

Family Connections Center



Election Day is Tuesday, November 3, 2020. All Massachusetts voters are eligible to vote by mail upon application for all elections in 2020.

To vote by mail, all you need to do is:

1. **Complete** a Vote by Mail Application by visiting sec.state.ma.us or contact your local Election office to request a Vote by Mail Application.
2. **Deliver or Mail** your application to your local election office.
3. **Vote** when your ballot arrives.
4. **Return** your ballot.

Applications must reach your local election office by **October 28** for the State Election. State Election ballots need to be postmarked no later than November 3 and must be back at your local election office no later than November 6. Apply early, in order to have enough time to return your ballot.

You can also vote in person at your local election office on November 3rd. Please visit sec.state.ma.us to find your local Election office or to register to vote.

Family Connections Center at The Nemasket Group

109 Fairhaven Road, Mattapoisett, Ma 02739

Tel: (508)999-4436

Emergency Tel: 508-207-2538

Fax: (508)997-9239

Find us on Facebook! <https://www.facebook.com/familyconnectionscenter>

Sandra Heller

Associate Executive Director
Family Connections Director
Ext. 128
SandyKinney@NemasketGroup.org

Heidi Pina-Barnes

Family Connections Assistant Director
Ext. 162
HeidiPina-Barnes@NemasketGroup.org

Patrick Russell

Family Support Advisor
Ext. 106
PatrickRussell@NemasketGroup.org

Ana Colon

Family Support Advisor
Ext. 118
AnaColon@NemasketGroup.org

Shanell Stewart

Family Support Advisor
Ext. 161
ShanellStewart@NemasketGroup.org

Reminder:

Sign up to receive this newsletter via email!

Did You Know

The Truth About Self-Contained Special Education Classrooms

Self-contained special education classes promise things they can't deliver.

Article by Tim Villegas

What if we were to challenge the assumption that we can't serve students with more significant disabilities in less restrictive settings?

As a special education teacher, I taught in a self-contained special education classroom for thirteen years. Nearly every day, I wished I didn't have to.



It wasn't because I hated my job; I loved it. It also wasn't because I didn't feel supported. For the most part, the three elementary schools that I had the pleasure of working with were loving, accepting places that invested time, energy, and resources in making me a better educator. Despite the work that we did for our students, there was something in the back of my mind, like an itch that I couldn't scratch. I knew then and know now that non-inclusive classrooms rarely provide the support that is necessary for students with disabilities to achieve the promised outcomes.

The least restrictive environment (LRE) is a legal term in the Individuals with Disabilities Education Act (IDEA) which states the following: "To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

That mouthful boils down into two main ideas:

- Children with disabilities ought to be educated with their nondisabled peers
- They can't be removed unless we have tried everything to make it work

Under LRE, general education is the first consideration for educating a student with disabilities before moving to more restrictive options.

If you are a parent of a child with a disability, and you have sat in an Individualized Education Program (IEP) meeting, then you know how easy it can be for teams to blow by the placement discussion without a robust debate about whether the general education setting is appropriate. For students who have more significant disabilities, LRE is seldom ever discussed seriously because of the "nature and severity" of disability doesn't lend itself to making any changes other than the most restrictive setting. But what if we were to challenge this assumption that we couldn't serve students with more significant disabilities in less restrictive settings?

Here we come to the truth about self-contained special education classrooms

The reason why they continue to manifest themselves in school districts across the United States is that families do not know to ask or expect anything different. For students who have intellectual and multiple

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disabilities in the lower grades (K-2), it is not an unreasonable expectation for families to advocate for an opportunity to interact and learn in a setting with their nondisabled peers. The standards are not so rigorous that the curriculum needs to be modified significantly. While harder for older students, it is certainly not impossible to modify the curriculum for grades 3-8 and even beyond.

According to the most recent data, students with intellectual disabilities and multiple disabilities participate in general education classes at 17 percent and 13 percent, respectively. That is far below the gold standard of 80 percent that inclusionists advocate.

What is disturbing to me is that despite the low averages for students with significant disabilities, the percentage of students with any disability in the general education classroom 80 percent or more of the time ranged from 37 percent in Hawaii to 83 percent in Alabama. The difference between states is more than 40 percentage points!

Moreover, we know that self-contained special education classes promise things they can't deliver on. In a 2011 study, Julie Causton & George Theoharis (among others) compared the literature on the justification for self-contained classrooms. They found that there were four main reasons why students were placed in self-contained special education classrooms:

- Issues of community
- Distraction-free environments
- Specialized curriculum/instruction
- Behavior support

So, to test the hypothesis of whether or not self-contained special education provides the necessary support, they examined some classrooms.

