

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

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## The Power of Storytelling

*How one mom found community and herself through sharing her story.*

We recently sat down with Heather Bowie, author of Family Synapse, a blog about raising a child with a rare genetic syndrome. The blog is really about so much more though, it's about living authentically, connecting with others and really getting stuff done in a BIG WAY.

**What led you to start writing about your experiences as a family of a child with special healthcare needs?**

I started blogging about four years ago when we had our first fundraiser, this one for an accessible van for Aidan. I was hesitant to put Aidan out there but knew that in order to ask people for help, we needed to tell our story. I knew nothing about the rules of blogging, like using Search Engine Optimization and scheduling content and having catchy titles. I still don't follow the rules. I had no idea what to say, what would make people connect. I certainly didn't consider myself to be a writer. When our fundraiser was over, I found that writing was therapeutic and I had become part of a wonderful online community. Over time, blogging has helped me find value in my experiences with Aidan.

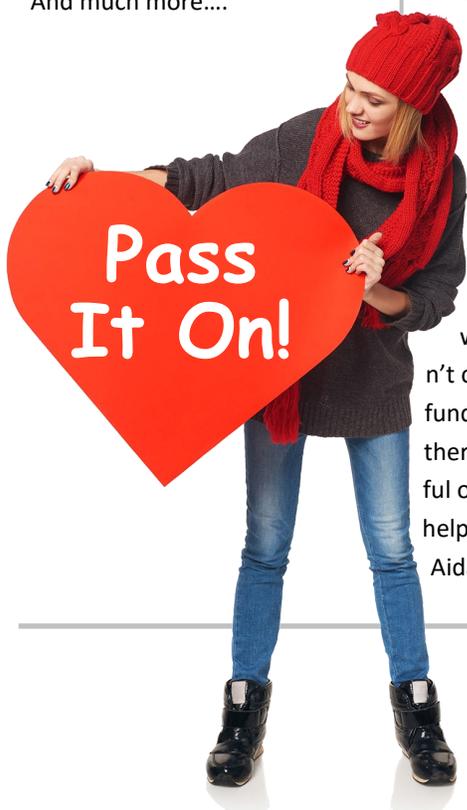
**Aidan went 13 years without a diagnosis, how did you describe his condition to someone new before and after the diagnosis?**

When Aidan was undiagnosed we definitely got our share of looks that indicated we perhaps had not seen the right doctor or asked the right questions because most people, including myself, believed that doctors have all the answers and "undiagnosed" can't exist. Now that he has a rare genetic syndrome, I'm still quick to point out that there are often more questions than answers in the medical world and that's ok! Because my child is more than a diagnosis. My elevator speech remains the same: His body doesn't work the way yours does, because his muscles are weak. I know he's smart, because he learned how to drive a power chair. Most importantly, he understands what you're saying and he's just learned how to speak for himself using a talker.

**What was it like to find out about the genetic mutations on Aidan's PURA gene after searching for a possible cause for all those years?**

Honestly, it threw me for a loop. I had gotten comfortable with not knowing. We did genetic testing, not really for Aidan, but to further sci-

Continued on page 14



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

[nhfamilvoices@nhfv.org](mailto:nhfamilvoices@nhfv.org)



[www.nhfv.org](http://www.nhfv.org)

# Letter from the Directors

## Martha-Jean Madison & Terry Ohlson-Martin Co-Directors, New Hampshire Family Voices

Dear friends,

We would like to take this opportunity to wish you a Happy New Year and welcome all new and veteran subscribers to *Pass It On*, our quarterly newsletter written for families and professionals caring for children with special healthcare needs and disabilities.

New Hampshire Family Voices is a unique organization in that it is staffed by professionals who are also family members of those with special healthcare needs and disabilities. This means that the resources and information in this publication are sourced by those who not only work in the field, but live it 24/7, just like you!

As professionals, we love this time of year particularly because our energy and enthusiasm for supporting our members is renewed. We have fresh ideas and are producing new resources for families and professionals throughout New Hampshire. As parents, we love the opportunity the New Year brings to reflect on the past, reinvigorate hope and approach things in new and different ways.

Check out our upcoming conference, *Partnering for Strength* or our new series *Take Control of Your Health* for young adults who are becoming more independent at managing their healthcare on page 8.

We open up each edition with a family story because we believe sharing our experiences is just as important as getting the right doctor or insurance policy. If you have an experience you would like to share, please contact our editor, information can be found on page 15. If someone has passed this newsletter on to you and you would like to subscribe, simply visit our website and sign up for a free membership!

As always, we are here to support you in any way that we can from navigating a new diagnosis to helping communicate your child's unique medical needs at school or understanding health insurance options and managed care, and everything in between. Start 2016 off by getting the information and resource you need to make informed decisions when it comes to the children and youth you care for.

Here's to a great new Year!

