

Fall 2023

Pass it On

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

An illustration of an iceberg floating in the ocean. The top of the iceberg is white and jagged, representing the visible part of the problem. The rest of the iceberg is submerged in dark blue water, representing the hidden complexities. The text 'NAVIGATING CHALLENGING BEHAVIOR' is written in red, bold, uppercase letters across the middle of the iceberg.

NAVIGATING CHALLENGING BEHAVIOR

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About this edition:

What do we mean by challenging behaviors?

Behavior – as mothers, just that word always gives us pause – and let's be real, it's not a good pause!

In our offices, we spend a lot of time talking to families who are already going the extra mile to ensure their children have the education, health care, and, most importantly, the love they need to become successful adults. Then someone has to go and throw in the behavior card!

It's no secret that all kids present difficult behavior at some point, but we are talking about the kind of challenging behavior that is persistent and can get in the way of a child's ability to form healthy relationships and access the health care, education, or support they need to progress.

What do we do when we notice these troubling patterns, or worse, someone outside our home brings it to our attention? How do we figure out what's happening below the surface of that iceberg that looks like "challenging behavior" at first glance? Who can help us? These questions are critical to making sure our kids don't sink or even just float along. Getting to the root causes of challenging behavior and identifying the appropriate interventions is often the key to helping our kiddos swim with the sharks and reach their fullest potential!

In this issue, we've shared helpful articles, resources, book suggestions, and anything else we could find to help you and your child navigate the choppy waters of challenging behavior.

It won't be easy, but you've got this, and you've got us! PIC and NHFV are staffed with trained professionals and parents who have waded in these waters too, and are just a phone call away.

Sincerely,

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

Terry Ohlson-Martin
Director, NH Family Voices (NHFV)



After-School Restraint Collapse:

When kids lose their you-know-what after school

By: Sam Collyar, NHFV Resource Specialist

Back to school is a phrase that can bring up many emotions in parents and caregivers of children of all ages. Many of us are sad to see the summer days winding down, or we may be a tad excited to see our kids getting on the bus because it means we are getting back on a more predictable schedule. Some might also worry about what this year will bring, especially when our kids come home from school and let loose all the feelings they have held in all day. You may be a family like mine who hears your child is well-behaved at school, but at home, you experience a completely different kid -- one that expresses anger, sadness, confusion, and tiredness through tears, meltdowns, or angry outbursts.

If this sounds familiar, there is nothing to be ashamed of. Many children get home and seem to lose control due to "after-school restraint collapse." This term, coined by Andrea Loewen Nair, is when a child makes great efforts to put on a happy or brave face at school and keep it together all day. When they get home, that mask comes off, and their genuine emotions, which have been bottled up during school hours, emerge in full force.

