

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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Lessons from Adam

A loving aunt shares the invaluable gifts and lessons her nephew has brought to their family and perspective for those who cannot see them

Every morning as I sip my coffee, I peruse the headlines on the internet and scan a few of the articles that interest me. Last week I came upon an article that made me wish I had slept an extra twenty minutes and skipped the internet.

On the splash page of AOL there was a headline, "Woman writes outrageously cruel letter to mom of autistic boy." The article showed the anonymous letter written about Max, a thirteen year old boy with autism. I'll spare you the details, but "outrageously cruel" doesn't begin to describe how reprehensible this letter was.

As I read the letter, I thought of my nephew Adam. Adam has Down syndrome and is autistic. He entered our lives twenty-five years ago, a frail little bundle with huge blueberry eyes that searched mine as I held him for the first time.

His heart was so weak that drinking from his bottle

exhausted him, requiring open heart surgery before he was a year old. Undoubtedly, his special needs were overwhelming to his birth parents, and they released him for adoption shortly after his birth. It took no time at all for him to claim his spot in the family...and in our hearts.

It's Saturday, and I visit my sister at her farmhouse. Adam greets me with a grunt and a hug. He can only say a few words, but despite severe hearing loss in both ears, he understands almost everything that is spoken. When he sees me approaching the front door, he usually flings it open and runs away, but today he stays long enough to give me a quick hug and an air kiss. He hovers in the kitchen, grinding his teeth and shifting his weight from one foot to the other until my brother-in-law tells him it's time to take the trash to the dump. He separates the bottles and cans from the paper goods and carries them to the work shop. And on Saturday, he helps his dad take the family's refuse to the dump. It may easily be the only chore he does, but he does it without fail.

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Pass It On!

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www.nhfv.org

Letter from our NHFV Team

Erika Downie, Outreach Specialist & Director of Library Services at New Hampshire Family Voices

Dear readers,

Happy spring! As we make the transition into this new season, I would like to remind you of one of my favorite resources NHFV has to offer, our Lending Library. The NHFV Lending Library is continuously growing and changing each month as we add new selections. For over 20 years, we have supported families and professionals who care for children with special healthcare needs and/or disabilities through this service. We currently have about 2500 books, cd's and dvd's which are available to be borrowed by NH residents simply by calling us or putting them into your "shopping cart" on our website. You can browse our whole collection at www.nhfv.org/how-we-can-help/lending-library/ and search by title or by a single word, such as "sensory" or "g-tube". When you order a book, it is delivered to your home or office free of charge and you can return it in a prepaid envelope that we provide. It doesn't get easier than that!

One area of our library I truly enjoy is the children's books section. We have books to help children understand a diagnosis or process what is happening in their lives such as having to go to the hospital for an upcoming medical procedure. There are books to help children develop healthy habits like hygiene and organization. Some of our best books illustrate acceptance and inclusion such as "Lemon the Duck" and "Zink the Zebra". Children's books about specific conditions or disabilities are a great way to provide quick information to someone about your child such as "This is Gabriel Making Sense of School". I brought this book to my son's first grade teacher for her to get a better understanding of what sensory processing is and how it impacts children in the classroom. It was a quick and easy way for her to understand what she might be seeing without having to take too much time out of her busy day.

Children's books are a great way for teachers and guidance counselors to build inclusion and understanding. Children may see behaviors or notice differences and not understand what they are seeing or why a child is behaving the way they are. Parents can talk to their child's teacher about having a book read in class that would explain a chronic health condition or disability. Young children are curious and want to learn. They generally accept new



information about their classmates and realize they are more similar than different! Not all books will reflect each child perfectly, parents should read them ahead of time and discuss them with their child's teacher. Parts that do not apply can be skipped over or simply be covered with post it notes.

For more information, see our publication "Using Children's Literature to Assist in the Understanding of a Chronic Health Condition or Disability" on our website at <http://nhfv.org/publication/using-childrens-literature/>

I look forward to hearing from you!

Erika Downie



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.

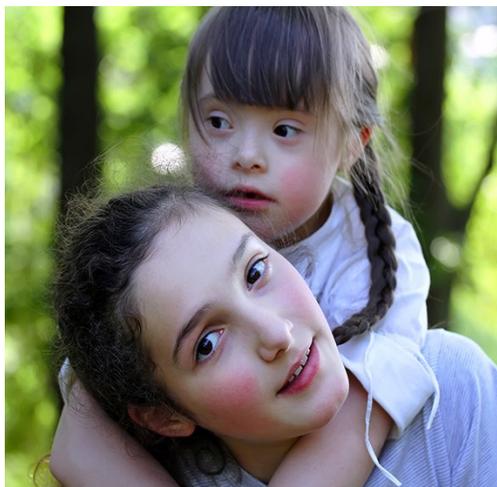
This is easy to do, just follow these steps!

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.

OT Corner

A stroll in the NH woods this spring provides many sensory experiences



With the winter thaw finally past us, let's talk about the many wonders springtime in the NH woods can bring to any child (and adult!) Hiking, camping, swimming, and nature walks are just a few of the great activities NH has to offer. No matter which activity it is, this is one of the best environments for a full body, multi-sensory experience that will help a child prepare for school and other functional activities. In addition, slowing down to explore what we take in through our senses strengthens self awareness skills which are critical to emotional regulation and resiliency.

Think of how a scenic view of the forest or mountains differs from the screens, books, or whiteboards lots of kiddos have been looking at all winter. The outdoors allows children to use their eye muscles in different ways. For example, if your child is visually scanning the environment to try to find the deer walking a few yards away, they are strengthening the muscles for visual acuity by looking at objects close to them, then quickly jumping to far away scenes. Other activities that strengthen these visual skills could be a game of I spy or a forest themed scavenger hunt. These visual skills come into play when a child is sitting in a classroom, taking notes from the board.

