

Medically Complex Program

Dear Family and Friends of The Nemasket Group,

Each year, we reflect on the role we play with the families we support. Many families open their homes and share their lives with us. We are grateful to be able to offer ideas, and share our experience with you, in the hopes of inspiring and encouraging you along this journey.

To everyone in our Nemasket community, we wish you a wonderfully peaceful holiday season.

Medically Complex Program at The Nemasket Group

109 Fairhaven Road, Mattapoisett, MA 02739

Tel: (508)999-4436 Emergency Tel: 508-207-2538 Fax: (508)997-9239



Sandra Heller

Associate Executive Director
Medically Complex Program Director
Ext. 128
SandyKinney@NemasketGroup.org



Shanell Stewart

Medically Complex Program Assistant Director
Ext. 161
ShanellStewart@NemasketGroup.org



Patrick Russell

Medically Complex Program Advisor
Ext. 106
PatrickRussell@NemasketGroup.org



After Months Of Special Education Turmoil, Families Say Schools Owe Them



Roughly [7 million children](#) in the U.S. receive special education services under a decades-old federal law — or *did*, until the pandemic began. Many of those services slowed or stopped when schools physically shut down in spring 2020. Modified instruction, behavioral counseling, and speech and physical therapy disappeared or were feebly reproduced online, for three, six, nine months. In some places, they have yet to fully resume. For many children with disabilities, families say this disruption wasn't just difficult. It was devastating.

Kate Maglothin in Waterford, Mich., says for her and her 7-year-old son, Finn, learning from home without extra support was "mentally and physically and emotionally draining."

"I just watched my child not learning and going backwards," remembers Rachael Berg, a mother in Anne Arundel County, Md., whose 6-year-old daughter, Maddie, has an intellectual disability and attention deficit disorder. "I'm just sad for her."

"I feel like they probably despise me by now," says Timothy Largo of his grandson's school in Crownpoint, N.M. Largo filed a special education complaint to compel the school to make up for services the sixth-grader did not receive during the pandemic. "It's not fair," says Chrystal Bell, a mother in New York City whose son, Caleb, is deaf, blind and nonverbal. "He requires a lot extra just to achieve a little bit of the same."

Without the usual access to educators, therapists and in-person aides, these families, and many like them, say they watched their children slide backward, losing academic, social and physical skills. And now they're demanding help, arguing to judges, state departments of education and even to the U.S. Department of Education that schools are legally required to do better by their students with disabilities. In complaints filed across the country, families say schools need to act now to make up for the vital services kids missed.

Parents "try to have grace"

The federal [Individuals with Disabilities Education Act](#) entitles children with disabilities to a public education that is two things: free and "appropriate." That means, if a child needs a speech therapist or special curriculum modifications to learn, schools must provide it.



According to IDEA, children with unique needs are to be assessed by school staff, in collaboration with the child's family, and given an individualized education program. Each IEP is a legal document, a kind of road map of required services and goals for every child. But schools' shift to remote learning made it difficult for many districts to follow students' IEPs. Special educators and therapists weren't allowed to work in person, and many services couldn't be done well, if at all, remotely.

In October 2020, [RAND researchers asked](#) a sample of K-12 principals to estimate how their students with disabilities would perform in fall 2020 compared with in fall 2019. A little more than two-thirds of those principals said their students with disabilities would perform somewhat or much lower than they had before the pandemic.

Families told NPR that, initially, they approached these failures with patience and understanding. "The teachers don't know how to use the computers ... Everybody else is having technical issues. You know,

none of that is anybody's fault. You try to have grace about all that," says Carolyn Shofner, of Nashville, Tenn. Her high-school-age daughter, Rachel, has severe autism and struggled to learn remotely without the paraprofessional who sits by her side in school.

For Shofner and some families, those early failures of spring 2020 continued into the fall and winter. In January, her patience ran out. "[Rachel] had made no progress ... and, in fact, had regressed on several things," Shofner remembers, including basic skills like counting money and expressing emotion. She hired an attorney and filed a due process complaint against the city of Nashville and its schools, for violating IDEA and failing to provide her daughter an appropriate education.

The city quickly settled with Shofner, agreeing to follow Rachel's IEP and to provide an in-person paraprofessional or tutor in the case of another school closure. The people who are actually working with students may believe those students need particular things, but they feel very powerless and the decisions get made at a higher level.