The researchers found that the students observed were not learning in a location with a protective and strong community, they were in much more (not less) distracting settings, they were not accessing the general curriculum in an individualized manner, and school staff were not using thoughtful behavioral interventions but were using threats, timeouts, and restraints.

Perhaps you think, well, they didn't observe the right classrooms! Speaking from the perspective of someone who has spent the entirety of my time as a classroom teacher in a self-contained setting, I can't disagree wholly with these findings. And I think I was a pretty good teacher. Every year I tried my best to deliver on all of these promises, and some years I was closer to my goal than others. But, when you put students who have intellectual, social, and behavioral difficulties all in one place, what do you think is going to happen?

Here is the other truth about self-contained special education classroom

I can say this with full confidence. If things don't go well, it is the byproduct of a system that is stacked against students with disabilities, not because of a "bad teacher." Teachers are put into difficult situations every day because of the educational system, the one that produces over a 40 percent swing in inclusion rates by state.

By and large, school districts do not train their teachers on how to work with students with behavioral challenges, autism, or intellectual disabilities. This goes for teachers who work in self-contained classrooms as well. So is it their fault that they can't do what they don't know? We wouldn't expect that from our students, but that is precisely what we are doing to our special education teachers.

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I have had the privilege of working with some fantastic special education teachers in self-contained classrooms. These teachers love their students, work tirelessly to give their students access to the general education curriculum, and who think up creative behavior support solutions that are child honoring. Great teachers are just that, great teachers, no matter where they are located. We need to keep mentoring, cultivating, and encouraging special education teachers.

But to think that creating more self-contained special education classrooms is the answer we need to produce better outcomes for students with disabilities is short-sighted. If we do that, we are looking backward instead of forward.

How do we fix it?

I have a few thoughts.

- First, we need **one educational system for all students**
- Next, we need to **make inclusive education a national (and societal) expectation**
- Finally, families need to **advocate for inclusive practices** in their school and community

My goal isn't to make any parent or educator feel bad about choosing or even preferring a self-contained special education classroom. But if I was able to help you think differently about them, or urge you to think about how you can create a more inclusive environment where you are right now, then it was worth it.

Community Integration

<https://www.centerforpublicrep.org/issue/community-integration/>

Every person with a disability has the right to live, work and fully participate in the community.

Every person with a disability has the right to be a valued member of the community – not just *in* the community – but *of* the community.

Yet hundreds of thousands of people with disabilities across the United States are victims of discrimination who still live or spend their days in segregated settings and remain separated from their communities. In the past, people with disabilities were institutionalized in large and usually horrific facilities. As some institutions closed, many people were transferred to other institutions like nursing facilities. Still others were placed in the “community,” but too often remain segregated in group homes, boarding houses, sheltered workshops and day programs.

Segregation in all of its forms is harmful to people with disabilities.

It robs people of a full and valued identity.

It separates people from family, friends, neighbors, and community.

It denies people the chance to live in real homes and have real jobs.

It forces young people into separate and usually inferior schools.

It makes it impossible for people to spend their leisure time where and how they choose.

It denies people the chance to worship as they choose.

CPR's enduring commitment to community integration for all individuals with disabilities is reflected in all of our legal and advocacy initiatives since our founding in the early 1970s.

We are determined to help everyone with a disability live a real life in the community.

COVID-19 Related Stories For Schools

More and more states and cities have put together plans for going back to school for the 2020-2021 school year. Each area in the country has somewhat different plans. Some are starting out with 100% distance learning, some are implementing a hybrid model and others are going back to in person learning with modifications. As we start to go back, using any of those approaches, children are going to need INFORMATION. What will they see that is different? What are the new norms? Are masks required? What about on the bus?

As humans, we all thrive on routine. Children's (and adults) routines have been disrupted over these past several months. Stories can help ALL children understand what is going on around them. Information about their new routines can reduce anxiety and fear. This will lead to smoother transitions into the new routine.



I've listed all of the COVID-19 stories that relate to schools here for easier access for parents and educators. When I write more stories that pertain to school, I will add them to this list. I wish you all well as we embark on this new school year. Stay well!

Riding the Bus Will Be Different
Coughing, Sneezing and More
Coronavirus, What Is It?
Distance Learning, What Is It?
Distance Learning Tips
Expectations For Online Learning
How To Video Chat With Other People
Going Back To School
What Is Social Distancing?
What Is Hybrid Learning?
Getting My Temperature Taken

Wearing A Mask
Wearing A Mask To School
When Can I Stop Wearing A Mask?
Putting A Mask On My Toys
Why Does My Teacher Look Different?
My Teachers Are Wearing Face Shields
Greeting My Teachers and Friends (during COVID19)
Masks, Face Shields and Gloves, Oh My!
Who Should Wear A Mask?
Mask Etiquette Story

Are you worried that your child is going to lose social skills while doing distance learning? Is your child at school but has limited contact with peers? These are 3 links to help.