With love,  
Martha Jean & Terry



*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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### For correspondence:

Robin deAlmeida  
[rda@nhfv.org](mailto:rda@nhfv.org)

New Hampshire Family Voices  
129 Pleasant St. Thayer Bldg.  
Concord, NH 03301

(603) 271-4653

[nhfamilyvoices@nhfv.org](mailto:nhfamilyvoices@nhfv.org)

[www.nhfv.org](http://www.nhfv.org)



# PARTNERING FOR STRENGTH 2016

APRIL 1-2 GRAPPONE CENTER CONCORD, NH



**Bringing families, schools, communities and youth together to support children with disabilities and special healthcare needs for a weekend of education and entertainment.**

The Parent Information Center, NH Family Voices and YEAH Council invite families, professionals and young adults ages 14-26 interested in working collaboratively to support children with disabilities and special health care needs to our **Partnering for Strength 2016** conference at the **Grappone Center in Concord, NH**.

Join us Friday, April 1, for networking, dinner and a few laughs with guest Tracy Strombom, PhD of Warren Street Counseling. Tracy will discuss the power of humor in his presentation, *Humor for the Health of It!*

On Saturday, April 2, our keynote speaker is Rachel Adams. Adams is an author and Professor at Columbia University. 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*. The day will continue with 12 workshops to choose from with topics ranging from enhancing access to services with technology to anxiety and IEPs. Be sure to register soon as workshops fill quickly! To register visit [www.nhfv.org](http://www.nhfv.org) or call 603-224-7005.

**Youth only conference track:** If you are between the ages of 14-26 please join us for *Your Vision, Your Future: Creating the Life for You!* This event is planned for youth by youth. Friday night there will be dinner and a presentation on managing stress. Saturday sessions include vision board making, self-advocacy, navigating disability resources, navigating the IEP, soft skills and using your vision to plan your future. Come meet other young adults, eat good food and have fun!

**Call for exhibitors:** Space is open in the exhibit hall for businesses and organi-

zations who support children with special needs. To reserve a space contact Erika Downie at [ebd@nhfv.org](mailto:ebd@nhfv.org) or call 603-271-4525.



# Ready, Set, Connect! Crotched Mountain Announces Additional Manchester Location



Crotched Mountain Foundation has opened a new Manchester, NH location for its Ready, Set, Connect! Applied Behavior Analysis (ABA) program for children with autism. The program serves children from 18 months old through early teens.

Ready, Set, Connect! is an intensive one-on-one ABA treatment program which helps children who have autism improve social, communication, daily living, motor and academic skills, while reducing problem behavior. Led by Board Certified Behavior Analysts (BCBA), ABA therapists provide treatment in a caring and engaging environment. Ready, Set, Connect! offers highly individualized full- and half-day programs on-site which help children learn new skills and apply these skills in everyday scenarios at home, school and in the community.

“We are thrilled to bring our Ready, Set, Connect! program to Manchester,” said Dennis Bradley, BCBA and executive director of Ready, Set, Connect!. “With locations in Concord and now Manchester, families in the southern region of the state have more convenient access to vital applied behavior analysis treatment services for their children with autism.”

Crotched Mountain’s Ready Set Connect! autism treatment program is located at 340 Granite Street, Unit #3, Manchester, and 57 Regional Drive, Concord, NH. Both locations are currently accepting referrals. For information and to make a referral, visit [www.cmf.org/aba](http://www.cmf.org/aba), email [aba@crotchedmountain.org](mailto:aba@crotchedmountain.org), or call 603-226-2900.



Want to learn more about ABA resources and get answers to your ABA questions? Check out the *I Love ABA* blog by Behavior Analyst, Tameika Meadows at [www.iloveaba.com](http://www.iloveaba.com).

## Workshop: Parent Writers, Parent Voices

Please join our *Partnering for Strength 2016* keynote speaker, Rachel Adams, for an afternoon workshop on writing and advocacy.

Long before the passage of the Americans with Disabilities Act in 1990, parents were advocating for their children with disabilities. Today, parents continue to be a vital resource for representing the needs and desires of individuals who might not be able to speak for themselves. Writing is a powerful tool to promote change by presenting positive images of our children or describing the struggles and challenges they experience. Parent-writers are making their voices heard online through blogs, websites, videos, and in print via magazines, newspapers, and books.

In this presentation, author Rachel Adams will speak about her experience penning a recent memoir and other published pieces she has written about raising a child with a disability. Audience members are encouraged to join the conversation and share how they have used writing as a tool for self-discovery, communication, and advocacy.

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

To register for this workshop at *Partnering for Strength 2016*, go to [www.nhfv.org](http://www.nhfv.org).