In a written response to NPR, a Metro Nashville Public Schools spokesperson says, "During an extraordinary year, our teachers and staff went to great lengths to educate all of our students. We don't agree with this parent's version of events, but cannot comment further because of student privacy concerns. There are a number of reasons to enter into a settlement and the agreement denies any fault on behalf of MNPS."

To be clear, Shofner and most of the families NPR spoke with do not blame teachers or school-based special education staff for these pandemic failures. "They're kind of in the same position I am," Rachael Berg says. Instead, Berg argues district and state leaders are to blame for failing to quickly plan for and provide these extra services to help kids like Maddie, Berg's daughter, make up some of the ground they lost.

"I've called countless IEP meetings. I've gone to so many webinars. I've joined every Facebook group you could ever possibly join. And I've never felt so unheard," Berg says.

"School systems are bureaucracies," says attorney Leslie Seid Margolis, who represents Berg's daughter. "They are not set up to be flexible ... What we heard over and over again is that ... the people who are actually working with students may believe those students need particular things, but they feel very powerless and the decisions get made at a higher level."

Margolis, who is also a managing attorney with Disability Rights Maryland, says the problem with extending districts more patience is that time is of the essence. Some students with disabilities have lost so much ground, it could take years to reverse the backslide. School systems are bureaucracies. They are not set up to be flexible. Also, in Maryland, the clock is ticking. Margolis and her colleagues have filed a class administrative complaint on behalf of Berg and other families against the state department of education because state regulations require that special education complaints be filed within one year. Already, schools' early failures in March, April and May of 2020 fall outside that window.

The Maryland State Department of Education did not immediately respond to a request for comment.

"It was an act of God"

There's a name for what many of these families now want from schools: compensatory services. The term isn't featured in IDEA but comes from past case law, as courts have sought a way of forcing schools to make up for failing to provide necessary special education services. Families now argue schools are legally required to do whatever it takes to get their special education students to where they would have been had there been no pandemic at all. To school districts, though, the words "compensatory services" strike a nerve, because they often involve attorneys and costly remedies and because, districts say, they imply wrongdoing.

"A compensatory education service is to be provided when a school failed the student, and here during the pandemic, it's hard to say that was the fault of the school or anyone, really. It was an act of God," says Andrew Manna, an Indiana-based attorney who advises school districts.

"We have to look at the pandemic as the culprit here," says Phyllis Wolfram, executive director for the Council of Administrators of Special Education and a retired public school educator. "So there is no umbrella or realm by which we should be looking at compensating for something that we didn't have control over." Advocates and disability rights attorneys say that regardless of fault, schools must step up.



"Students are entitled to a [free and appropriate public education] regardless of the circumstances," says Blaire Malkin, an attorney with Mountain State Justice in West Virginia. "It does not mean that [schools] are at fault for not providing those services in a global pandemic. What it does mean is that they have a duty... to provide that child compensatory education and to put that child back in the place they would have been if school had been open."

Central to this dispute is guidance the U.S. Department of Education issued at the beginning of the pandemic, [in March 2020](#). It warned districts that "if a child does not receive services after an extended period of time, a school must make an individualized determination whether and to what extent compensatory services may be needed, consistent with applicable requirements, including to make up for any skills that may have been lost." Many families tell NPR their districts have delayed assessments and, even now, remain more focused on cheaper, schoolwide "recovery services." "Trust me, I ask, and I say, 'What are we doing for compensatory services?' " says Berg, adding that the members of Maddie's IEP team "just don't have the answers."

A spokesperson for the school district Maddie attends, Anne Arundel County Schools, said in a written statement that all children with disabilities will be considered for recovery or compensatory services, but "the eligibility process is a lengthy one and will continue into and through the next school year." This slow, disjointed approach to compensatory services isn't specific to Maddie's school or to Maryland. A class action complaint filed in late 2020 against the New York City and State Departments of Education said much the same:

"Defendants have already publicly acknowledged that compensatory services should be available for those students with disabilities who were denied their instruction and services during remote learning. Nonetheless, eight months into the pandemic, Defendants have offered no hint of a plan for processing and delivering upon claims for compensatory services owed to tens of thousands of New York City students, whose losses continue to accrue."

In response to a request for comment, a New York City Department of Education spokesperson said the department began to offer in-person services as soon as the governor allowed. They said the department also closely monitored students' progress, prioritized device distribution for children with disabilities and worked with families to identify when students would need additional support.

A spokesperson for the New York State Department of Education said they do not comment on pending litigation.