<https://www.laparent.com/10-ways-to-practice-social-skills-at-home/>

<https://www.keyministry.org/specialneedsparenting/2020/5/8/3-tips-to-keep-social-skills-strong-during-quarantine>

<https://www.nytimes.com/2020/06/18/parenting/kids-social-needs-quarantine.html>

PACE Fuel Assistance Program

Our Fuel Assistance offices are closed to the public, but our staff members are working remotely to meet the needs of our clients. Applications may be completed by mail, fax, and secure e-mail. Please call us at 508-999-9920 if you have an urgent question or utility emergency. Note that Eversource has stated they are discontinuing shutoffs during this time.

PACE's Fuel Assistance Program (LIHEAP) assists eligible homeowners and renters in New Bedford, Dartmouth, Acushnet, Fairhaven, Mattapoisett, Marion, and Rochester with their home heating bills during the winter months. Last year, the program served over 10,000 households in the Greater New Bedford area.

About PACE Fuel Assistance

Staff Available by Phone Only: 508-999-9920

Location: 261 Union Street (CLOSED AT THIS TIME)

Hours: 9am-12pm & 1:15pm-4:00pm Mon-Thurs, Fridays reserved for emergencies

Am I eligible for fuel assistance?

Eligibility is based on the gross annual income of all household members. Individuals who are self-employed, own additional property, or live in subsidized housing may have additional requirements.

How do I apply?

Please call us at 508-999-9920 for information on applying or to schedule an appointment. Our offices in New Bedford are located at 166 William Street and 308 Cottage Street. Our Cottage Street location is fully handicap accessible. Staff will let you know what you need to bring to your appointment when you call or stop in.

Emergency Situations

If you have no heat, a shutoff notice, or are nearly out of fuel, please call our office immediately at 508-999-9920 and follow the menu to report your emergency. Emergency situations are given priority. If the household's primary heating system is in need of repair or replacement, please see the details about our Heating System Repair and Replacement Program below.

Heating System Repair and Replacement Program (HEARTWAP)

This program, also known as the Heating Emergency Assistance Retrofit Task Program, exists to repair or replace primary heating systems. Homeowners who qualify for Fuel Assistance are eligible. In winter, priority is given to clients with no heat or unsafe heating situations. In order to be eligible for this program, you have to be eligible for fuel assistance first. Please see the information above or call 508-999-9920 for more information about applying. If you have no heat or an unsafe system, please mention that when you call.

Weatherization Program

The Weatherization Program helps clients install attic and/or wall insulation, and to perform air sealing measures to prevent loss of heat from your home. Clients who are eligible for fuel assistance are eligible for weatherization help. Priority is given to the elderly, disabled, and households with young children. Please see the information above or call 508-999-9920 for more information about applying.

Appliance Management Program (AMP)

The Appliance Management Program may be able to replace older, inefficient appliances such as refrigerators and freezers after an auditor reviews your electricity usage. Homeowners and tenants are eligible.



FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

INFORMING, EDUCATING, EMPOWERING FAMILIES

The Federation for Children with Special Needs advocates for quality education, strong parent participation and access to quality health care services for all children, especially those with disabilities. Here are some of the resources offered by the Federation:

Parent Training and Information Center (PTI)

Provides information and assistance on special education laws and related questions through Call Center; support groups for parents who speak languages listed at bottom of page; training on special education related topics through workshops and webinars; and intensive training on special education laws and procedures through Parent Consultant Training Institute. Call 617-236-7210/1-413-323-0681 (western MA), or online at: <http://fcsn.org/ptic/call-center/>

LINK Center/PTI

Provides students and families with information about transition planning and services to achieve student's post-high school vision. Planning a Life is a two-day transition planning conference held three times a year statewide.

Family TIES of Massachusetts

Provides emotional support, information, and referrals to local resources. Connects parents experiencing challenges to parents experienced with those challenges. Call 1-800-905-8437

Mass Family Voices/Family to Family Health Information Center

Provides information on health insurance related issues including eligibility for MassHealth and private insurance coverage for children. Call 617-236-7210 ext. 301. Also hosts an online group where families and professionals share resources and information. Go to: <https://groups.yahoo.com/neo/groups/massfamilyvoices/info>

Family Engagement

Provides information, resources and training to help facilitate family and school engagement towards student success.

Massachusetts Association of Special Education Parent Advisory Councils (MassPAC)

Provides information, training, and networking opportunities to Massachusetts special education parent advisory councils (SEPACs) and the professionals who collaborate with them. Call 617-399-8307 or online at: <http://fcsn.org/masspac>

Recruitment, Training & Support Center (RTSC) for Special Education Surrogate Parents (SESPs)

Provides training and support to volunteers who become special education decision makers for eligible students in the care of the Department for Children and Families (DCF). Go to: www.fcsn.org/rtsc for more info.