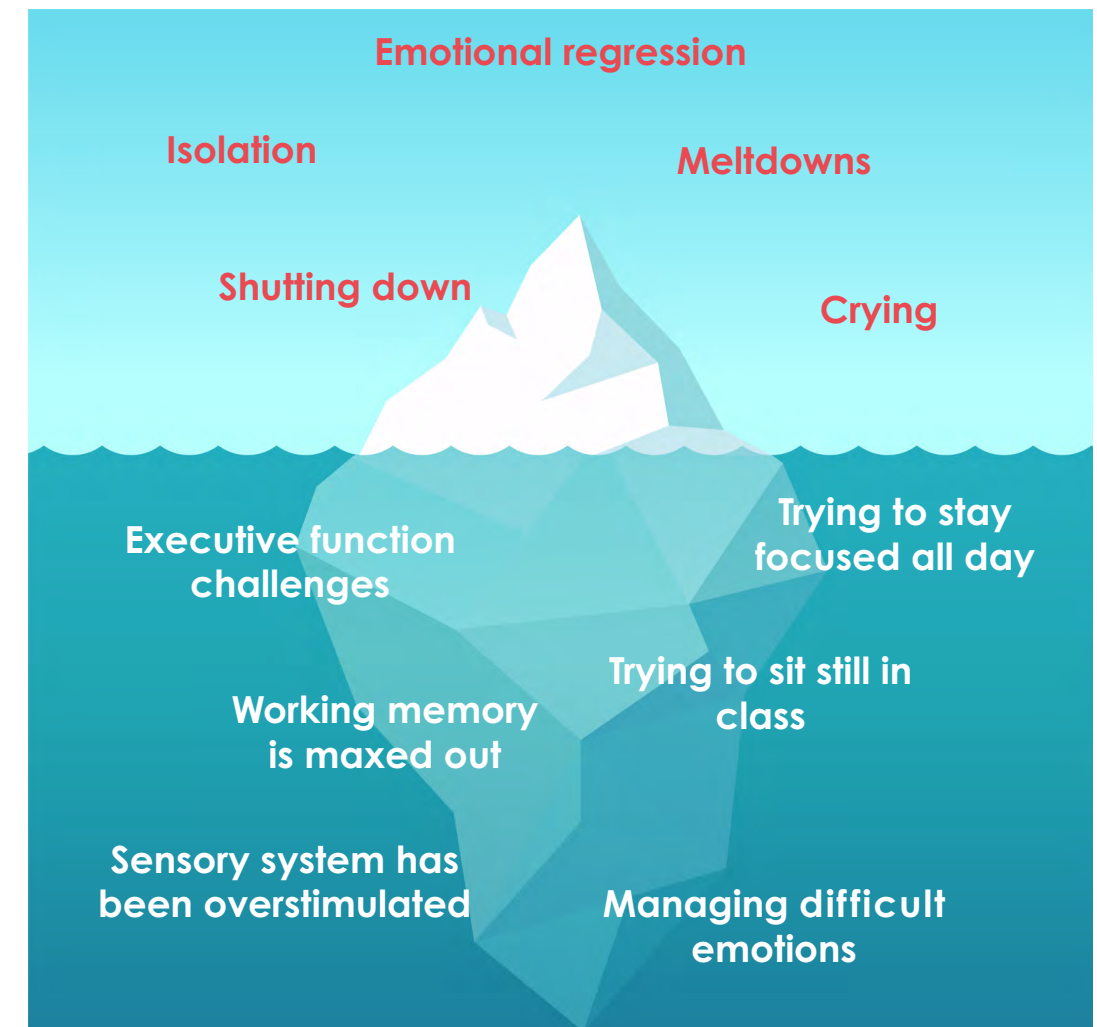
It can be frustrating to experience this as a family, but it shows your child feels safe processing their day at home. Children struggling academically or socially are more susceptible to after-school restraint collapse, but any child can experience this.

It's important to remember that children are learning to regulate their emotions, and there are things we can do, as caregivers, to help them

transition from school to home more easily. Some experts point out that starting the day with extra snuggles before school or letting a child pick a favorite family photo to bring to school can help them feel more connected to home (their safe place) throughout the day. Then at the end of the day, instead of jumping right into questions about school and homework, families can create a decompression routine that works for them.

Consider a quiet ride home from the pick-up line where your child picks the music or has a healthy snack as they shift from school to home life. Some kids may need half an hour to unwind quietly, while others may be eager to chat about anything not school related (maybe now is a good time to look up some funny jokes to get them laughing!).

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How Anxiety Leads to Problem Behavior

Kids who seem oppositional are often severely anxious

Written by Caroline Miller and reprinted with permission from the [Child Mind Institute](#)



A 10-year-old boy named James has an outburst in school. Upset by something a classmate says to him, he pushes the other boy, and a shoving match ensues. When the teacher steps in to break it up, James goes ballistic, throwing papers and books around the classroom and bolting out of the room. He is finally contained in the vice principal's office, where staff members try to calm him down. Instead, he kicks the vice principal in a frenzied effort to escape. The staff calls 911, and James ends up in the Emergency Room.

To the uninitiated, James looks like a boy with serious anger issues. It's not the first time he's flown out of control. The school insists that his parents pick him up and take him home for lunch every day because he's been banned from the cafeteria.

Unrecognized anxiety

But what's really going on? "It turns out, after an evaluation, that he is off the charts for social anxiety," reports Jerry Bublick, Ph.D., a child psychologist at the Child Mind Institute. "He can't tolerate any — even constructive — criticism. James is terrified of being embarrassed, so when a boy says something that makes him uncomfortable, he has no skills to deal with it, and he

freaks out. Flight or fight."

James's story illustrates something that parents and teachers may not realize — that disruptive behavior is often generated by unrecognized anxiety. A child who appears to be oppositional or aggressive may be reacting to anxiety—*anxiety they may, depending on their age, not be able to articulate effectively, or not even fully recognize.*

"Especially in younger kids with anxiety you might see freezing and clinging kind of behavior," says Rachel Busman, PsyD, a clinical psychologist, "but you can also see tantrums and complete meltdowns."