Notice of all the different sounds you hear in the woods! A babbling brook, different birds chirping, bugs flying around your head, the breaking of sticks, swishing of grass as you walk forward, or maybe even a car passing by as you get closer to a road. You can look up some different bird calls before you go out into the woods and try to count how many you hear. You could also work on auditory localization by listening for a sound, then walking closer to it until you find the sound's source.

One sense we tend to forget is that of smell. From natural smells like flowers and sap, to man-made ones like sunscreen and bug spray, the possibilities are endless for what your nose can sense. Try closing your eyes and identifying the scents around you.

For both the sensory avoider and the sensory seeker, going for a hike in the woods can help to satiate your child's unique sense of touch. Seekers could feel how cold the water of the stream is on their hands and feet, climb on a fallen tree trunk to feel the roughness of the bark and test to see which tree has the stickiest sap. For the avoiders, walk with them to a sunny patch and quickly change to a shady patch in the woods and feel the difference between the two. Have them touch different leaves and bark from trees to determine the roughest and softest. Avoiders and seekers can both wear thick, tight wool socks and heavy hiking boots for deep pressure to the body as they hike.

Libby Sullivan, M.S. OTR/L is a pediatric occupational therapist working in Early Intervention (ages Birth to 3) in Brockton, MA. A graduate of UNH, Libby is passionate about adapting everyday activities children do so they are more meaningful.



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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Medication Management

Tips for youth with special healthcare needs beginning to manage their medications



I've been in charge of managing my own medication for about 11 years now, starting when I was a freshman in high school. I've only been *successfully* managing my own meds for about two weeks however, due to accidentally missing one of my nightly Iron pills. Nobody's perfect, so I won't pretend that this is the first time that something like this has happened to me by a long shot but I also won't pretend that missing an iron supplement every two weeks or so is something to panic about. One shouldn't make a habit of it, but at worst, this leaves me feeling crappy the day after I miss my dose. I notice it the next day, make a mental note of it, start taking my pills regularly again, mistake fixed.

Unfortunately, it's not always that simple for youth who have special healthcare needs. The pill that I missed was just for an iron deficiency but I also take a blood thinner that keeps me from getting blood clots and one that keeps my thyroid in check. When I miss these, which

has happened, I end up having physical side effects the next day that usually range anywhere from being completely unpleasant to those around me to being hospitalized with the threat of losing my blood-clot filled legs. Others out there take pills for things like maintaining seizures and keeping their heart beating at a regular pace.

I'm not trying to scare whoever is reading this. Missing a single pill isn't necessarily going to send you to the hospital. In fact, as long as you or someone in your life has an idea of what your healthcare needs are, it should be rather simple to put together a plan of action just in case a medication is missed. Successful medication management is a skill that is critical to your health and your independence. The meds you take on a regular basis are, in fact, there to help you instead of just take time out of your day for no reason - which is what I used to think.

If you are thinking about starting the transition of managing your own medication, know that it should be a regular part of your daily, weekly and monthly routine.

On a daily basis, you have to manage the times meds should be taken. I keep a pill planner that's separated into morning, noon, afternoon and night in order to keep track of what I need to take and when I need to take it. As I mentioned before, nobody's perfect, so I also find it helpful to set multiple alarms on my phone as back up reminders. There have been times when my alarm went off while my phone was silenced or I forgot to bring my pills with me while I'm out, but 99% of the time, its gets the job done. I also have a couple of friends who have memorized my pill schedule for me, just in case something goes wrong with my alarm. It's always a good idea to have a backup.

Each week, you should plan out the meds for the upcoming week. The pill planner that I mentioned before is filled on a weekly basis and has slots for every day of the week so it doesn't need to be refilled every night. I have found that filling the planner can be challenging due to the small size of most of my medications, so I ask my visiting nurse to fill it for me. If you choose to set up

Check This Out!

The MediSafe meds & pill reminder app will remind you when to take your medication. If you forget a dose a family member or caretaker can be notified so they can remind you only if needed.

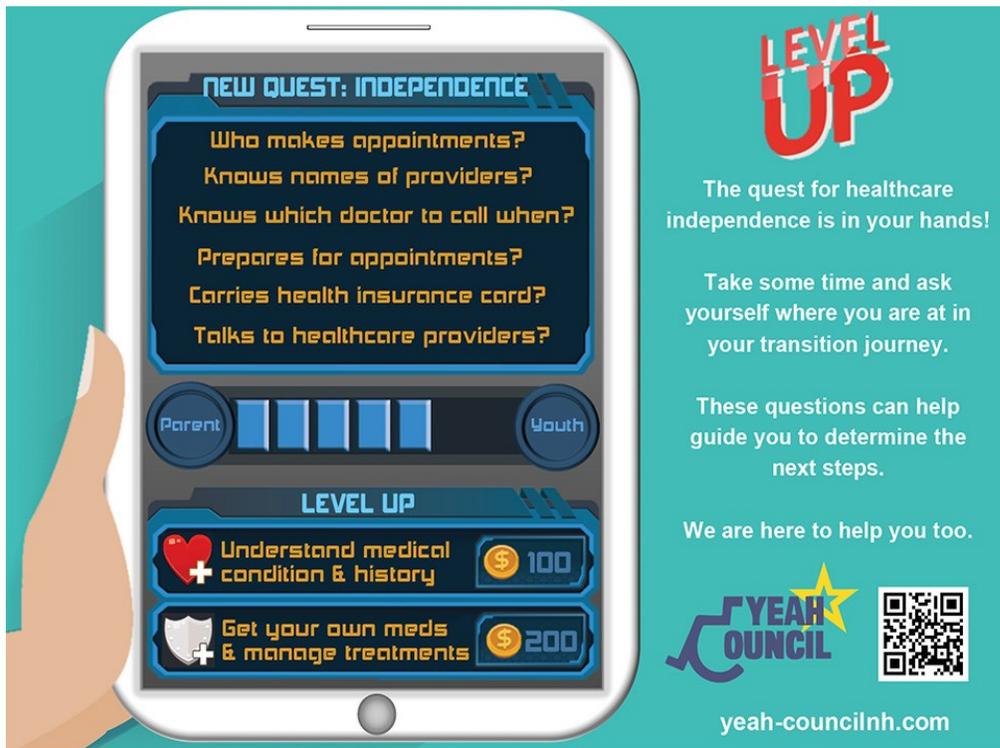
Features:

- Visual, super easy to use medication reminder.
- Sync family members' devices and medication in real time.
- Reliable even if your device is asleep.
- Rx refill reminds you when to reorder meds & offers discounts.
- List on demand/as required medications
- See your medication progress report and send it to the doctor or nurse.
- Automatic secured backup and restore on the Medisafe cloud server (HIPAA compliant servers).



Continued on Page 15

New Transition Tool for Youth Level Up to healthcare independence cards and magnets



NH Family Voices and Special Medical Services has launched a new tool for youth with special healthcare needs and their families called **Level Up**. The **Level Up** project is designed to get families and youth talking about what steps they need to take in the transition from pediatric to adult health care. The infographic (above) is available on a 5x7 card or magnet and shows the process of healthcare independence for young adults through a series of questions and “levels”. It is designed to look like a video game interface leading youth on their “quest for independence”. There is a QR code on the card that can be scanned with a smartphone to visit the YEAH Council (Youth Education Advocacy & Healthcare) website to learn more about the journey to independence.

“The goal is to get young adults with chronic conditions managing their healthcare as much as possible” said Terry Ohlson-Martin, Co-director of NHFV. “In certain cases, total independence may not be possible, but this tool is still useful as it will foster a greater feeling of interdependence and allow young people to take additional ownership of their care” she said.

Level Up is a project of the Health Care Transition Coalition which is chaired by Special Medical Services and NH Family Voices with membership from YEAH Council, Families, School nurses and physicians throughout NH.

This card or magnet is a great tool for anyone with an interest in promoting independence for youth with special healthcare needs. Medical practitioners, counselors, schools and families can order these to distribute to the young adults and families they work with free of charge by calling NHFV at 603-271-4525 or emailing admin@nhfv.org.



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!

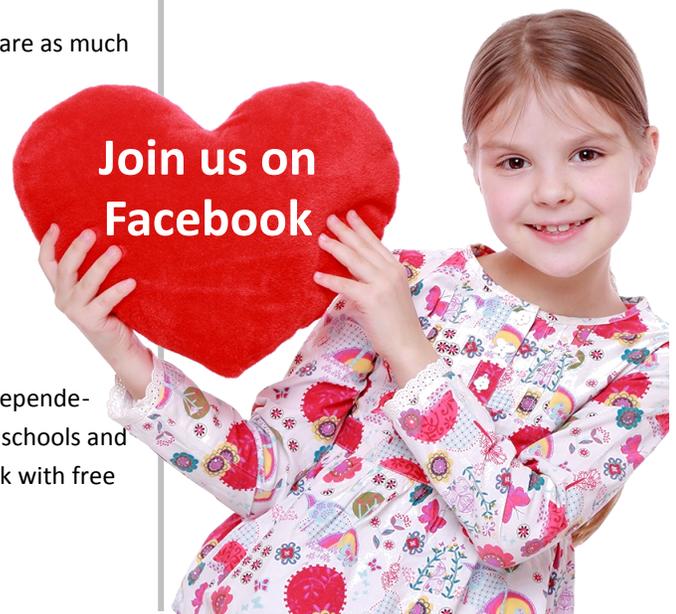
Be sure to click the “get notifications” option so that you receive all updated information.

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?

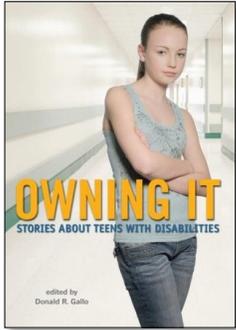
Be sure to add
nhfamilyvoices@nhfv.org to
your safe email list - otherwise you
could miss out on this and other great
news from NH Family Voices!





New Hampshire FAMILY VOICES[®] Lending Library

Books to put a little spring in your step!



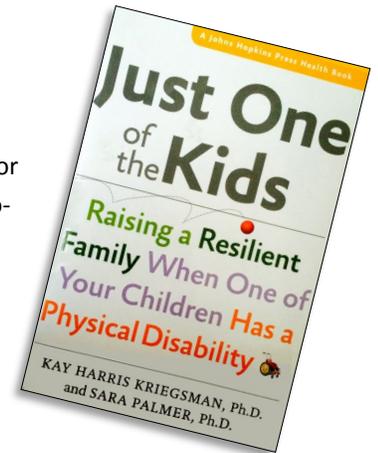
Owning It: Stories about Teens with Disabilities by Donald Gallo

Chris Crutcher takes us on a wild ride through the mind of a teen with ADD, while David Lubar's protagonist gets a sobering lesson from his friends. In Gail Giles's tale, Brad can't help barking at his classmates but finds understanding when he gives a comical (and informative) presentation to his entire school. And Robert Lipsyte introduces us to an elite task force whose number-one enemy is cancer. Whether their disabilities are physical or psychological, the subjects of these powerful short stories — written by ten outstanding young adult authors — meet every day with wit, intelligence, and courage.