FEB

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It's Your Move Mental Health Advocacy Training

NAMI  
85 N. State Street  
Concord, NH  
For more info contact:  
Annette Carbonneau  
[acarbonneau@naminh.org](mailto:acarbonneau@naminh.org)  
or 225-5359 x325

FEB

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Friendship & Intimacy in Teens with ASD

Teresa Bolick, PhD  
SERESC  
29 Commerce Drive  
Bedford, NH  
Pre Registration Required  
[www.smore.com/enur0](http://www.smore.com/enur0)

MARCH

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Around the World in Special Education

Lakes Region  
Community Services  
719 Main St.  
Laconia, NH  
For more info:  
[picnh.org/our-calendar/](http://picnh.org/our-calendar/)



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 up-dated 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/nhfamilypoices/>

LOCAL

# EVENTS

APRIL

1-2

Partnering for Strength 2016  
Grappone Center  
70 Constitution Ave.  
Concord, NH.  
For more info:  
See page 3 or  
visit [www.nhfv.org](http://www.nhfv.org)

APRIL

16

NAMI NH  
Annual Conference  
Save the date!  
More info coming soon!

MAY

10

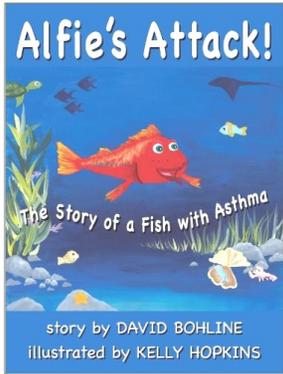
Introduction to Personal FM Systems  
ATECH Services  
Training Room  
57 Regional Drive  
Concord, NH  
For more info  
603-226-2900, ext. 10



For more happenings visit our events calendar at [www.NHFV.org](http://www.NHFV.org), just click on the events tab. Our calendar is updated weekly. To submit an event, email [ebd@nhfv.org](mailto:ebd@nhfv.org).

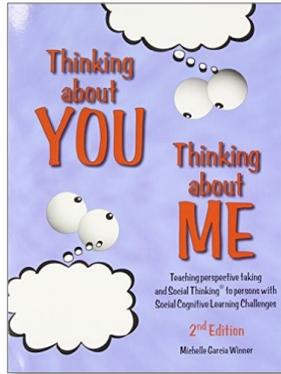


## Cozy up for a long winter's read....



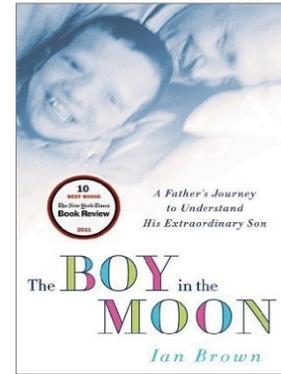
**Alfie's Attack!**  
**The Story of a Fish with Asthma**  
By David Bohline

Our beautiful New Hampshire winters bring with them cold and flu season, a major trigger for those with asthma. There are over six million children in America diagnosed with this condition. "Alfie's Attack" gives parents and school nurses an effective tool to help children manage this condition with confidence. The entertaining story is based on the belief that by providing children and their caretakers with a working knowledge about asthma, and instilling a positive mindset to overcome related fear, asthma can be managed more successfully. This message is colorfully portrayed by fun characters and an unusual twist at the end. Various references and resources are provided to learn more about asthma and related conditions.



**Thinking about You, Thinking about Me**  
By Michelle Garcia

A fundamental social deficit skill is perspective taking - the ability of one person to consider the point of view and motives of another. Although this sounds like a simple process, it is in fact a hugely complex task that is crucial to successful interpersonal relations, and is a skill that anyone with a social cognition disability can struggle with. This book addresses the different ways this problem can present itself, the current thinking on how to approach the problem and a wealth of exercises and activities that can immediately be applied to the student. Illustrated with clear diagrams and tables, and with handouts that can be photocopied, this accessible text will be invaluable for anyone assessing, living with or teaching children and adults with this most abstract of all learning disabilities.



**The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son**  
By Ian Brown

Ian Brown's son Walker is one of about 300 people worldwide diagnosed with cardiofaciocutaneous (CFC) syndrome, a rare genetic mutation that results in unusual facial appearance, inability to speak and a compulsion to hit himself constantly. At age thirteen, he is developmentally between one and three years old and will need constant care for the rest of his life. Brown travels the globe, meeting with genetic scientists, neurologists and parents to solve the questions Walker's doctors can't answer. He offers an insightful critique of society's assumptions about disability and discovers a connected community of families living with this illness. As he lets go of his self-blame and hope for a cure, he learns to accept and love the son he has. An honest, intelligent, and deeply moving memoir.