A great masquerader

Anxiety manifests in a surprising variety of ways in part because it is based on a physiological response to a threat in the environment, a response that maximizes the body's ability to either face danger or escape danger. So while some children exhibit anxiety by shrinking from situations or objects that trigger fears, some react with an overwhelming need to break out of an uncomfortable situation. That behavior, which can be unmanageable, is often misread as anger or opposition.

"Anxiety is one of those diagnoses that is a great masquerader," explains Laura Prager, MD, director of the Child Psychiatry Emergency Service at Massachusetts General Hospital.

"It can look like a lot of things. Particularly with kids who may not have words to express their feelings, or because no one is listening to them, they might manifest their anxiety with behavioral dysregulation."

The more commonly recognized symptoms of anxiety in a child are things like trouble sleeping in their own room

or separating from their parents, avoidance of certain activities. "Anyone would recognize those symptoms," notes Dr. Prager, co-author of *Suicide by Security Blanket, and Other Stories* from the Child Psychiatry Emergency Service. But in other cases the anxiety can be hidden.

"When the chief complaint is temper tantrums, or disruption in school, or throwing themselves on the floor while shopping at the mall, it's hard to know what it means," she explains. "But it's not uncommon, when kids like that come into the ER, for the diagnosis to end up being a pretty profound anxiety disorder."

Problems at school

It's not uncommon for children with serious undiagnosed anxiety to be disruptive at school, where demands and expectations put pressure on them that they can't handle. And it can be very confusing to teachers and other staff members to "read" that behavior, which can seem to come out of nowhere.

Nancy Rappaport, MD, a Harvard Medical School professor who specializes in mental health care in school settings, sees anxiety as one of the causes of disruptive behavior that makes classroom teaching so challenging. "The trouble is that when kids who are anxious become disruptive they push away the very adults who they need to help them feel secure," notes Dr. Rappaport. "And instead of learning to manage their anxiety, they end up spending half the day in the principal's office."

Dr. Rappaport sees a lot of acting out in school as the result of trauma at home. "Kids who are struggling, not feeling safe at home," she notes, "can act like terrorists at school, with fairly intimidating kinds of behavior." Most at risk, she says, are kids with ADHD who've also experienced trauma. "They're hyper-vigilant, they have no executive functioning, they misread cues and go into combat."

Giving kids tools to handle anxiety

When a teacher is able to build a relationship with a child, to find out what's really going on with them, what's provoking the behavior, she can often give them tools to handle anxiety and prevent meltdowns. In her book, *The Behavior Code: A Practical Guide to Understanding and Teaching the Most Challenging Students*, Dr. Rappaport offers strategies kids can be taught to use to calm themselves down, from breathing exercises to techniques for distracting themselves.

"When a teacher understands the anxiety underlying the opposition, rather than making the assumption that the child is actively trying to make her miserable, it changes her approach," says Dr. Rappaport, "The teacher is able to join

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What are Functional Behavioral Assessments (FBAs) and Behavior Intervention Plans (BIPs)?



Being proactive is the key when your child exhibits challenging behavior patterns at school. Here are some suggestions and resources from the staff at PIC and NHFV:

Consider requesting an IEP team meeting and asking for a Functional Behavioral Assessment (FBA) the first time your child is suspended or exhibits patterns of challenging behavior in school so that the team can create a behavior intervention plan (BIP) to address the behavioral issues in a positive manner.

A functional behavioral assessment (FBA) is an observation tool used to help analyze a child's behavior, and a behavior intervention plan (BIP) is how the behavior will be addressed and prevented from reoccurring.

A Functional Behavioral Assessment (FBA) is an observation used to help analyze a child's behavior and possible root causes. This is done by observing the child in a structured setting (like math or reading class) and an unstructured environment

(like lunch or gym). Previous student files or evaluations will be reviewed too as part of the FBA to inform the findings.

The FBA is then used to develop a hypothesis or a theory about the purpose or function that the behavior serves. Is this behavior an attempt to get out of something, to assist the child to self-regulate or express emotions? This information is then used to develop a Behavior Intervention Plan (BIP).

A BIP documents the strategies, supports, and methods that will be used to address problematic behaviors and teach more appropriate ones. It should include strategies that will prevent the behavior from reoccurring.