Just One of the Kids:

Raising a resilient family when one of your children has a physical disability by Kay Harris Kriegsman, PhD. & Sara Palmer, PhD.

If you have a child with a physical disability, how can you plan your family's life in a way that is inclusive for everyone? What can you do to create a family where every member pulls his or her own weight (in appropriate measure), meets challenges, and has moments in the spotlight along the way? Most parents of a child who has a physical disability want their child to have fun, be responsible, make friends, and take acceptable risks—in short, to feel like "just one of the kids"—and they want to make sure that the needs of the whole family are met, too. This book is designed to help parents focus not on what could have been but instead on what can be, so that they, their children, and the grandparents thrive as individuals and as a family. The advice from psychologists Kay Harris Kriegsman and Sara Palmer is valuable for any family with children who have a physical disability, from any cause. Their warm and encouraging book is full of family stories, tips, and tools. Parents of children with physical disabilities can help them develop the skills needed to meet life's challenges and launch into independence. Parents, building on that foundation and acknowledging each person's contributions, interests, and aspirations, create an inclusive and resilient family.



What's Happening to Ellie? A series on Sexuality & Safety for Teens with ASD by Kate E Reynolds

Follow Ellie as she begins to notice changes to her body. This simple resource helps parents and professionals teach girls with autism and related conditions about puberty. It covers emotional issues such as new feelings and physical ones such as periods. These attractively illustrated books, with their clear, anatomically correct pictures and simple, unambiguous text, deal bravely with the aspects of sexuality that are challenging to teach and will facilitate discussion and learning. This is part of a series of books dealing with sexuality and safety. Keep an eye out for the full series for boys in our library soon!



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

Just Arrived... Asthma DVD for newly diagnosed children and their families

According to the American Academy of Pediatrics, asthma affects more than 23 million Americans, more than a quarter of which are children and adolescents.

As we welcome a long awaited spring throughout the granite state, this delightful season can bring with it more wheezing and worsened symptoms for children and teens diagnosed with asthma. Thankfully, Community Bridges



and the Partners in Health Program recently joined forces to create an empowering and informative DVD for children recently diagnosed with asthma and their families called ***Asthma Awareness***. This half hour video is facilitated by Susan Thibodeau, APRN, MSN and is loaded with expert tips and facts that even the most seasoned asthma veteran may not know.

Asthma Awareness describes what happens in the body when one is experiencing asthma symptoms or an asthma attack in a way that children can understand. Descriptions are accompanied by detailed illustrations done by the children who worked on this project. Throughout the video, real kids ages 6-19 diagnosed with asthma ask real questions and share real experiences.

Some of the topics covered include:

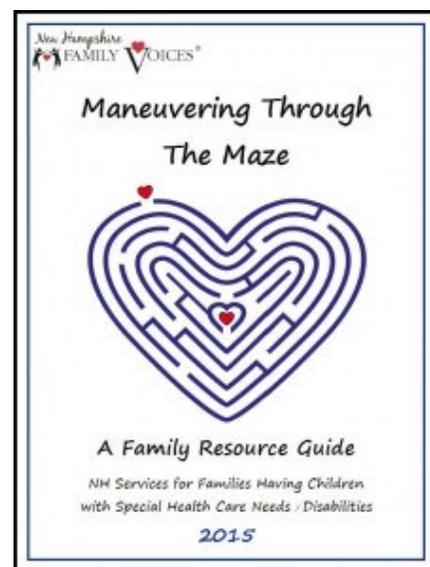
- Asthma triggers and prevention
- How asthma symptoms can be different for each individual
- Emotions surrounding asthma
- How to be prepared
- What to do in an emergency
- How to use your inhaler for the best results

The children who participated in this project also created a quilt of creative artwork depicting various aspects of the diagnosis. The quilt will be on display at Community Bridges and then it will tour Merrimack County.

“After seeing the video and learning more about the diagnosis, we had quite a few kids actually improve their condition significantly” said Janice Boudreau, Partners in Health Coordinator at Community Bridges.

This great resource is now available through the NHFV Lending Library, for more information visit www.nhfv.org, choose the “*how we can help*” tab and select Lending Library.

The Maze 2015 A Comprehensive Resource Guide



Our most recognized resource is hot off the presses! This 154 page family resource guide for families who have children with special healthcare needs and/or disabilities takes the reader from birth through adulthood with listings of state health and human services agencies, educational resources, private associations and organizations that serve people with physical, developmental, mental health and chronic health conditions and their families.

This guide includes listings of organizations and services that can be accessed by all state residents, such as housing, childcare, etc. It also includes tips on “getting the answers to your questions” and “information you should always have at your fingertips” along this journey.

Visit www.nhfv.org to order your hard copy of *Maneuvering Through the Maze 2015* (a \$15 donation to cover printing costs is recommended) or download the book for free!

There's an App for That! Executive Functioning

By Stacy Driscoll, M.Ed.



Choiceworks by Bee Visual, LLC

One of my favorite apps to help students with a variety of executive functioning concerns is *Choiceworks* by Bee Visual, LLC. *Choiceworks* benefits individuals who need assistance with scheduling, waiting and emotional control. Just about everything in the app is customizable and users benefit from both visual and audio feedback. Let's say my child needs a visual schedule for the steps she needs to complete while in the school lunchroom. Each task can be customized with either icons within the app or photos taken on the device. It may benefit her to see her actual school cafeteria and this app allows that. Text can be added and either the app will read the text or the person setting up the schedule can record their own voice for each task. Each task allows for a timer associated with that task if necessary. When the student is using their visual schedule they will swipe the task from left to right as each task is completed and hear an audio response with the

words, "All Done". Students can also listen to the whole schedule read aloud in order to understand the tasks ahead.