**Attention guidance counselors, therapists, educators, and school nurses.**  
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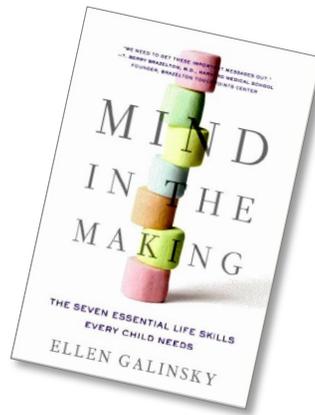
To borrow a book call 603-271-4525 or visit [www.nhfv.org](http://www.nhfv.org)



## Mind in the Making

By Ellen Galinsky

Galinsky has spent her career observing and analyzing how children learn. Collaborating with top researchers in the science of childhood brain development for the past decade, she identifies seven life skills that help children reach their full potential and unleash their passion to learn. The skills are presented in a readable and accessible volume enlivened by parents' narratives about what works and what doesn't, hints and tips, and over a hundred suggestions (games and family activities) for involving kids in the pursuit of learning. Each of seven chapters focuses on one skill, most of them involved with the executive (or management) function of the brain, such as focus and self-control, communicating, and critical thinking. Galinsky urges parents to instill in their children a grasp of different kinds of knowledge to best tap inborn sense and foster self-motivation. The big message is simple: teaching children to think may be the most important thing a parent can do. It doesn't take a village and it doesn't require fancy courses or equipment—Galinsky's everyday, playful, parent-child learning interactions offer a place to start.



## Helping Teens Who Cut: Understanding and Ending Self-Injury

By Michael Hollander

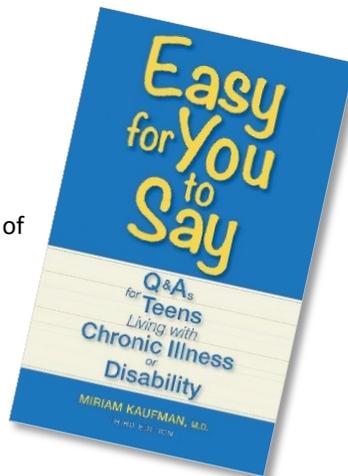
Discovering that your teen “cuts” is absolutely terrifying. Is your teen contemplating suicide? How can you talk to him or her about this frightening problem without making it worse or driving a wedge between you? Dr. Michael Hollander is a leading authority on self-injury and dialectical behavior therapy (DBT). In this compassionate, straightforward book, Dr. Hollander spells out the facts about cutting--and what to do to make it stop. Vivid stories illustrate how out-of-control emotions lead some teens to hurt themselves, and how proven treatments such

as DBT can help. You'll learn concrete strategies for parenting your emotionally vulnerable teen, building his or her skills for coping and problem solving, dealing with crises, and finding an effective therapist or treatment program. Winner of the American Journal of Nursing Book of the Year Award.

## Easy for You to Say: Questions and Answers for Teens Living With Chronic Illness or Disability

By Miriam Kaufman

This book profiles the lives of teens who experience chronic health conditions or disabilities as they work to make sense of the world and their places in it. The questions they pose are frank and courageous and use language that teens can identify with and readily understand. The issues front and center in their lives are addressed, such as family, doctors and medical issues, friends and dating, school and work, alcohol and drugs, medications and sexuality. Useful charts provide information on topics that are critical to teens becoming more independent like medication interactions and side effects. Kaufman is straightforward and honest, and provides useful real life information. Easy for You to Say addresses issues that often are not easy or pretty. It offers solid practical advice, straight talk and honest answers to questions that many would be too embarrassed to ask.



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# Youth Transition Resource

## Take Control of Your Health!

### A tool for families and professionals



As parents and providers, we strive to help the children in our care learn how to take responsibility for and manage their special healthcare needs. During the tween and teen years, our youngsters naturally express an increased desire for independence. We can support their journey by identifying tools to help get them started. The earlier adolescents are taught to manage their own treatment and well-being, the better they will be at this as adults.

The *Take Control of Your Health Series* is a new set of resources to educate teens and young adults about taking an active role in managing their healthcare. The four card set covers the topics of managing appointments, medications, health insurance and health information. Each subject card outlines how to get started, important facts and what questions to ask to get the information needed to become more independent. Parents can use these tools to start a dialogue with kids about the transition from pediatric to adult healthcare. Tweens and teens will find the cards useful as a starting point for gaining more independence and practitioners can distribute them to the young adults and families they work with.

These resources are provided free of charge from New Hampshire Family Voices. To download, visit <http://nhfv.org/resources-category/publications/>. Practitioners who would like bulk quantities can order by calling 603-271-4525 or emailing [admin@nhfv.org](mailto:admin@nhfv.org).



# Youth Blog

## Living with Chronic Illness

Becca Atherton is an amazing, insightful 23 year old woman born with Tetralogy of Fallot, Pulmonary Atresia and Pulmonary Hypertension. In 2009, she began blogging to raise awareness and inspire others.

Six years later, she is still blogging - most likely because of the impact her voice has had on so many. She gets feedback and questions from teens who are chronically ill themselves, professionals in the field and moms all over the country.

Becca candidly describes what every day life for a young person with a chronic condition is like. She explains that even on a "good day" she still has to take 45 pills, sleep with oxygen and anxiously await the call that will prompt her to move cross country for a heart and lung transplant.