Visions of Community Conference

March conference held in Boston. Workshop topics include behavior management, transition, medical and insurance issues, language access, Autism, bullying, trauma and learning, and much more. Network with other families and professionals in the field; learn about resources from more than 70 exhibitors.

For assistance in the languages listed below, call 617-236-7210 or 800-331-0688 and the following extensions:

Cantonese & Mandarin (中文) – Ext. 358
Haitian Creole (Kreyòl Ayisyen) – Ext. 366
Portuguese (Português) – Ext. 329

Spanish (Español) – Ext. 330
Vietnamese (Tiếng Việt) – Ext. 328

Federation for Children with Special Needs | The Schrafft Center | 529 Main Street, Suite 1M3 | Boston, MA 02129
Phone: 800-331-0688 | 617-236-7210 | Fax: 617-241-0330 | www.fcsn.org | info@fcsn.org



To Parents of Children With Autism Who Worry About the Future

<https://www.themighty.com>

Dear parents of children with autism,

You are true warriors. You're the most determined individuals on Earth. You're tired. You're probably in need of a shower because you haven't been able to leave your child's side for even a few minutes. You may be running around trying to balance work and meeting your other family needs. Yet you're here, pushing through each day giving your child with autism the world. You only want him/her to have the very best.

Every day, the thought will cross your mind; as you're driving or as you try to sleep at night, this thought will not leave your head. The thought of what your child will be like when he/she is older: the future is coming. Will he have friends? Will he be in college? Will he be able to communicate effectively? Will there be a job out there that he will be able to enjoy and keep? Is independent living an option?

Chances are, it'll be way different than you imagined it. This is totally OK! There are no road maps for raising a child with autism. Life after high school looks different for every individual. It's never too early to take this into consideration. My twin brother Daniel has autism and is 27 years old. My parents and I have discussed his future for as long as I can remember. He was nonverbal and struggled with activities of daily living. He could barely get through the days without meltdowns, self injury or elopement. I could see as a child that it was difficult for my parents to take us out in public because of the looks and comments we received. Our lives flew by. Next thing we knew, Daniel and I were graduating from high school. I was heading off to college to study Special Education, our older brother had been attending automotive school, and we were exploring different options for Daniel.

He really enjoys art (and is *great* at drawing), so our parents enrolled him in a typical secondary art school in our hometown for about a year. My mother would shadow him there at times. The fact that he required accommodations (such as more time to complete assignments and a decrease in his workload) made it difficult for him to continue down that path. From there he was home, attending job training and several interviews at grocery stores, movie theaters and restaurants. These places proceeded to turn him away, as he displayed anxiety and some trouble managing his behavior when he was under stress.

Just as my family started to feel hopeless, we found the perfect opportunity. I had become a Special Education teacher about four-and-a-half years ago. I had a student in my class (who I still teach to this day) whose parents own a pizza chain restaurant in our area, Jets Pizza. I became close to his family and started telling them about Daniel and how he has struggled with his livelihood. I mentioned how sweet and smart he is, but no one would give him a chance. I came to them frustrated, as autistic people are capable of so much if we give them a chance!

Without hesitation, they took him in. They did not feel the need to conduct a job interview. Having their own child with autism, they already understood my brother without even meeting him. Guess what? Daniel has been working for Jets Pizza for almost four years now. The owners and his coworkers have come to be some of his closest friends. He has gained skills such as using the oven, setting up the pizzas, preparing the dough, cutting with a knife and maintaining the cleanliness of the store. When he is experiencing a meltdown, his coworkers know what that looks like and are able to help him step away and work it out.

My parents and I get emotional when we think about what Daniel's job has meant to him. He absolutely loves working at Jets, and asks to go there on his days off. He is someone who has always preferred to be

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alone, and now he gets to be loved, social and productive every day. He was a child that could not speak or leave our sight and now he's working — without his family having to be there. It's something we thought he might never do. He's happy.

Parents, it does get easier in little steps at a time. Don't stop fighting for your child. Keep seeking out resources, or start now if you haven't considered it. With autism rates on the rise, there are more and more businesses that are willing to hire these amazing kids. Start networking and meeting positive influences; talk to other families in your community. Keep your child's teachers and school close; you never know what information you can learn. Don't ever give up hope, because the perfect opportunity can pop up right in front of you. It will be the best feeling for you and your child when he/she feels like an independent and productive adult.

How autism shapes sibling relationships

Having an autistic brother or sister can pose challenges, but it can also make children patient, empathetic and resilient.