The app also provides customizable waiting boards and feelings boards. If a student is working on not interrupting, the board provides a visual timer of how long the student needs to wait until it is his / her turn. It also shows two choices of what the student can be doing during the time they are waiting. When creating a feelings board, the creator would choose a feeling, two strategies the student may use when displaying that feeling and two activities for the student to choose from when they have successfully used a strategy to regain emotional control.

Choiceworks is available in the iTunes App Store for \$6.99. It is compatible with iPhone, iPad and iPod touch making it quite versatile. Many parents and teachers especially appreciate the ability to lock the boards once they are created and set a passcode for boards if needed. There are a wide variety of implications for this app. My guess is, the more boards you create the more ideas you will come up with for how to expand on an already excellent app.

Stacy Driscoll, M.Ed. is an assistive technology specialist with a background in special education. She is the founder of LifeLong Assistive Technology find out more at www.lifelongat.com.

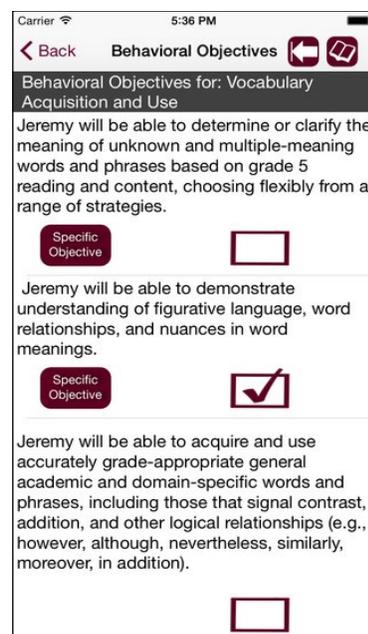
Staff Pick! IEP Goals & Objectives with Common Core



IEP Goals & Objectives with Common Core by NASET

This app can be used by parents and professionals. Professionals can easily build a list of students, and for each one, choose & build a list of IEP annual goals, short term objectives, and behavioral objectives that include Common Core State Standards (CCSS). Parents can do the same for one or more children. Goals are customizable and can be saved, edited and deleted as needed. For each objective, you are provided with the option to add a mastery Level.

Assembled annual goals, short term objectives and behavioral objectives for each child can be exported via email, or text message for collaboration purposes. This is very useful in planning certain significant components of each student's educational curriculum in a collaborative way between professionals, families and students if they are old enough to be involved in the IEP planning process. The app also enables users to build an exportable list of enrichment experiences to enhance student's development from a list of over 2,700 suggested activities. The application is available through iTunes app store for \$9.99 and can be used on iPhones and iPads. It is well worth the money to have everyone involved using the same terminology and improving collaboration between schools and families. See screen shots below for an idea of how it works.



Special Education

Discipline-Related Suspensions & Expulsions

By Charlene Mayo and Bonnie Dunham, Parent Information Center



When parents get a call from school telling them their child is being suspended, it can be overwhelming, they may not remember how many prior days the child has been “sent home”. It also can be difficult to remember when each previous incident occurred and whether the current and previous incidents involved similar behaviors or situations.

When a child with disabilities is suspended or expelled from school because he or she has violated a code of student conduct at school or at a school function, it is important for the individualized education program (IEP) team to determine whether the child’s behaviors that led to that removal from school were related to the child’s disability, if they were due to the IEP not being followed, or if there was another reason for the behavior. To support the child and to address the reasons for the child’s negative behaviors, the IEP team should also consider conducting a functional behavioral assessment (FBA) which will provide them with the information they need to develop a positive behavioral intervention plan, including strategies to assist the child, and to help the teachers/service providers learn appropriate ways to support the child.

Special education laws include specific disci-

pline-related requirements and procedures, including a requirement to provide services to any child with a disability who has been removed from school for violations of a code of student conduct for 10 cumulative days in a school year. The services that are provided must be sufficient to enable the child to continue to participate and progress in the general education curriculum and to progress toward meeting the goals in his or her IEP. When parents get a call from school telling them their child is being suspended, it can be overwhelming, they may not remember how many prior days the child has been “sent home”. It also can be difficult to remember when each previous incident occurred and whether the current and previous incidents involved similar behaviors or situations.

The Parent Information Center of NH (PIC) has developed a “Discipline/Behavioral

Incident Tracking Sheet” (on page 13) that parents can use to help keep track of discipline-related incidents, including information about the specific incident, the school’s response to each incident (including in-school suspensions), and how the child’s behavioral needs at school are being addressed. The rules related to discipline are complicated. Additional information may be found in PIC’s “Steps to the NH Special Education Process” – <http://nhspeciald.org/wp-content/uploads/2014/12/Steps-in-NH-Special-Education-2013.pdf>.

PIC also offers free workshops, materials and individual technical assistance. A copy of the NH Rules for the Education of Children with Disabilities, which include the discipline requirements may be found on

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Project Spotlight: **ASD State Needs Assessment**

NHFV works to improve care for children and young adults with ASD in New Hampshire

For over 20 years, NHFV has worked to improve the quality of care families of children and young adults with special healthcare needs and/or disabilities receive statewide. Our office works at the state level to assure important programs are funded and that health policy is family-centered, making certain that the voices of NH families are heard. One of the ways we do this is by working with key stakeholders to collect data and research on what the needs of families are and where resources need to be directed in the future. For the past two years, Martha-Jean Madison, Co-Director at NHFV and Jennifer Pineo, Project coordinator at NHFV have worked on the Autism Spectrum Disorder Needs Assessment.



What is the needs assessment?