In a recent post addressing the offensive behavior of a reality TV actor towards his costar who is diagnosed with chronic Lyme disease, she set the record straight by educating readers on common misconceptions about those who live with chronic conditions. Her voice is strong, intelligent and real.

This blog provides lots of information and inspiration for young people facing similar challenges and for those who are not.

There are some great write ups on the transition to from pediatric to adult care like important *questions to ask before a test or procedure or the truth about transition* in which she explains the not so pleasant experiences she has had with adult care.

Becca is honest and candid about the negative experiences she has had. However, she is impartial and just as forthcoming with her positive and powerful encounters like in her post *A Tribute to Nurses*.

Check out her blog for yourself at <http://lifeasachronicallyillteen.blogspot.com/>.

# Express Yourself!

## Online gallery for teens and young adults with special healthcare needs & disabilities



Are you creative? Do you like to express yourself through art, poetry, music and more?

YEAH Council (Youth for Education, Advocacy and Healthcare) is in the process of creating a new website just for young people ages 14-26 with special healthcare needs and disabilities. The site will be loaded with resources, news and entertainment.

We are currently looking for submissions to the online gallery. The YEAH gallery will be a place where teens and young adults can express themselves creatively through paintings, drawings, poetry, stories, videos, music and more. It is an opportunity to share, inspire and enjoy the work of others in the community. Submissions can only be accepted from those 14+ and can be sent to [yeahnh@nhfv.org](mailto:yeahnh@nhfv.org).

# Your Vision, Your Future!

## Youth conference keynote Julie Bond Genovese

The youth only conference, *Your Vision, Your Future: Creating the Life for You* will be held April 1-2, 2016 at the Grappone Center in Concord, NH. Sponsored by YEAH Council and held for those ages 14-26 experiencing chronic conditions and/or disabilities, the conference is unique because it is planned for youth by youth.

Our keynote will be Julie Bond Genovese, an inspirational speaker, life coach and best-selling author of the award-winning memoir, *Nothing Short of Joy*. Julie has been featured on TV & radio including Anderson Cooper Live, NBC LX & Oprah.com radio with Gayle King.

Julie was diagnosed with dwarfism and degenerative arthritis at birth. Realizing these labels were not the poison she originally believed, eventually became the answer for her. After desperate years of humiliation and shame, medical studies and operations (including two brain surgeries), Julie realized that the biggest thing standing in her way was her own belief system (she calls it her BS). Happiness, it turned out, wasn't dependent on her circumstances but on her response to them.

Come hear Julie and learn about developing a new mindset and approach that you can apply to everyday life. One that will open doors and increase your capacity for resilience by re-framing your thoughts and reactions to common situations.

"As we become more aware of the fear and negativity that was handed down to us, we also become aware of our amazing ability to turn the tides. Our inner power, although may be buried under past conditioning, is more and more present as we change our mindset. And as we reclaim our peace and power, we also find out how much our lives matter. We can find purpose, self-love and meaning, no matter what our circumstances. Small joys build into larger ones as our understanding, determination and inner fire is unleashed", says Julie.

To register visit [www.nhfv.org](http://www.nhfv.org).



## THE NEW IEP?

*The Department of Education recently issued a statement reminding families, teachers, school administrators and policy makers that all IEPs must be aligned with grade level state standards. What does this mean for your child?*



On November 16, 2015 the US Department of Education (DOE) issued a “Dear Colleague” letter entitled *Clarification of FAPE and Alignment with State Academic Standards*. The purpose of this letter is to make sure that parents, education professionals, school administrators and policy makers have high expectations for all children, including those with disabilities. The letter serves as a reminder that in order to do this, we must establish rigorous standards for children with disabilities and assist them in meeting those standards. While this letter reflects the current practice in NH, it is an opportunity to check in and be sure that the children we care for have IEPs that are written with high expectations and the appropriate services and high quality instruction to meet or exceed such expectations.

This reminder is in fact, law. IDEA (Individuals with Disabilities Education Act) sets high expectations in its purpose statement, “to ensure that all children with disabilities have available to them a free and

appropriate public education...to meet their unique needs and prepare them for further education, employment and independent living.” Additionally, the Elementary and Secondary Education Act, now called the Every Student Succeeds Act (ESSA) requires states to apply the same challenging academic grade-level achievement standards to all schools and all children, including those with disabilities.

The National Center on Educational Outcomes, the leading research organization on accountability for the achievement of students with disabilities, concludes, “The vast majority of special education students (80-85 percent) can meet the same achievement standards as other students if they are given specially designed instruction, appropriate access, supports and accommodations, as required by IDEA.”

### What does all this mean for my child?

Regardless of your child’s disability, this letter provides a great opportunity to check in with the Individualized Education

Plan (IEP) team and to get a sense for where your child is at. Asking some of these questions could help open a dialogue with your child’s team;

- Is your child currently meeting grade level standards?
- If not, what is the gap?
- What special education and related services will assist in closing the gap for your child?
- Does the IEP need to be written differently in order for you and the others on your child’s IEP team to measure progress towards grade level standards?