BY EMILY LABER-WARREN

In late March, Michelle Byamugisha reached out to a local celebrity in an email with the subject line "A Message for Your Biggest Fan, My Autistic Brother." It was two weeks into the coronavirus-related lockdown, and her 34-year-old brother, who has significant speech challenges and likes to be called Mark B, was distraught. Deprived of his cooking class, bowling and other favorite activities, he was feeling so low he could barely get out of bed.

As the family discussed what to do, Byamugisha had an idea. Her brother is fascinated by weather and has for years tuned in every evening to broadcasts from meteorologist Steve Rudin of WJLA in Washington, D.C. What if Mark B heard from Rudin directly? That might jolt him out of the doldrums, Byamugisha reasoned.

In her email, Byamugisha explained Mark B's distress, noting that the loss of routine "is especially difficult for someone on the autism spectrum." Then she made a request: "If you have a moment," she wrote, "it would be incredible if you could record a video message for my brother. It would lift his spirits exponentially." She was not counting on a response but thought it was worth a shot if it could help her brother.

Siblings such as Byamugisha often play an important support role in an autistic person's life, but they are in some ways the forgotten family members in autism research. Though the younger brothers and sisters of children with autism attract expert attention because of their higher chances of having the condition, studies about the experience of having an autistic sibling are sparse. And until about 20 years ago, the few that existed started from the premise that a child with autism was a problem for the other children in the home.

Over the past decade or so, however, researchers have begun exploring siblings' actual experiences, and they are learning that autism flavors these relationships in myriad ways. "It's not that disability is this outside force. Disability is actually part of the relationship," says Ariella Meltzer, a research fellow at the Centre for Social Impact at the University of New South Wales in Australia. "It's part of the essence, part of what's communicated and felt between siblings."

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The relationship can have upsides for both the typical and autistic siblings. A typical child may develop qualities such as maturity, patience, resilience and empathy. And for a child with autism who finds socializing challenging, the banter and bickering of siblinghood may provide a meaningful experience of friendship.

Although having an autistic sibling can be difficult at times, many typical children feel protective of their autistic brother or sister and invested in their sibling's success. They may act as translators if their sibling's speech sounds garbled to strangers, and they may understand their brother or sister's needs and abilities even better than their parents do. "For many siblings, diversity training begins before breakfast, 365 days a year, and starts at a very, very young age," says Emily Holl, director of the Sibling Support Project, a nonprofit organization based in Bellevue, Washington.

Bolstering the bond between siblings when one has autism has practical benefits for families. As parents age and become unable to care for their adult children with autism, siblings often become the principal caregivers. And they are more likely to take on these duties willingly, research suggests, when there is a history of shared closeness.

Michelle Byamugisha, 27, who works in public relations and lives in Washington, D.C., and her other brother Jeremy have kept Mark B's needs central as they have gone about building their adult lives. Jeremy Byamugisha, 32, who is an accountant, still lives with Mark B and their parents in Gaithersburg, Maryland, and helps with Mark B's care. "It has made me patient," Jeremy says. "Mark has had a big influence on that." For her part, Michelle is careful not to bring home friends until she knows they are keepers, because Mark B will ask about them (and remember their birthdays) forever. "It just kind of creates this shared commitment between me and Jeremy, to just only want to bring nothing but peace and stability to the family," she says.

In return, Mark B cherishes them. "It's one of the first things he says when he meets people. He's like, 'I'm Mark B, I have a sister, I have a brother.' He gives them the whole rundown about my life and Jeremy's life," Michelle says. "To have a brother that is so happy to see me and so excited by every development in my life, it's like having a cheerleader through thick and thin."

One hug only: The sibling relationship is among the longest and most formative of a person's life. Children learn with their siblings how to play, argue, share and negotiate. Research suggests that close sibling relationships are associated with better mental health later in life.

The nature of autism can make closeness difficult, however. People with autism often have difficulty identifying and expressing their emotions, as well as understanding what others are feeling. They may be uncomfortable with affection: "One hug only," Mark B often politely reminds people. Many studies suggest that sibling relationships tend to be less close when a brother or sister has autism than when a sibling has another developmental condition, such as Down syndrome, that does not affect the ability to connect.

"Social interaction requires two people, right? It's kind of like a dance," says psychologist Theodore Tomeny of the University of Alabama. When a sibling has autism, the dancers may be out of sync. Typical children with autistic siblings are more prone to anxiety and depression, on average, than their peers, according to a 2019 analysis of 69 studies. They also tend to have more difficulty establishing positive relationships with others and to possess more negative beliefs, which can take the form of low self-esteem, a poor view of disability or a general lack of optimism, according to lead investigator Carolyn Shivers, a psychology researcher at the Virginia Tech Center for Autism Research.