Families, advocates and providers in NH have worked to improve the services and supports available for children and young adults with autism spectrum disorder (ASD) and other related disabilities for over a decade. The needs assessment is a report that gathered information in regards to the needs of individuals with ASD in NH. This needs assessment focused on children and young adults birth to 26 years old. We looked at information that was already available, including information from the Department of Education and the NH Registry for ASD. We also collected additional information from families, stakeholders and self-advocates by hosting focus groups and forums across the state. We asked questions about how they get information, services in school and the community, resiliency and hope, transitions throughout their lives, and about coordination of care. We took all of this information and used it to write the Comprehensive Needs Assessment Report.

Why is this important for NH families?

This State Needs Assessment report is an important component to informing the state plan to improve the overall system of care for children and youth with ASD and related developmental disabilities and their families.

What role did NHFV play in the State Needs Assessment?

NHFV was part of the core team on this project. Other team members included Special Medical Services, Child Health Services, the LEND program at UNH, and the NH Council on ASD. This workgroup was supported by a federal grant*. As program coordinator for this project, NHFV's Jennifer Pineo, supported the core team by coordinating and facilitating focus groups and work groups which included families, self advocates, professionals and

stakeholders from across the state. Readers can access a copy of the final State Needs Assessment on the NH ASD Council Website. www.nhcouncilonasd.org/CouncilFiles/Proceedings.html

What happens next ?

The work groups will review the information compiled through the State Needs Assessment and begin outlining a state plan. They will be collecting information from families and stakeholders about what should be included the plan and what it might look like. Forums and collaborations with other groups will be held over the next few months and then the core group will begin work on officially writing the state plan.

What is the state plan?

The state plan will be a blue print to address the needs of children and young adults with

Continued from Page 10

ASD and related disabilities throughout NH. It will serve in the development of goals and objectives to improve access to family centered health care and related services for this population in the future and will be endorsed by key stakeholders and partners throughout the state. The core group will be applying for a future implementation grant to support the work on the development of the state plan. This group hopes to have the state plan go public by late 2015. For more information visit www.nhfv.org, select the projects tab and then Improving Services for Children and Youth with ASD or contact Jennifer Pineo, NHFV Project Coordinator & Liaison to the NH Council on ASD at 603-271-4525 or jsp@nhfv.org.

NH STATEWIDE AUTISM SPECTRUM DISORDERS NEEDS ASSESSMENT 2014

Families, advocates, and providers in NH have sought to improve the services and supports available for children, youth, and young adults with autism spectrum disorder and related developmental disabilities for over a decade.

Autism spectrum disorder (ASD) is a developmental disability that is caused by differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways.

This needs assessment focused on children and youth birth to 21 years and young adults 18-26 years

Partners

NH Family Voices
NH LEND
NH Council on Autism Spectrum Disorders
Special Medical Services
Child Health Services

DATA SETS REVIEWED

- Department of Education Census by Disability (Federal and State)
- NH State Registry for ASD
- National Survey of Children with Special Health Care Needs
- NH Needs Assessment Survey 2012

DATA COLLECTION

- 8 Focus Groups Including 2 for Spanish Speaking Families
- 1 Self Advocate/Young Adult Focus Group
- 3 Stake Holder Forums

AREAS OF FOCUS

- Services
- Information about Services
- Coordination of Care
- Transition
- Resiliency

Needs Assessment Activities

SERVICES

- Difficulty in finding qualified providers
- Need for training for providers
- High provider turn over
- Perceived lack of consistency of availability and quality of services across the state in education system, community based services, and clinical services.
- Need for more access to services to support transition to adult life.
- Resources – need for funding and allocation to schools, community based services, and Medicaid

INFORMATION ABOUT SERVICES

- Families wanted information about respite, education opportunities, services, funding, support groups
- They get information from other families, their own research, internet, or social media
- Variation of information across the state
- Resource information needs to be kept up to date
- Accessible formats – readable and easily understood

COORDINATION OF CARE

- Families and stakeholders agreed PARENTS are the ones who primarily provide care coordination
- They identified the importance of care coordination following an ASD diagnosis
- The importance of coordinated medical care within a medical home
- Critical need for Funding of care coordination
- Parents level of involvement in care coordination directly correlates with their level of satisfaction

TRANSITION

- Support is needed during transitions through the life span
- Transitions were often described as "hitting a brick wall" or "falling off a cliff"
- Families wanted information regarding transitions early in the process
- Support is needed during transitions
- Lack of services for young adults over the age of 21
- What about those not eligible for Area Agency Services

RESILIENCY

- Access to support (funded and natural supports)
- Strong sense of community
- Social media
- Connection with other families
- Parent to Parent
- Many families expressed concern around what will happen to their family member when they are gone.
- Value being heard and involved

NEXT STEPS

Families, self advocates, experts in the field, and key stakeholders will review findings of the needs assessment and identify core issues to be addressed by the state plan

New Hampshire Autism Spectrum Disorder State Plan rolled out Late Fall 2015

TO VIEW THE NH STATEWIDE ASD NEEDS ASSESSMENT
WWW.NHCOUNCILONASD.ORG

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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!