### What tools can I use to get a preliminary picture of the gap?

The NH state academic standards establish what all children (with and without disabilities) are expected to know and be able to do at each grade. They can be found at <http://education.nh.gov/instruction/curriculum/index.htm>. Parents can use this site to look at what their child should be



child reaching grade level, they should be “sufficiently ambitious to help close the gap”, and include the specialized instruction the child needs to ensure the child can access the general curriculum, so that he can meet the academic content standards the State has established for all children.

The letter says that the child’s IEP Team may consider the following;

- The special education instruction that has been provided to the child.
- The child’s previous rate of academic growth.
- If the child is on track to achieve grade-level proficiency within the year.

The letter gives an example of a child with a specific learning disability who is in the 6th grade, reading at the 2nd grade level, but with listening comprehension at grade level. For this child, based on his present levels, individual strengths, needs, and other information, the IEP should set an ambitious annual goal and the specialized instruction he will need to improving his reading fluency and close the gap. The IEP would also include modifications for reading assignments, and accommodations, such as audio-books so that he can learn the content and meet grade level achievement standards in other content areas, such as science and social studies.

The letter notes that aligning the IEP with the State’s academic content standards will “help to ensure that an IEP for a child with a disability, regardless of the nature or severity of the disability, is designed to give the child access to the general education curriculum based on a State’s academic content standards for the grade in which the child is enrolled, and includes instruction and supports that will prepare the child for success in college and careers.”

#### **Capitalizing on your child’s strengths.**

Just as children experience challenges or areas in which they struggle, they all have unique strengths. A child who has a reading disability may perform above average in math. The same applies to a child who experiences a social/emotional disability but excels in technology classes. It is

**Continued on page 12**

able to do at each grade level. The DOE points out that the state’s “standards in mathematics and English language arts/literacy are commonly referred to as the Common Core State Standards”. The language of these standards can often be difficult to understand for those who don’t work in education. Parents should feel comfortable asking teachers and case managers to show examples of assignments their child has completed to meet these standards. From there, they can begin a dialogue to see how their child is performing in relation to grade level expectations.

“The key here is to identify the gaps between the child’s current performance and the grade level standards. From there the team can write effective IEP goals to close the gap”, Said Bonnie Dunham, Associate Project Director of NH’s Parent Information Center on Special Education project.

“Special education evaluations and other data can be used by IEP teams to establish challenging, but attainable goals. Parents can work with their child’s IEP team to en-

sure that, in accordance with this letter, the IEP is written to include the services and specialized instruction that will assist the child in meeting goals that lead to the gap being closed”, continued Dunham.

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*“Treat a child as he is and he will remain as he is. Treat a child as he can and should be and he will become as he can and should be.”*  
– Steven Covey

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#### **What if my child is performing significantly below grade-level?**

If a child is performing significantly below grade-level, the IEP team should establish ambitious but achievable goals. While the goals may not immediately result in the

## IEP... continued from page 11

important to capitalize on children's strengths, and not solely focus on areas in which the child is performing below grade-level standards.

"Students with disabilities are entitled to equal access to accelerated programs such as Advanced Placement and International Baccalaureate classes. In late 2007 the U.S. Department of Education acted upon reports of school policies that restricted access for students with disabilities. For example, qualified students with disabilities could not be required to give up any specialized services that had been designed to meet their individual needs as a condition of their participation. In a 2007 "Dear Colleague" letter, the Office for Civil Rights at the U.S. Department of Education clarified that limiting access by students with disabilities to challenging academic programs on the basis of their disability violates both Section 504 and the ADA. Additionally, it was made clear that the imposition of conditions on participation in accelerated classes or programs by qualified students with disabilities (e.g., the forfeiture of necessary special education or related aids and services) amounts to a denial of a free appropriate public education under both IDEA and Section 504. (USED OCR, December 26, 2007).

### What does this mean for your child?

- Work with your IEP team to identify strengths and opportunities available to foster them.
- Ask about advanced placement classes or enrichment opportunities in these areas and know that your child has the same right to participate in these programs and activities as a child who does not have a disability. Appropriate accommodations must be provided, as needed, so that your child has an equal opportunity to participate in and benefit from the program or activity.

### How can you be sure high standards are set for your child who experiences intellectual or other developmental disabilities?

It is important to note that while the "Dear Colleague" addresses academics, it does not require a child's special education program/services to be limited to academics. Special education is individualized, based on each

child's strengths and needs. It is also important to understand that education is more than academics. In fact, NH's Career Development Curriculum Frameworks, which are part of the state standards, include broad goals, knowledge, behaviors and skills leading to career development, and success in school, work and everyday settings.

New Hampshire's state academic standards are comprised of three components. The components are labeled knowledge, skills and work study practices. These components establish what all children with and without disabilities are expected to know and do at each grade level. When advocating for a child's special education program/services consider all three areas.