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The sibling relationship may be particularly strained if an autistic child takes out her anger and frustration on her brothers or sisters by hitting, punching or yelling at them. In a long-term study published in 2007, psychologist Richard Hastings, now at the University of Warwick in the United Kingdom, interviewed the mothers of 75 sibling pairs in which one child has a developmental disability. When the disabled child had a high level of behavior problems at the start of the study, the typical sibling was likely to be withdrawn, angry or restless two years later. "If you're growing up in a situation that presents some unique challenges and maybe threats to personal safety and, in some cases, real trauma, you can feel very alone," Holl says. Living in poverty and having parents who are stressed or depressed can also put siblings at risk for mental health issues. Raising a child with a disability, who may need special classes and constant supervision, requires time and money that many families can ill afford, and these unmet needs can put extra pressures on siblings.

Still, research suggests that most people with autistic siblings are psychologically healthy, and just as well adjusted as their peers. "A lot of kids do just fine. They do really well, in fact. They're no different from a sibling in any other type of relationship," Tomeny says.

Because they grow up familiar with disability and as peers to their autistic brother or sister, nonautistic siblings have a unique perspective compared with parents, Meltzer says. For Brett Aurin, 15, of Foothill Ranch, California, whose twin brother Kyle has autism, that perspective leads to acceptance. "Sometimes things can be a little bit more difficult, but he's not a separate species," Brett says. "I just see it as his personality. He's just my brother. I forget even that he has autism."

Compared with other children and teenagers, those with an autistic brother or sister may be more mature and more adept at a form of empathy called perspective-taking, which means they can consider another person's point of view. Having a sibling with autism can also nurture gratitude. Abigail Diaz, 29, says her brother Daniel, 20, calls her up to 100 times a day to say "I miss you" or to chat, a frustrating number of interruptions for someone with a full-time job. "It's tough," says Diaz, who is director of education and public programs at the Wisconsin Maritime Museum, "but I remember a time that he couldn't talk. So I will take this over not being able to talk to him, any day."

In a 2019 study titled, in part, "I don't live with autism; I live with my sister," researchers interviewed nine girls aged 10 to 14 whose autistic siblings do not speak. Many of the girls were exhausted and worried about the future. Yet they appreciated their siblings' sensory differences (two girls called them "superpowers"), knew how to stave off meltdowns, and expressed feelings of acceptance, love and hope.

Many siblings express this kind of appreciation for their autistic brother or sister, according to a meta-analysis published earlier this year. "There was an overarching narrative of love, empathy and compassion," says lead researcher Alexandra Leedham, a clinical psychologist at the Chesterfield Royal Hospital in the U.K. "Some people certainly felt that it made them a stronger person."

Stop being the dad: Some autistic children require so much attention that their siblings get lost in the shuffle. "Their needs may be overlooked, or have to come a bit second," Leedham says. In a study published earlier this year, for example, one girl complained that her parents downplayed her learning issues because they were minor compared with her brother's challenges. As a result, she was not diagnosed with dyslexia until she was 12.



Three's company: Michelle Byamugisha (left) and her brother Jeremy (right) play integral parts in the life of their brother Mark B (center).

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The siblings of children with autism fare better when they have people in their lives — parents, extended family, coaches, teachers or friends — who listen to and appreciate them and whom they know they can rely on for help. Tomeny and his colleagues have found that children with autistic siblings who want and receive support have relatively few emotional and behavioral problems. By contrast, the children who say they do not get the support they need have more problems — for instance, angry outbursts or feeling afraid or worried.

One thing adults can do to support typical children is to help them understand that an autistic sibling's difficult behaviors are a function of brain wiring. "Around when I was 6 years old, my mom explained everything about autism," says Luciana Heresi, an 11-year-old in Orange County, California, whose 13-year-old brother Santi has autism. Her mother showed her videos that explained that some people with autism talk repeatedly about special interests. "When I was younger, I was like, 'He already told me this, he already told me that.' I thought he was doing it on purpose just to annoy me," Luciana says. "But now that I know, I'm like, 'Oh, okay, I understand.' Like, I can deal with it because I know he has autism."

Siblings should be allowed to calibrate the relationship, experts say, and not, for instance, be required to act as impromptu tutors, babysitters or rule enforcers. Brett Aurin says that he does keep an eye on his twin brother at times, but his parents try not to lean on him too much for help. They sometimes even tease that he "needs to stop being the dad," he says.

When siblings take on responsibility for a brother or sister by choice, experts say, they are far less likely to feel resentful than if they are forced to do it. By the time she was in high school, Diaz was keeping track of her brother Daniel's prescriptions and bringing him to doctors' appointments, not hanging out at the mall. "I didn't do the things that typically a kid would do, but I don't feel I missed out on anything, because I was there for all the milestones with Daniel," Diaz says. "Something about our bond has been magical. My name was his first word. His first steps were to me."