An FBA should:

- Answer critical questions regarding when the behavior is most (and least) likely to occur.
- Identify the antecedent by answering the following questions:
 - What is the situation that leads up to the behavior?
 - Who is present?
 - What is going on at the time the behavior occurs?
 - When and where does the challenging behavior typically occur?
- Define the behavior in specific, concrete terms, labeled according to its seriousness (disruptive, distracting, etc.). It should detail how long challenging behavior episodes typically last and how often they occur.

- Identify the consequences or what happens as a result of the behavior, both in terms of punishment and potential benefits for the child.

A BIP must include positive interventions and strategies to:

- Address and prevent or alter environments or events that typically occur before the challenging behavior (antecedents) does.
- Teach the child an appropriate replacement behavior/strategy.
- Positively reinforce the appropriate replacement behavior (consequences).

When is an FBA required?

Consideration of special factors: When developing the IEP, the IEP team must consider whether a child with a disability has behaviors that impede their learning or that of others and, if appropriate, include strategies, positive behavioral interventions, and supports to address that behavior.

Suspension: An FBA is required when a child with a disability is suspended or removed for more than ten school days (consecutive or cumulative) in a school year.



Behavior Tools & Resources

START
HERE

I need to request a Functional Behavioral Assessment (FBA), but I don't know what to say.

Use PIC's Sample Request Letter for an FBA

This can be used as a starting point to request that your child's school conduct an FBA formally.

Download it at bit.ly/3E7AulQ

I need an organized way to track my child's behavior incidents at school.

Use PIC's Behavior Tracker

This will allow you to record all incidents, see patterns of behavior, and assist in discovering the root cause. You can bring it to a meeting with your child's school to discuss options and effectively advocate for your child.

Download it at bit.ly/3skXI5p

WHAT
DO YOU
NEED?

If you can't find what you need here, call PIC at 603-224-7005 or NHFV at 603-271-4525 for a FREE, confidential phone consultation.

I need to learn strategies to deal with my young child's challenging behavior.

Explore Waypoint's Parenting Support and Child Development programs.

Waypoint offers free workshops for parents and caregivers of young children. To learn more, visit waypointnh.org/happenings/parenting-child-development

I need to talk with other families working hard to manage their child's challenging behavior.

Check out NAMI NH's Parent/Caregiver Support Groups

These groups are for parents of children/adolescents with social-emotional challenges. There are a variety of groups. Some meet virtually, and some in person.

Visit naminh.org/support-groups/ to find the one that is right for you.

I need something fun that will teach me and my child how to be more resilient.

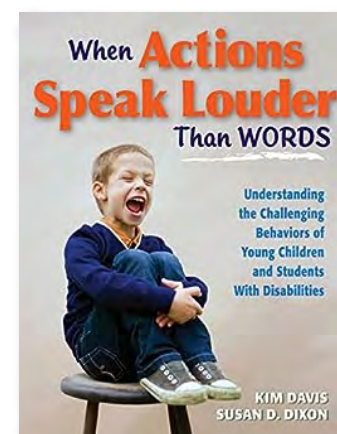
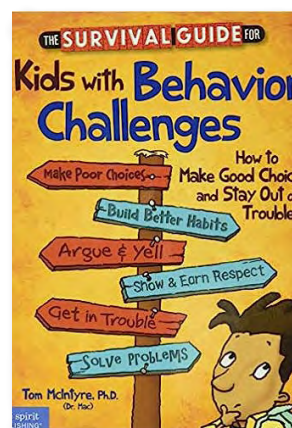
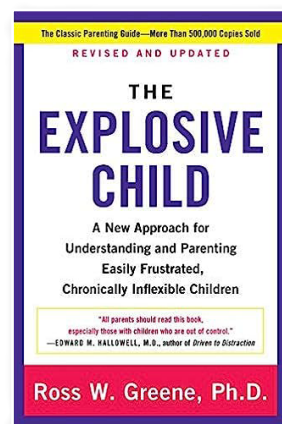
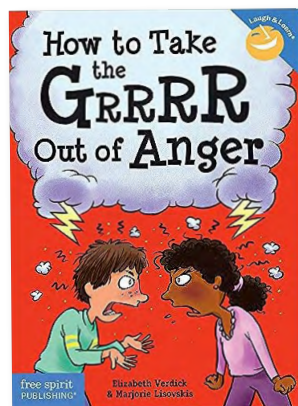
Try the Wondergrade App

Learning to handle difficult moments in healthy ways helps them form the foundation to grow into confident, resilient adults. Kids love the engaging animation, and parents enjoy the articles explaining the "why" behind the activity.