**Knowledge:** Students need background knowledge in a variety of subjects in order to efficiently and productively engage in academic and career products of learning and work.

- **Skills:** The skills students are required to demonstrate are written as learning goals for a variety of content areas and are based on the respect and work of experts in their respective fields.
- **Work study practices:** Include attributes such as creativity, collaboration, communication, critical thinking, persistence, tenacity, regulating behavior and emotions, approaches to learning and other expressions of what is sometime referred to as habits of mind.



We often tell children not to give up. It's important that we, as parents and educators do the same by not setting limitations on their success. We must lead by example, strive for exceptional outcomes and show our children why their efforts are worth it.

### Takeaways:

- It is important that we set high expectations for all children with and without disabilities.
- With appropriate special education, supports/services and accommodations, most children will be able to achieve the grade level standards we set for them.
- Families and Schools/School districts can work together to ensure that we set policies and have practices in place that will result in all children achieving high expectations.

### Resources and links

NH College & Career Ready Standards: <http://education.nh.gov/instruction/curriculum/>

"Dear Colleague" Letter Clarification of FAPE and Alignment with State Academic Standards: <http://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/guidance-on-fape-11-17-2015.pdf>

i) Hettelman, K. R. (2013). *Students with Disabilities Can Succeed!* (7th ed., Vol. 26, pp. 1-8, Publication). Baltimore, MD: Abell Report.

ii) Yudin, M. K., & Musgrove, M. (n.d.). Clarification of FAPE and Alignment with State Academic Standards [Letter written November 16, 2015 to Colleague]. Retrieved January 21, 2016, from <http://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/guidance-on-fape-11-17-2015.pdf>

iii) Cortiella, C., & Horowitz, S., Ed.D. (2014). *The State of Learning Disabilities* (3rd ed., pp. 1-52, Publication). New York, NY: National Center for Learning Disabilities.

# *There's an App for That!*

## *Auditory Processing Skills App created by Speech Language Pathologist*



Auditory Workout was created by a certified speech and language pathologist for students ages 4–10 who exhibit auditory processing disorders or other related disorders (e.g., receptive language disorder or autism). Auditory Workout is research-based and focuses on improving auditory attention and memory and auditory processing of verbal directions. This engaging, colorful app includes over 1,000 audio instructions. Children are welcomed by the basketball coach, who encourages them to work hard. Children earn a basketball for

each correct response, and when they accumulate enough balls, they are rewarded with a game (a game of catch for younger children or/and basketball for older children).

Auditory Workout allows children to follow increasingly longer and more complex directions and includes more than 13 levels of difficulty. The directions are divided into four categories, Basic Directions, Quantitative and Spatial directions, Temporal directions, and Conditional Directions.

## *Family Fun for All in NH!*

### *Snowshoeing and adaptive sleds*

Looking for something fun to do with the whole family now that we finally have snow in the Granite State? Look no further than your town conservation trails after picking up a supportive sled and renting some snow shoes!

“We love snowshoeing!”, said NHFV member, Kristine Charles. Our sled is from LL Bean. It is the large size, the old fashioned kind that has a sturdy back to it. It came with a push bar. We use the push bar because we can see our daughter better”.

Kristine says you can snowshoe wherever you can hike. They try to stick to places that are relatively flat with small hills, sometime they go to golf courses that have beautiful views.

Any area that has designated trails are great to try out and most town halls have trails maps of their conservation trails available. For a day trip, Great Glen Trails in the Mount Washington area makes their own snow, providing great conditions all winter. They also rent snowshoes and offer guided snowshoe tours. Check them out at [www.greatglentrails.com](http://www.greatglentrails.com).



A big thanks to everyone who took the Pass It On survey a few months ago. Your feedback is what drives the content of this newsletter. Many asked for more articles on education and we are delivering!

In the months to come, readers will see even more of what they asked for. We value your voice and your time as it is the driving force behind what we do here at New Hampshire Family Voices.



We recently started a twitter account for families and professionals to share resources. Here are some great reasons to get on twitter;

1. You can quickly find information by subject just by search #ADHD, #SpinaBifida etc.
2. You will get news from organizations around the world, real time in quick bits.
3. Your inbox wont be over crowded with lengthily announcements and info that you have to sort through, because twitter provides all the headlines you are interested in.
4. Based on the organizations and people you follow, Twitter exposes you to more you may not have known about.
5. The interface is super easy and fast to use.
6. New Hampshire Family Voices is on twitter, so follow us [@NHFamilyVoices!](https://twitter.com/NHFamilyVoices)

## Storytelling... continued from page 1

ence. What I didn't realize, is that once again, I'd find community. Instantly there were 5 of us PURA parents communicating on Facebook. Since Aidan was born before social media, I'd never had that experience before. I wasn't expecting to become so personally invested in other families. The truth is, part of it was re-traumatizing. I was re-living Aidan's early years to share information and it became a bit much. The learning curve on genetics and how that field seems to be exploding right now is totally overwhelming. Because I've been on this journey so long, I recognized the need to take deep breaths and get some perspective.

