their lack of vision means sometimes they don't make eye contact. He's been with the same group of kids since kindergarten, so they are used to who he is and how he functions best. Middle school brings together students from five elementary schools, so there will be lots of new faces.

Middle school was the worst three years of my life and our IEP team is well aware that I come into this with a chip on my shoulder. All of my worry for my daughter was wasted. She encountered the occasional bump, but otherwise thrived. While my son is very different from his sister my daughter's success makes me feel like my nerves are just my baggage, not the reality my son will encounter.

Preparing for middle school

This summer we've made a point to spend time with a few select friends to strengthen friendships with those who will be his support system when he gets to middle school. Just before school starts, we also host an annual back-to-school breakfast where we invite friends to practice getting up early and joining us in saying goodbye to summer

Timmy and his TVI visited the middle school several times at the end of last school year so he could become familiar with the layout and how transitions worked between classes. He learned what it's like to navigate the mob in the hallways and how to buy lunch. These things might seem trivial, but can be very stressful. Now that we have his schedule, the day before school starts he'll visit one last time and do a walk through with his TVI so he knows how to get from one class to the next.

Over the years I've learned that back-to-school can be crazy. The temptation is to try and catch up on all the things that didn't get done over the summer, but I've learned it's better if I try and keep my schedule light for the first week or two. This lets me be available to handle any issues that might arise and to celebrate even the smallest of victories.

We always have an IEP status meeting towards the end of September or beginning of October. This way the teachers have had a chance to get to know my kids and we can address any issues or answer any questions. Before this meeting I'll set aside some time to talk with both kids (one has a thing for Starbucks and the other is partial to Dunkin' Donuts). We'll grab a beverage and talk about how things are going and what they might need their teachers to know.

Change is hard, but it is a constant. We do what we can to mitigate the stress and then buckle our seatbelts for the ride.

Lee Laughlin is a writer, wife and mother, frequently all at the same time. She writes marketing and communication materials for small businesses and opinion pieces for the Concord Monitor. She is also hard at work on her first novel. She lives in Loudon with her husband and two children.

Supporting Parents

There are many different ways parent support and information opportunities become available to families. Some are directed by professionals and others are directed by parents. Support can be provided in a group setting or individually.

Sharing the family experience with others in similar circumstances is an important source of social support.

NH Family Voices is proud to offer parents an opportunity to support each other by writing articles for our newsletter. Through sharing experiences, it is our hope that these personal stories will help, encourage, and support others.

If you have a story to share or know of someone who does, please contact our editor at rda@nhfv.org.

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☐ physical disability ☐ learning disability ☐ developmental disability ☐ behavioral challenges
☐ I am interested in materials relating to: _____

I am a ☐ Professional working with families and/or children/adolescents/adults (circle) with a:
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☐ developmental disability ☐ behavioral challenges
☐ I am interested in material relating to: _____

I am a Professional in ☐ Education (circle one), EI, Head-Start, Pre-school, Elementary, Middle, High school, Residential setting. ☐ Health Care Field (circle one), Community clinic, Hospital, VNA, Physician, Family Practitioner, Nurse.
☐ Human Services (explain) _____ Other: _____

How did you hear about our *Pass It On* newsletter? _____