Visit wondergrade.com/for-parents



New Hampshire FAMILY VOICES® Lending Library



How to Take the Grrrr Out of Anger By Elizabeth Verdick & Marjorie Lisovski

Anger is a natural human emotion we all experience, but what are the most healthy ways to express and deal with anger?

This self-help style book is for kids around 8-13 who are learning to get a handle on who they are and how they handle stress and emotions. It walks your child (or you, because honestly, I took a lot away from this book myself) through everything anger-related: what is anger, examples of kids' experiences, working through anger aimed inward AND outwards. This revised edition addresses children's exposure to increased societal violence. It includes discussion and examples of anger related to texting and social media.

The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children By Ross W. Greene, Ph.D.

With so many parenting styles, it can be hard to identify what's a good fit for your family or even what's right for one child and what's suitable for another. Finding the right approach can be even more confusing when parenting a child with behavioral challenges.

The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children is a parenting book that will have you turning page after page as you learn to solve problems with your child as a team, understand the factors that may contribute to challenging episodes, and find skills to help your child be more flexible in their thinking and problem-solving.

The Survival Guide for Kids with Behavior Challenges By Tom McIntyre, Ph.D. (Dr. Mac)

The pre-teen and teenage years can be tricky. Navigating more challenging subjects in school and getting along with teachers, family, and friends while changing in ways they may not fully understand sometimes lead young people to make choices that aren't in their best interest and can land them in trouble.

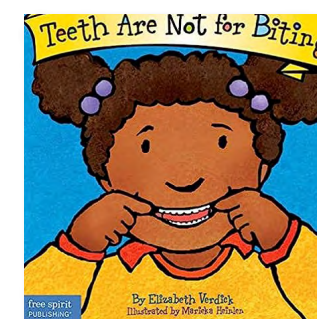
This book is designed for kids 9-14 experiencing behavior challenges and looking to change. As they read this book, they will get true stories from other kids that lead into reflection and learning sections to guide readers through the root causes of behaviors and how to change them. This book is easy to follow and very engaging!

When Actions Speak Louder Than Words: Understanding the Challenging Behaviors of Young Children and Students with Disabilities By Kim Davis and Susan D. Dixon

This book is for teachers and other adults who support children with challenging behaviors. Breaking down behaviors children use to communicate with, the messages behind them, and how adults can work to address the child's needs makes this book a must-read when engaging with young children and students. Some topics covered are functions of communication, creating a supportive learning environment, and proactive instructional strategies. Nearly every chapter contains stories to highlight the theme of the chapter, engaging exercises, and end-of-chapter questions to reflect on.

Teeth Are Not for Biting By Elizabeth Verdick. Illustrated by Marieka Heinlen

This colorfully illustrated board book is part of a "Not For" series for children ages 0-3. This book addresses that our teeth are not for biting, a topic many parents of toddlers and preschoolers are familiar with. This book provides different ideas for comfort when the urge to bite pops into your little one's mind. So grab a blankie, cozy up in a comfortable chair, and read "Teeth Are Not for Biting" together.



The end of this book also provides teething tips for caregivers and a few tips for addressing the inevitable biting behavior.

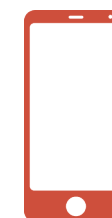
Hi! I'm Sam Collyar, a Resource Specialist at NH Family Voices.



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

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

Borrowing from the NHFV Lending Library is Easy and FREE for NH Residents!



Call 603-271-4525 or go to nhfv.org/how-we-can-help/lending-library/



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If Challenging Behaviors Interfere with Learning at School, Reach Out - Early and Often



It takes a village to raise a child, and a school behavior specialist is an essential village member for many families. I sat down with Amanda Butcher, the Regional Coordinator of School-Based Services for Constellations Behavioral Services, a few weeks ago to talk about how families and schools can collaborate to support students as they work on challenging behaviors.

Amanda has extensive experience working in schools and helping school teams support students with behavior challenges. “Parents are an important part of a child’s school experience. Parents know their kids best, and it’s okay to ask questions of those working with your kids.” She notes the importance of parents being included and respected as equal members of their child’s IEP team. “It is so critical to bridge the gaps to set students up for success, which, in turn, sets up staff for success.”