The language in that New York complaint is exactly the kind of thing that worries Wolfram, at the Council of Administrators of Special Education, because she believes the U.S. Education Department erred in using "compensatory services" at all in its 2020 guidance. "How could you compensate for all that time when we were thinking first and foremost about the health and the safety of all of our students and our staff and our families?" Wolfram asks.

When asked by NPR to clarify its position on compensatory services, an Education Department spokesperson said that the department stands behind its March 2020 guidance and that it would be releasing additional guidance in the near future.

Wolfram and attorneys who advise school leaders argue this talk of compensatory services is unnecessary. After all, some children may not have regressed at all. And, they say, schools can and will help without being forced to. First, though, students need to be assessed, to see precisely what kind of services they may need, and that will take time. So will managing how to provide all this extra support to students in a timely way, often without being able to add staff. For example, having to provide dozens of additional hours of speech therapy, in an area with only one school-based therapist, could require schools to contract with private providers.

"All of my clients... are scrambling to find additional personnel to work during the summertime — to provide a lot of these services that have been missed up to this point," says Jim Keith, chair of the Council of School Attorneys for the National School Board Association. "That's more difficult than it might seem, because I can tell you, it's been a hard year for everybody... We have educators who are basically worn out. And so we're trying to find people to provide these extra services."

Keith and Wolfram say families should trust that schools are doing their best. Manna adds, families must remember that the pandemic put unprecedented strain on schools. What's important, he believes, is that districts acted — and continue to act — in "good faith" to provide what services they can. And he encourages families seeking extra help for their kids to work with school leaders — not against them by rushing to file potentially costly complaints.

"Is there something where we say, 'Look, this wasn't the school's fault, this wasn't the family's fault, this wasn't the teacher's fault, it's nobody's fault. But certainly we acknowledge that the student had some instructional time lost. And how do we bridge that?' " asks Manna. "Is there a way to have a provision where families and schools come together on collaborating to get that recovery instructional time without lawsuits?" The problem with all of this, parents and advocates say, is that they don't always trust districts to prioritize their students with disabilities and to provide them the services they need. Is there a way to have a provision where families and schools come together on collaborating to get that recovery instructional time without lawsuits?

"There is a process already," says Janeen Steel, a prominent disability rights attorney at Vanaman German in Sherman Oaks, Calif. "We have it in the law. It's called an IEP." Schools simply need to follow the law, she says. Steel has also seen districts offer families a modicum of help, but only in return for waiving their rights to any other pandemic-related services. Therese Yanan heads the Native American Disability Law Center in Farmington, N.M. She remembers being on the phone once with a school attorney, long before the pandemic, fighting over whether a district should have to pay for her client's special education services. "I said to him, 'What are we really fighting about here? You know this student needs these services.' And he said to me, 'Therese, if the school provides this student with these services, the football team won't get new uniforms this year.' And I responded, saying, 'Do you know how much I don't care about the football uniforms?'"

What families can do

Rancher Timothy Largo lives with his wife and grandchildren in Crownpoint, N.M. His grandson, Domeniqu, attends a tribally controlled Navajo grant school and receives special education services, including for attention deficit hyperactivity disorder.

After his school shut down and the services Domeniqu relies on stopped, Largo sought the help of the Native American Disability Law Center and filed a special education complaint with the relevant education agency — in his case, the Bureau of Indian Education. Largo accused Domeniqu's school of failing to provide special education services during the pandemic. His ask: compensatory services.

"I told the [special education] team that I feel like he's been left behind," says Largo. In February, the BIE ruled in his favor, saying "the school failed to provide services consistent with the IEP or undertake an individualized determination of how services would be provided during the pandemic and amend the IEP accordingly." The BIE ordered the school to give Domeniqu a comprehensive evaluation, to provide 45 hours of compensatory services and to quickly submit a plan for providing those services. Neither the BIE nor the school Domeniqu attends responded to a request for comment.

Families in Largo's position can also file a complaint with the [U.S. Department of Education's Office for Civil Rights](#). Another, more costly and cumbersome option is filing what's known as a due process complaint, as Carolyn Shofner did in Nashville. This allows families and schools to make their case before an administrative judge, in a trial-like setting. Though, in Shofner's case, the city settled before it came to that.