Specialized support programs can also help siblings with their own moods and behavior. The Sibling Support Project, for example, runs groups called Sibshops in communities around the United States and abroad for children aged 8 to 13 who have a disabled sibling. "It's an outlet, a place where they can go to talk about their experience, thoughts and feelings," Holl says. "You can feel very alone if you don't know other people who are going through similar situations."

The experience of having a sibling with autism is complex. A child may resent that her brother's behaviors make family vacations impossible, but also feel pride when he learns to tie his shoelaces at age 13. "The sibling experience is really a mixed bag," Holl says. "It's not all great or all terrible. It's kind of all of the above at any given time." Experts emphasize that no one should feel guilty for not having a good relationship with their autistic brother or sister. "Some of [the stories] are great, and some of them are not. All of them are equally valid," Shivers says.

"Something about our bond has been magical. My name was his first word. His first steps were to me."
Abigail Diaz

Whether the relationship is close or problematic, children tend to 'get' their autistic sibling's sensitivities and strengths. In the 2019 survey of sisters, one young girl groused that her parents continued to try to make her autistic brother eat foods he did not like, even though it predictably ended in a tantrum. And Holl recalls a Sunday morning workshop full of sleepy teenagers that came alive around the issue of unequal expectations. Many griped good-naturedly that their parents underestimated their siblings' abilities. "I know he can empty the dishwasher," one boy said of his brother, "because when our parents aren't home, I get him to do it. He actually likes it!"

...continued on page 13

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In the past few years, experts have begun to look at these relationships from the other side too, soliciting the voices of autistic siblings. This new research is revealing that people with autism often see nothing unusual about their sibling relationships. Whatever issues the typical sibling may encounter are not always evident to the sibling with autism. "Siblings with and without disabilities don't always agree on what's happening in their relationship," says Meltzer, who has led much of this work. "And we didn't really know that until we actually started talking to both of them."

That disconnect occurred for brothers AJ and Jarrett Link. Their parents divorced when they were young, and AJ, who was diagnosed with autism as an adult, helped raise Jarrett, who is four years younger. Jarrett recalls awkwardness and silences that confused him when he was a child. After AJ, who is now 30, was diagnosed, everything made more sense. "It explained a lot of things," says Jarrett, who now feels comfortable with his brother's need for alone time.

For his part, AJ was unaware that the awkwardness existed. "It's weird to think about how for me, it was just normal experience," he says. "But for [Jarrett], it was kind of a different experience where he didn't quite understand what was going on." The brothers appreciate each other's strengths. AJ admires Jarrett's emotional supportiveness, and Jarrett says AJ, who graduated from law school this year, is the smartest person he knows: "If I could just try and do some of the things he does on an intellectual level, I'd be very well off."

A similar loyalty inspired Michelle Byamugisha to contact Rudin, the TV weatherman, on behalf of her brother during the pandemic. And less than an hour after she pressed send, a custom-made video arrived. "Hey Mark B, it's Steve. I am so happy to know that you've been watching me for over a decade," it began. "I know things are a little bit different right now because so much is changing in our world, but we're all going to get through this together." After more reassuring words, Rudin concluded with an invitation: "I hope that one day when things get better, you and your sister can come visit me here at the station. I'd love that."

As Mark B watched Rudin's message on his mother's smartphone, his brother Jeremy filmed his quietly delighted reaction. Michelle posted that video on Twitter, where it has been viewed more than 64,000 times.

How is your stress level these days?

Please visit the link below as the Autism Research Institute discusses **Emotional Support for Families during COVID-19**.

<https://www.autism.org/managing-autism-stress-during-covid-19>



250+ Creative Ways to Keep Your Family Sane During the COVID-19 Crisis

<https://providence.kidsoutandabout.com/content/250-creative-ways-keep-your-family-sane-during-covid-19-crisis>

Upcoming *Events*

SELF-DIRECTION PROGRAMS



SUPPORT



EMPOWERMENT



CHOICE

DDS SELF-DIRECTED SERVICES

Please join us for an interactive discussion about expanding choices and control in your life through Self-Directed Supports. This is an opportunity to hear how participants and their families can design individualized services to meet their needs through the

Participant Directed Program

or

Agency with Choice

WHEN:

10/7/2020 10:00am to 11:30am
10/28/2020 4:00pm to 5:30pm
11/4/2020 10:00am to 11:30am
11/17/2020 4:00pm to 5:30pm
12/2/2020 1:00pm to 2:30pm
12/16/2020 4:00pm to 5:30pm

Offered via WEBEX

To register please contact: jennifer.r.benoit@mass.gov

Calling Self Advocates!

Join the Self Advocate Leadership Series (SALS) presented by South Shore Support Services Inc.