“The shame and stigma for parents of children whose behaviors interfere with school can make them wary of asking for help or finding support networks. Amanda wants parents to reach out if they need support and know they aren’t alone.

You can feel like you’re on an island when dealing with your child’s challenging behaviors.

But remember, all parents are dealing with challenging behaviors in some way.”

The key to effective support is communication with the school -- early and often. As soon as the school alerts families about behavior interfering with learning, they should ask for a meeting. Amanda says it’s necessary to continue reaching out even once behavior strategies are in place and they are working. The give and take of letting the school know what works at home and asking what is working at school helps build wrap-around support for the student in both environments, and that is essential to a child’s success.

“Applied Behavioral Analysis (ABA) is behavioral science. It is not punitive. It’s a person-centered approach and should be a positive experience for the child,” says Butcher. ABA strategies are often talked about in tandem with Autism, but Amanda says it’s important to realize that these strategies are for all people, including typical students. “It is all

about bypassing punishment and accessing positive reinforcers,” she continued. Adults supporting the student must remain calm and neutral while addressing challenging behaviors. Coregulation is crucial for students to feel supported and confident as they participate in school and build strong relationships with classmates, staff, and others. Adults need to model functional communication and reinforce appropriate behaviors. Sharing control and decision-making is a way to build positive, trusting relationships.

of managing behaviors. Students who don’t have the skills to self-regulate and behave appropriately need to be taught these skills. The best time to teach these skills is when a child is regulated and calm. “Too often, people try to talk to kids during a meltdown. Adults don’t take feedback when they are in an argument, and neither do kids. When students are calm and neutral is when learning takes place. Always wait until a child is calm to deliver feedback,” Butcher said. Students should always be given an opportunity to reflect on what



Students who struggle with challenging behaviors can get a lot of negative feedback throughout the day from peers, so the adults in their lives need to praise these students for their efforts and small wins. “Eighty percent of what you say should be positive. That gives room for constructive feedback,” suggested Butcher. “Focusing on positive behavior encourages students to stay motivated and build their skills to become successful. Building skills is an integral part

happened and what strategies will help them the next time.

Talking about, reflecting upon, and building skills like this requires vulnerability, and that can’t happen without the student having adults they genuinely trust to support them. Learn about what a student likes and dislikes and their interests, share some challenges you have faced, and how you worked to build your own skills to navigate them. “Rapport building is the foundation

of all relationships in effective behavior change,” Butcher says. Reflecting on her time working with families, she said she wants parents to know they are their child’s first teachers. It can be hard to ask for help in these situations, but building a strong relationship with their child’s school is always the first step to a child’s success. “Your child will receive the best support, services, and outcomes with a collaborative team who communicates openly and honestly. Parents know their kids best and are crucial members of the team. Sometimes this can mean talking about difficult or uncomfortable things. Still, I would encourage all parents to reach out to their teams/providers with any questions or concerns, share goals and priorities for their child, or ask what things they could do at home to support their child’s progress best. Teamwork makes the dream work!”



Joanne Grobecker is a Resource Specialist at PIC. She holds a BA in English Teaching from UNH and is passionate about empowering children with dyslexia and learning disabilities through effective advocacy.



The dance and discomfort of supporting youth with chronic conditions as they learn to manage their healthcare independently

Adolescence is, by definition, a time of transition.

It's a time packed full of changes and often some anxiety for teens and parents alike. It's a time of stretching and sometimes testing boundaries. It's a time when parents are concerned about risk-taking behavior, and youth are often more focused on things of interest in the moment rather than long-term goals. It hardly seems like the right time, or that there IS time, to help youth develop skills to manage their own healthcare, but it is precisely the time!

Not surprisingly, as we work with youth and families around health care transition, we often hear of challenges. Conversations with youth and families sometimes go like this:

A youth's health is their own, but learning to manage it



Youth: "I want my parent to trust me and to stop asking me, "Did you take your medicine?"

Parent: "I need to be sure the medicine is taken on time. Every time I ask, it hasn't been done yet. How can I trust them to remember?"

Parent: "My youth doesn't pay attention to their health at all. How are they going to do this at college?"

Youth: "College! I just started high school! That's years away!"

can be overwhelming. Caregivers have a significant role, but as reflected above, getting on the same page can be tricky.