In the settlement, the city denied any wrongdoing but agreed to pay Shofner's \$8,000 in legal fees and another \$5,750 toward expenses she incurred hiring a private tutor for her daughter during the shutdown. Shofner says, "I did it to make sure that any other parent who ever faced something like this again would not be afraid." What Largo's and Shofner's paths have in common is that they require families to advocate aggressively — or pay someone else to do it. The results are deeply inequitable, with income, language and knowledge barriers preventing many families from fighting for their child's rights. "Nobody drops your kid off at school to think, 'you've got to hire a lawyer,'" Janeen Steel says. "You trust that [school staff] are the experts."

Kate Maglothin in Waterford, Mich., says she felt like she had been given the "brushoff" when her school district denied makeup services to her 7-year-old son, Finn, who has a severe speech and developmental delay. Then her sister-in-law, who happens to be a special education teacher, recommended that Maglothin retain a well-known advocate in the region — to help make her case to the district. "The minute that I did hire an advocate," Maglothin remembers, "everybody [in the district] paid attention."

"The pandemic just exposed every problem"

Steel says the problem — that many districts have failed to provide special education services and are now failing to communicate with parents about remedies — is an old one. "I didn't do this for 20 years because things were working before the pandemic, right? The pandemic just exposed every problem."

Largo, who spent much of the past year staying home to help his grandson with remote learning, wonders, "How many students are out there, not getting the same services they're entitled to? A lot of these parents or guardians, they're not literate and, you know, the students are falling through the cracks."

Largo says making sure his grandson Domeniqu gets the compensatory services the boy entitled to is his way of keeping a promise to his own son, Domeniqu's father. As Largo's son was dying, Largo says he gave his word that he and his wife would take good care of their grandchildren. "That's basically what I'm doing is trying to advocate for my kids."

I just want our kids to be valued as much as others. ... They have potential, too.

The system that Congress designed to educate children with disabilities on an equitable, individual basis has always been fragile, but, in many places, it has buckled under the weight of the pandemic, forcing many parents and caregivers to seek remedy however they can.

"I just want our kids to be valued as much as others," says Chrystal Bell. She's part of that class action complaint against the New York City Department of Education. "They have potential, too."

Rebecca Klein is a New York-based freelance journalist who primarily covers education, labor and politics. She most recently worked as a senior reporter for HuffPost.

Nicole Cohen and Steve Drummond edited this story for broadcast and for the Web.

Planning for a Loved One with Special Needs: Special-Needs Trust



Webinar

December 7th, 2021

Arc of Haverhill-Newburyport, MA.

Hear a comprehensive overview of Special Needs Trusts, including how to determine if this may be a viable option for you and your loved ones.

Presented by:

Michael Heberlein, CFP®, ChSNC®, Commonwealth Financial Group

Matthew Moody, Commonwealth Financial Group

To register visit https://us06web.zoom.us/meeting/register/tZluduCorDsjH9MbhwB5Sijef_KtVDuJlIEb or contact Andrea Morris, Director of Family Supports, The Arc of Greater Haverhill-Newburyport, andrea.morris@thearcofghn.org

Special Education Law in Massachusetts



Webinar

December 10th, 2021

Special Needs Advocacy Network, Inc in Massachusetts (SPaN).

Coffee Talk with Dr. Russell Johnston, Deputy Commissioner of Education.

- ❖ 2022 will be the 50th Anniversary of Chapter 766 Special Education Law for the Commonwealth of Massachusetts.
- ❖ The Deputy Commissioner of Education, Russell Johnston will present a look back on the journey of special education from its early beginnings, current status and where we are going.
- ❖ This event will be a closer look at topics that SPaN members want to explore in greater depths. Taking the viewpoint of where we are now and where we are heading in the future, explore the following:
 - SEPAC engagement
 - Mental health crisis
 - Equal access in vocational programs
 - Transition and adult outcomes
 - DESE enforcement of the IDEA and Section 504
 - Covid outcomes

When you register for the event, you will have an opportunity to ask your questions and provide information regarding your concerns and experiences on the above topics. * SPAN will be providing this information to Russell Johnston in advance to allow his team to gather any statistics or relevant information to share during the workshop.

Register early in order to have your general questions considered

to <http://events.r20.constantcontact.com/register/event?oeidk=a07ei7p7h9o78932417&llr=pxn6x5ia> or contact Elaine Rabbitt, Event Coordinator, Special Needs Advocacy Network, Inc., (508) 655-7999, info@spanmass.org

"Morningstar Access" Boston Children's Museum



**BOSTON
CHILDREN'S
MUSEUM**

December 27th, 2021

10 am-12 pm

All Masks On Event.