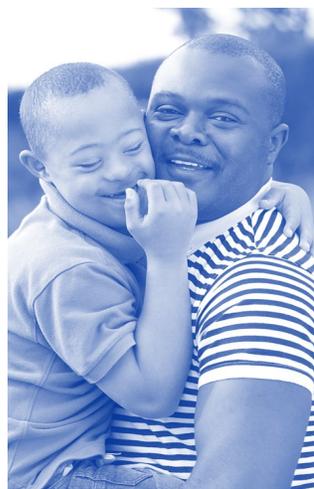
Dads of Disability

A local author explores the experience of being the father of a child with a disability from various perspectives

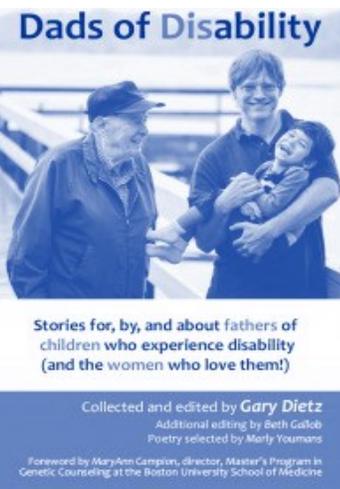
In honor of Father's Day, we recently chatted with Gary Dietz, author of *Dads of Disability*™, a collection of essays and poems exploring what it is like to be a father of a child who experiences disability. This book gives readers a glimpse into territory that is rarely explored, the emotional landscape of fatherhood. Writings traverse a myriad of feelings ranging from intense love and

NHFV: Some of the writings are very candid and raw. One writer shared that he had received some negative reactions from readers. How do you feel about this?

GD: Any time one writes from the heart, one is exposed. On the whole, I have personally received very few negative reactions.



I intended for the power in the essays to come from the less-often-heard fathers' experiences or the womens' reflections on the fathers.



strength to devastating fear and isolation. Selections are not only written by fathers, but by those that have witnessed their journeys. This book is sure to spark many great conversations in and outside of the disability community and hopefully shed light on the pivotal role that fathers play in the lives of their families. Many thanks to Gary for writing this book and taking the time to discuss it with us. Gary not only honored dads and families and the disability community with this publication, but also the beauty of real life and all of its rough edges.

NHFV: Your book has been described as “powerful, but not saccharine”. Was this the intent when you first began collecting various pieces or did it just evolve that way?

GD: Yes. When I set out to find essayists and poets, I didn't shy away from authentic emotion. (In fact, I sought it out.) What I did try to avoid was *schmaltzy* materials designed only to cause a lump in the throat or generate a tear. While those kinds of materials are valid, in my opinion when they appear in the mainstream they don't necessarily support folks in various disability communities. Rather, they are often there to make other folks “feel good.” I intended for the power in the essays in the book to come from the less-often-heard fathers' experiences or the womens' reflections on the fathers.

When I receive them, I try to understand where they are coming from. This is the age of the Internet and you have to expect that someone, somewhere is going to publicly say something negative or tell you that you are wrong. Sometimes I try to respond if the criticism is valid and the person seems like they would value authentic engagement. Sometimes I just let it be. And sometimes we deserve the criticism and change our thoughts.

NHFV: What do fathers of children who experience disability need right now?

GD: A clear understanding by schools, doctors, family members, and the public at large that fathers of children of all types are far more involved in parenting than the stereotypes would indicate. Everything else a father needs falls under that umbrella. For example, employers need to understand that fathers have to take time off for doctors visits and school meetings for their children. Reactions to an unexpected or “non-standard” life experience such as depression, anger, and confusion are not limited to women. Communication about a family member with a disability should be addressed to the individual with a disability (if possible) and to the parents -- not just the mother. The reality that a majority of child rearing is done by women shouldn't mean that a father who happens to be doing the majority of child rearing shouldn't be invited to social events for young families (for example, play dates during

the week, etc.) Don't not invite a father because you assume he will just be "hitting" on the females in the group or otherwise make things uncomfortable for the ladies. He'll likely be busy with his child.

NHFV: Is there anything you learned from publishing this book that really stopped you in your tracks and made you think differently?

GD: Yes. I learned that some of the largest critics of "mommy bloggers" and "daddy bloggers" and "parent authors" are individuals with disabilities themselves. I always knew this, but it was strongly reinforced to me, including individuals with disabilities themselves is essential to any quality conversation about these issues. For my book, I reached out to fathers with disabilities themselves whose children also had disabilities. But I was not able to get essays from those folks to put into the book.

NHFV: Did writing this book change anything for you?

GD: Yes. Through some talking engagements, I was able to network

with advocates who were subsequently able to offer some help to one of the author's families. So, while I didn't make a monetary profit from the book, it ended up being a priceless gift to at least one family. Plus, it was a fun project where I got to meet a lot of new people.

NHFV: What is your favorite essay or poem and why?

GD: That's not a fair question. If I had to choose one, it would be Lila the Philosopher because it is pure love from a young child.

Dads of Disability™ is available from the NH Family Voices Lending Library. To have this book delivered to your home, contact Erika Downie at ebd@nhfv.org or 603-271-4525.



School suspensions and expulsions continued from page 9

the NH Department of Education's website at: http://education.nh.gov/instruction/special_ed/documents/nh_rules_amendment_may_2014.pdf.

Discipline / Behavioral Incident Tracking Sheet

(please include dates and other specific information related to each activity/incident)

<i>--For each specific individual behavioral incident --</i>				<i>--- Related to this overall school year ---</i>			
Date	Brief Description of Incident	Outcome *	**Number of days child was removed (incl. ½ days)	**Total days removed during this school year	**Has a functional behavioral assessment (FBA) been requested	**Has an FBA been conducted	**Does the IEP include a Positive Behavioral Intervention (PBI) plan

* **Outcomes may include:** warning to child; parent asked to pick up child from school early [note time of day child was picked up]; removed from class to principal's/other administrator's office; removal to "time-out" or seclusion room; after-school detention; Saturday detention; in-school suspension; out-of-school suspension; "easement day"; restraint of child; expulsion; other. Also, please note if the child was removed from his/her general or special education classroom, did he/she continue to receive all special education and related services in the alternative environment (including interaction with typical peers if that is included in the child's IEP)?