Here are some things to keep in mind:

- Start where their interest is. What do they want to learn more about? What skill do they want to practice? What task do they want to take on?
- Engage them to identify barriers and solutions. What might get in their way of "owning" this part of their health care? What do they think could help them be successful?

- Be flexible. If your youth wants to start taking medicine more independently, talk about how and when you will check in. While 5 minutes after it is due may seem reasonable to you, 30 minutes may seem more feasible to a youth. Set them up for success.
- Assume a support role. Supporting youth as they do it, rather than continuing to do it for them, is one of the things caregivers say is their biggest challenge, but it leads to confidence and competence.
- Accept the bumps - because there will most certainly be bumps. Youth won't always remember to take their medication on time, get a good night's rest, attend a doctor's appointment, or eat the way their caregivers prefer, but they will figure it out with continued support.
- Be patient. Youth have a lot going on. Their health care won't always be a top priority to them. It is better to make slow progress than to have them shut down and make no progress.
- Keep talking. Maintaining an open line of communication is key during these transition years! Celebrate the successes, no matter how small, and let them feel safe reflecting on their missteps without harsh judgment so they can problem-solve with you and get back on track.
- Visit our health care transition hub with resources to spark conversations with the youth you care about at nhfv.org/projects/initiatives/health-care-transition/

What's Up with YEAH Council?

The YEAH Council has met regularly this summer to keep up their awesome work on several exciting projects!

This fall, look for a new podcast series where YEAH members discuss hiring support staff. In this series, we'll examine how staff have shown up in our lives to increase our independence. We will also discuss the interviewing process, and share tips and tricks to maintain good communication with support staff.

The YEAH Council has been putting together a presentation for the 17th Annual Transition Summit 2023 - Different Paths: Each Journey is Unique to highlight each participating member's journey through transition. These stories will include our youth member's perspectives on meeting challenges along the way and important notes they'd like to share with other youth and families.



Ansley, the new youth transition initiatives coordinator, deeply appreciates the continued engagement, feedback, and encouragement of our fantastic YEAH Council!

If you're interested in joining YEAH, email us at yeahnh@nhfv.org and visit us at yeahnh.org

How Anxiety Leads to Problem Behavior continued from page 5

forces with the child himself and the school counselor, to come up with strategies for preventing these situations."

If it sounds labor-intensive for the teacher, it is, she notes, but so is dealing with the aftermath of the same child having a meltdown.

Anxiety confused with ADHD

Anxiety also drives a lot of symptoms in a school setting that are easily misconstrued as ADHD or defiant behavior.

"I'll see a child who's having difficulty in school: not paying attention, getting up out of their seat all the time, asking a lot of questions, going to the bathroom a lot, getting in other kids' spaces," explains Dr. Busman. "The behavior is disrupting other kids, and is frustrating to the teacher, who's wondering why they ask so many questions, and why they're so wrapped up in what other kids are doing, whether they're following the rules." People tend to assume what's happening with this child is ADHD inattentive type, but it's commonly anxiety. Kids with OCD, mislabeled as inattentive, are actually not asking all those questions because they're not listening, but rather because they need a lot of reassurance.

How to identify anxiety

"It probably occurs more than we think, either anxiety

that looks disruptive or anxiety coexisting with disruptive behaviors," Dr. Busman adds. "It all goes back to the fact that kids are complicated and symptoms can overlap diagnostic categories, which is why we need to have really comprehensive and good diagnostic assessment."

First of all, a good assessment needs to gather data from multiple sources, not just parents. "We want to talk to teachers and other people involved with the kid's life," she adds, "because sometimes kids that we see are exactly the same at home and at school, sometimes they are like two different children."

And it needs to use rating scales on a full spectrum of behaviors, not just the area that looks the most obvious, to avoid missing things.

Dr. Busman also notes that a child with severe anxiety who's struggling in school might also have attention or learning issues, but they might need to be treated for the anxiety before they can really be evaluated for those. She uses the example of a teenager with OCD who is doing terribly in school. "She's ritualizing three to four hours a day, and having constant intrusive thoughts — so we need to treat that, to get the anxiety under control before we ask, how is she learning?"