Program offers children with special and medical needs the opportunity to enjoy the Boston Children's Museum in an uncrowded environment, with few other visitors and less concern about infections and large crowds.

COVID-19 Protocols:

To accommodate different needs related to the COVID-19 pandemic, there are now **two different versions of Morningstar**.

- 1) **All Masks On!** All staff and visitors ages 2 and older are required to wear masks.
 - This session happens when the Museum is freshly cleaned with no visitors prior to the scheduled time. No mask exceptions will be considered.
 - Families with any needs are welcome as long as they can follow this strict mask rule, which is in place to create a medically safer environment.
 - Families with any needs are welcome as long as they can follow this strict mask rule, which is in place to create a medically safer environment.
- 2) **Mask Exceptions Considered:** All staff and visitors ages 2 and older are required to wear masks. However, mask exceptions will be considered in advance at registration for children who have sensory needs or other types of needs that prevent them from keeping their masks on.

Morningstar Access Admission: A link to pay online will be sent a week prior to your visit.

Half price general admission (\$9.00 per person)

Free for Museum members

Other discounts may apply (such as the EBT/WIC discount)

Pre-registration is required to <https://bostonchildrensmuseum.org/morningstar-program-registration-form> or contact lwamoto@BostonChildrensMuseum.org or call 617-986-3697.

The Salvation Army 2021 Christmas Assistance



Registration is now underway! Due to increasing needs, please sign up early!

All questions can be directed to our Social Service Office at 508.997.6561.

As we continue to recover from the pandemic, we anticipate that more people in our community will need assistance this year. Registration has returned to "in-person only."

Masks are required. Early registration is recommended.

For more information, visit: <https://massachusetts.salvationarmy.org/MA/NEBHoliday>



VaxAbilities Hosts Disability-Friendly Vaccine Events

VaxAbilities is hosting disability-friendly vaccine events across Massachusetts. These events will have extra staff on hand to provide skilled support to people with disabilities and/or sensory support needs.

Most of these events will offer COVID vaccinations for children ages 5 and up, as well as adult initial vaccines and boosters. People with and without disabilities can get vaccinated – including the whole family ages 5+ or staff that may come supporting people with a disability.

Step 1: Sign up for one of our events

Go to www.VaxAbilities.com to find dates and locations. New events will be added in the weeks to come. Each event has its own sign-up link to reserve an appointment that includes disability supports. These appointments provide extra time and reserve your spot at a designated disability-friendly vaccine station. We encourage you to book an appointment to reserve your preferred time. Walk-ins will also be welcome at the sites as capacity allows. To be fully vaccinated, children will need two doses of the vaccine, 3 weeks apart.

Step 2: Tell us about specific support needs

Once you have scheduled your appointment tell us about any specific support needs you may have using the [link provided on our website](#) or this QR code.



Questions about the vaccine?

Talk with your health care provider or one of our clinicians on site.

VaxAbilities
VaxAbilities.com #VaxAbilities

VaxAbilities is organized by the Massachusetts Developmental Disabilities Network and funded by the Administration on Community Living.



Holiday Cash & Chance Item Raffle

Both raffles will be drawn on Monday, December 13th.

You do not need to be present to win.

Winners will be notified by phone or email provided.

1st Prize \$500

2nd Prize \$250

3rd Prize \$150

+Over 30 Non Cash Prizes

\$10.00 for 1 book of 10 Tickets

To purchase tickets, view a list of available prizes & for more information visit

Nemasket Holiday Basket Raffle



Basket 1

Hand Made Baby Quilt

dimensions 67" x 50" mostly pink

Twinkle & Cuddle Soother

Piggy Bank

Oh Baby the Places You Will Go

Dr. Suess

Value \$355

Basket 2

Great Wolf Lodge

\$400 use anytime gift card

Wiley the Wolf Toy



Value \$420

Basket 3

Cricut Joy

Storage Case

Cricut Joy 2021 Bible

Permanent Vinyl Rolls

gold, black, white

\$100 Michael's Gift Card

Value \$311

Ticket Pricing

Most Credit Cards Accepted

One \$3.00

Two \$5.00

Five \$10.00

Eleven \$20.00

Basket 4



Farm Visits

Travelling Petting Zoo

Piggy Planter

Value \$370

Basket 5

Ryobi Snow Blower

40V HP 18 in cordless electric

2022 Farmer's Almanac



Value \$439