### Is there a "next step" to discovering more about Aidan's condition? If so, is it a step you want to take?

We have a big picture cause of Aidan's medical issues, meaning he has a diagnosis. It's just two little spelling mistakes on one little gene (PURA) on the 5th chromosome. I'm definitely ready to take the next step so doctors can better understand how this gene affects our kids. Most importantly, we really need to understand and then defeat his seizures. This can all be done in the lab with just a touch of his blood. I can walk away and let the doctors learn how this spelling mistake affects the production of protein and ultimately has a neurological impact on our kids. I can't even speculate as to what I'll do when it comes to medicine



trials or gene therapies, but I'm open to feedback from your experienced readers.

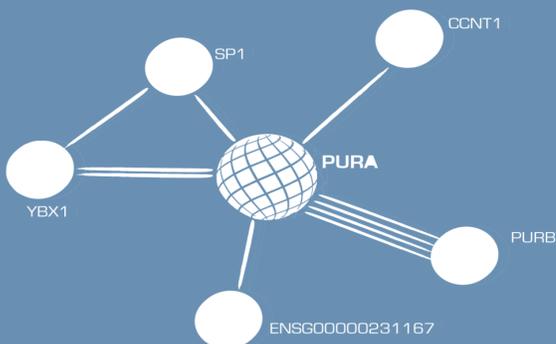
### What have been the outcomes of blogging about your experience? Have you been contacted by many families, scientists, medical professionals?

I've been incredibly surprised by the community I stumbled upon when I started to

blog. There were lots of people reaching out to say, "me too" and "tell me more." My blog became a dialogue both in helping others and in creating a space for my child in this world. What I mean by that is, the people who don't travel in the Disability World really wanted to know more. This became a place to address some of the awkwardness and questions so they can better be a part

## HEATHER'S PICKS

Resources for families who have children with rare genetic conditions or undiagnosed



**NORD** (<http://rarediseases.org>): Lots of information and resources for families and caregivers of those diagnosed with rare diseases. They are the force behind Rare Disease Day.

**GLobal Genes** (<https://globalgenes.org>): International organization which promotes the needs of those with rare diseases and provides copious information nicely organized into toolkits.

**Aware of Angels** (<http://awareofangels.org>): Advocacy organization for children who have genetic, rare or undiagnosed disorders. AOA assists children needing a diagnosis and research opportunities through raising awareness, promoting research and connecting families in similar situations. This is a great resource for both feeling less alone and trying to get a diagnosis.

of my world. I've had people ask me to address topics such as the issue of drool and the cuteness factor (*see links below*). I've corresponded with and provided as much assistance as possible to families who are starting AAC with their children. I've presented to nursing students in the past and have been published in a nursing journal. I'm always encouraged by their real desire to see this side of their work. Incidentally, my oldest son was also published in the same journal sharing his sibling story. I want my blog to be a place where people hear "this might hurt like hell and you can do it".

**I heard you are helping to start an organization for PURA research, can you tell us more about it?**

Can I tell you the truth? I'm the President of the Board for PURA ([purasyndrome.org](http://purasyndrome.org)) and we're in the process of becoming a non-profit to support parents and researchers and sometimes I feel like a fraud. I know nothing about starting a non-profit. I know nothing about scientific research. I've really had to struggle through how Aidan's diagnosis is shaping my own life. But there was a time I knew nothing, ZIP, ZERO, ZILCH, about raising a child with a disability. Here's what I do know - I know how to bring people together. I know how to ask questions and find answers. I know how to encourage and value other people's contributions. When our little group first gathered on Facebook I threw out an invitation to get together in real life. I didn't really expect people to get on planes and come to a stranger's home, but they did. That first gathering was just moms sharing our stories. The next gathering I hosted was families in conjunction with two doctors. They were both powerful experiences. Since that time, through people talking to people, by sharing our stories, we've built a collaborative medical team, a vibrant online support group, and are in the process of planning our first conference in London for June 2016. Your life really can change in a moment. It really can change through telling your story.

To read the blog posts that Heather referenced in our interview visit <http://familysynapse.com/drip-drip-drop/> and <http://familysynapse.com/dont-call-my-son-cute/>.

To read the sibling story written by Aidan's older brother visit [www.pediatricnursing.net/interestarticles/3806\\_Bowie.pdf](http://www.pediatricnursing.net/interestarticles/3806_Bowie.pdf).

## Supporting Families

*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](mailto:rda@nhfv.org).*



## 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](http://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](mailto: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.



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physical disability  learning disability  developmental disability  behavioral challenges

I am interested in materials relating to: \_\_\_\_\_

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chronic health condition  physical disabilities  learning disabilities

developmental disability  behavioral challenges

I am interested in material relating to: \_\_\_\_\_

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Human Services (explain) \_\_\_\_\_ Other: \_\_\_\_\_

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