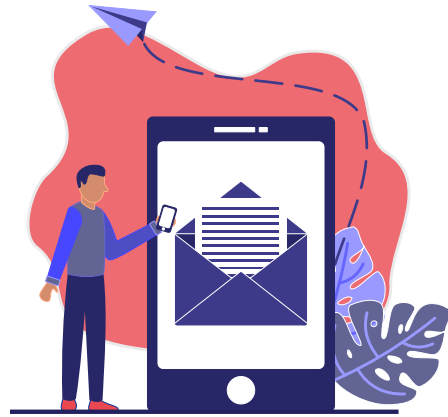
**After-School Restraint Collapse
continued from page 3**

Meltdowns happen, and it's okay. As adults, we need to prepare ourselves for them. Reminding myself that my son is still learning to regulate his emotions is helpful because it's all too easy to forget that we all need to learn how to do this.

No one is born with the ability to control their feelings and process them safely and healthily. Talking your child through these emotions and modeling examples from your day can help them see that you have these feelings, too, while showing them how to process them. In my family, we like to go for after-school walks to talk about anything non-school related at first, then shift into questions like, "What were two things that made you laugh today?" and "What did you do at recess?" before we start talking about anything else.

As the new year starts and we get back into our school routines, remember to take care of yourself and take time to process and reflect on all that is happening. Our self-care will teach our children how to respond rather than react to the day-to-day chaos we will inevitably encounter.

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NH Family Voices and The Parent Information Center are committed to delivering valuable information and resources to families of children with disabilities and the professionals that work with them.

The *Pass It On* newsletter is among our most valued resources and appears in many doctors' offices, schools, and public libraries across New Hampshire. If you would like hard copies for your place of work or community space, please email rda@nhfv.org.

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Meet Sam Collyar, NHFV's Newest Resource Specialist!

Sam is often the first point of contact families make when they call NH Family Voices (NHFV). She also manages our Lending Library, writes a column for the *Pass it On* Newsletter, and is responsible for developing new or finding existing new resources for families.

Since your experience as a parent is what brought you to us, could you tell us a little about your son, Aiden?



I love that kid! He was diagnosed with cancer when he was 8, and the way he handled everything was just so much better than his dad and I could have imagined. Before his diagnosis, he struggled in school with what we now know to

be ADHD. But I think, in some ways, having ADHD helped because he couldn't focus on his cancer long enough to stew in it. Even when we told him about his amputation – he just decided to name his residual limb Bob, and that was it! He's even got another name picked out in case he ever needs his other leg amputated (which is very unlikely). Aiden just goes with the flow – trying different meds and coping with his social and physical differences. He handles it all. I really think it's his sense of humor that gets him through. I want to be like Aiden when I grow up!

What interested you about working at NHFV?

At first it was talking to Jenn and Sylvia because I know them from The Childhood Cancer Lifeline. Then it was learning about NHFV because I hadn't heard of it before. Working with other families was a real draw because I know it would have been helpful to me – I didn't know about Katie Beckett or NHFV and I think it would have helped (If you don't know about it call me).

What has been the biggest surprise since starting at NHFV?

How many programs exist in NH -- I had no idea! And all

the acronyms. The military uses a lot of abbreviations, but apparently, not as many as state agencies!

Have there been any unexpected benefits to working with families looking for assistance at NHFV? How has it helped you?

It's helped me not feel as guilty for what I didn't know when Aiden was sick. I thought I was way behind, but as I talk to more and more families, I see that is not the case. It's helped with my "mom guilt." I wish the hospital social worker had mentioned things like Home Care for Children with Severe Disabilities (HCCSD). I just had no idea how many services and supports were out there.

As a parent of a kiddo with a very serious and complex medical condition, how have you balanced all his different needs and systems you've had to work with?

It was trial and error. I tried planners – that worked for about a week. Now I rely heavily on my phone calendar and my patient portal. Also, choosing what to focus on during Aiden's treatment and deciding what could fall to the side. If it wasn't going to help during his treatments, it wasn't necessary for survival at the moment, and I didn't need to worry about it. I knew it would be there later.

How do you balance everything? Work, family, medical, school, etc.?

Very carefully [laughs]. I'm still learning. It's about figuring out what's important – even just for that particular week. Trial and error – that's how I live my life.

What would you do if I told you you could take the next 48 hours off without worrying about family, schedules, or money?

Sit there, overwhelmed with all the choices [laughs]. Or I might make very impulsive decisions like swimming with sharks like I did this past Saturday.

What would you advise a parent who just received a new diagnosis for their child?

It's okay to wing it when you are going through the very early stages of a new diagnosis. I wish someone had told me that. It's overwhelming, and you don't have to get everything right on the first try.

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