- **Notes:**
- A parent or other IEP team member may request reevaluations, including a FBA whenever the child's academic, social/emotional or behavioral needs indicate one is necessary to provide the IEP team with information to develop or revise the child's IEP.
 - If a child has been removed for more than 10 days in a school year, he/she is entitled to receive special education services in his/her interim alternative educational setting (may be the child's home or alternative setting) during any days of removal beyond 10 days in a school year.
 - If one has not yet been conducted, a FBA and PBI plan should be developed by the IEP Team.
 - If a child has been removed for 10 days at one time, or for a pattern of short-term removals totaling 10 or more days in a school year, the IEP team must conduct a manifestation determination meeting.

Adam... continued from page 1

After returning from their errand, my brother-in-law resumes working on the outbuilding he is constructing for his tractor. Adam sits in a chair at the edge of the construction site, swaying to Toby Keith on the CD player and watching the cars and trucks pass by the house.

You may read this and wonder why God would put such an unfortunate human being on this earth. While it is true that Adam will not ever support himself, or drive a car, or cook his own meals, he adds to his family in ways that cannot be measured.

Adam teaches us perseverance. He hates wrinkled socks and whines and fusses if they are not perfectly smooth. Over and over, he pulls them off his feet and pulls them to his knees again in an attempt to calm his overloaded sensory system. Finally, when they are adjusted to his satisfaction, he can move on. How often do we slop together a job just to get it done, or give up when a task cannot be completed in a few moments?

Adam teaches us to be non-judgmental. Adam doesn't size up people's appearance. He doesn't care how well-educated they are, or what job they have, or how much money they have. He teaches us to let go of expectations and take people at face value, with no bias or prejudice. He doesn't realize what a powerful lesson that is. But I do.

Adam teaches us to take time and laugh.



He has a little game which nobody quite understands. Sitting next to me, he pinches his fingers together, touches his forehead between his eyebrows and then reaches out to touch mine in the same

During Mom's last days at the Hospice House, my nephew Jason brought Adam by for a visit. He ran into the room and plopped himself down in the recliner next to Mom's bed.

"Adam teaches us to let go of expectations and take people at face value, with no bias or prejudice. He doesn't realize what a powerful lesson that is. But I do."

place. Back and forth, he goes, chuckling as if it is the funniest thing in the world. His laughter is contagious. I laugh with him, and my day is immediately better.

Adam teaches us unconditional love. During most of Adam's life, my mother lived in the farmhouse with my sister and her husband. She was an integral part of Adam's life and he adored her. When I visited my mother in her room, Adam would burst through the door and plop himself on her bed or on the floor in front of her television set. He did not interrupt. He did not ask for anything. He just wanted to be near her.

My mother loved Adam as much as he loved her. Night after night, Adam brought his pajamas to her room so she could help him get ready for bed. Helping him dress, she would evoke from him the only sentence I have ever heard him say. Signing at the same time, she would start him off, "Adam, I..." Adam would sign back and yell to complete the sentence, "Love..you!"

He was clearly confused by the surroundings, but he knew his Grammie was there. After a short visit, Jason said it was time to leave. Mom kissed Adam and started the routine, "Adam, I..."

"Love... you!" belted Adam. It was the last time he spoke to her.

For days after Mom passed away, Adam would stand at the door of her empty room, pajamas in hand, waiting for his beloved Grammie to help him get ready for bed. His silence spoke the emptiness that we all felt.

To the person who wrote that nasty letter on the internet, I am sorry. I am sorry you are so biased with your own prejudice that you miss out on the value of those different from you. I am sorry you are so filled with hate that you miss out on love. And I am sorry you will never know the wonderful lessons that Adam and those like him can teach. It is you who suffers most.

Written by: Garrie Madison Stoutimore "A Cup of Tea with Momma G" stoutimore.wordpress.com.

Medication continued from page 4

a planner like I've described, I'd recommend setting another alarm to remind you to fill your planner the same day every week.

The most important part of med management, in my opinion, is checking at the start of every month to make sure that you have enough of your pills to last you the upcoming month. If you're low or out of any meds, you or someone else will need to call the pharmacy to make sure that your meds are refilled. There's no point in remembering to take your medications if you don't have any. Calling in refills is another thing that I ask the local VNA to help me with due to phone anxieties but if you don't have daily nurse visits, having a parent or a friend do the same thing for you works just as well. Just make sure that these pills actually get picked up or you're back to being reminded to take pills that you don't have.

In some cases, like mine, taking the leap towards managing your own meds may seem like going backwards because you still need others to help you manage them. However, what you are taking on is the responsibility of the planning, scheduling and asking for help if you need it. You need to remember to take your pills, have your meds picked up and, most importantly, you need to know what your pills do. This could mean having a cheat sheet of medication names, doses and effects. Medication is tricky and the prescriptions you are given are tailored specifically to your needs. Therefore, if you don't know what they do or what they're called, there's no real way for others to figure out what you need to keep your body running. There's also no way for you to have your meds picked up if you don't know what's waiting for you at the pharmacy.

Like I said before, it's very likely that you'll miss a pill here and there if you're an average human being. Medication management is a very tricky business. Thankfully, with the help of alarms and a support system of friends and professionals, it's easy enough to keep your mess-ups to a minimum and keep med management going smoothly. All you really have to do is make sure that you know what you take, when you take it and where you keep it, whether that be through memory or via a cheat sheet. If you keep tabs on your pills, take them regularly and know who to turn to should issues arise, you'll be able to look towards the future with a clean bill of health.

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/>



Supporting Parents

There are many different ways parent support and information opportunities are available to parents. Some are directed by professionals and others are directed by parents; sometimes the support is provided in a group setting and sometimes the support is provided 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.

It is understanding that gives us an ability to have peace. When we understand the other fellow's viewpoint, and he understands ours, then we can sit down and work out our differences.

- Harry S. Truman



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