Trainers Bex Fillmore and Patrick Birmingham with Laurel Hickey Support Trainer

6 WEEK ZOOM SERIES
Thursdays 3:00-4:30pm

Class 1: Who I am

Participants will have a full understanding of the leadership course and its expectations, get to know teachers and other participants, and complete personal assessment exercises.

Class 2: Communication

Participants will learn why communication is important, learn different communication skills and styles, and practice listening, observing and asking questions.

Class 3: Team Building

Participants will learn why working in a team is important and how to use listening, asking, trusting, problem solving, and collaborating skills.

Class 4: Rules and Laws

Participants will learn about laws created to protect people with disabilities and be introduced to the legislative process.

Class 5: Public Speaking Tips

Participants will learn public speaking tips and the importance of personal appearance and presentation style.

Class 6: Graduation

Participants will present on a topic of their choice to family, friends and fellow students and be acknowledged for 6 weeks of hard work.

To request an application or if you have questions,
please call or email Laurel Hickey at:
781-383-0902 or laurel.hickey@gmail.com

Compensatory Services - Basic Principles And What's New Since COVID-19 Live Webinar

With Tim Sindelar Esq. & Constance Hilton Esq.

Tuesday Evening, September 15th

School building closures in 2020 resulted in cessation of services and remote learning services that proved to be inappropriate, and inadequate for many students with disabilities. Many of these students will require some form of compensatory services. This webinar will provide both the theoretical and practical basis for presenting these claims.

1. Review of the basic principles for compensatory services for students with disabilities.
2. Compensatory services in light of the COVID-19 Pandemic.
3. The mechanics of seeking compensatory services.
4. Building the best case for compensatory services.
5. Fashioning appropriate relief
6. Barriers to seeking relief: statute of limitations, burden of proof, "clean hands".
7. Making a case in these "challenging times."

When:

Tuesday Evening, September 15, 2020
6:30 to 9:00 pm

Where:

Virtual Presentation Via Zoom Webinar

Registration Rates: Member \$25 Non-Member \$40

Registration closes on Sunday September 13th. Walk-in/late registrations please email info@spanmass.org for availability.

Presenters

Tim Sindelar, Esq.

Tim Sindelar has been a practicing attorney for more than 43 years with a practice specializing in disability and education issues for the last 25 years. After spending 25 years in public interest law, he started a solo practice in Newton, where he represents students and their families and adults with disabilities. He has had the pleasure of working on a wide range of matters, representing 100s of families at the BSEA and in state and federal courts.

Constance Hilton, Esq.

Connie Hilton has recently retired from private practice after more than thirty years representing children with disabilities and their families in special education cases and other school related matters. Connie also served as a guardian ad litem in probate court and juvenile court cases. Connie previously served as a hearing officer for the Bureau of Special Education Appeals (BSEA) and as a staff attorney with the Massachusetts Office for Children (OFC).

We invite your family to join our Family Connections Center on Zoom!

Join us on Wednesday, October 7th at 1:00 pm, as Family Support Advisor Shanell Stewart will be assembling a tool bench for your family to enjoy.

To reserve your FREE tool bench kit, please contact Shanell Stewart at 508-999-4436 or email ShanellStewart@nemasketgroup.org

Meeting ID: 864 6284 5540
Passcode: 949387
One tap mobile
+16465588656
+13017158592 (Germantown)

Join Zoom Meeting

<https://us02web.zoom.us/j/86462845540?pwd=d1ZYeDVXRvFhFUzQ0UzZ4aTVadkZoUT09>

*Note: Tool Bench is approximately the size of a Post-It Note or 3 in. x 3 in.



“Paper Tigers” Documentary



Virtual Viewing, September 16, 2020, 6:00 pm, with the Parent Professional Advocacy League of Massachusetts.

This event is part of PPal’s support group for parents and caregivers of a child/youth/young adult with emotional and behavioral healthcare needs, you know this can be a difficult journey.

“*Paper Tigers*” is a documentary about high school students at an alternative school that works with traumatized teens. It was filmed within and around the campus of Lincoln Alternative High School in the rural community of Walla Walla, Washington. *Paper Tigers* asks: What does it mean to be a trauma-informed school? And how do you educate teens whose childhood experiences have left them with a brain and body ill-suited to learn?

To register for the this Zoom event:

<https://zoom.us/j/96193689480?pwd=d3pVeEN2MVNLWkkrMnRUcUJaa3VPO>

Meeting ID: 961 9368 9480
Password: 959446
Number: +1 929-205-6099

OR contact Kathy and Ann at Parentsupportgroup@ppal.net

Stay Connected with Zoom Calls!

Meet your Family Connections Center Support Advisor

Join us on **Tuesday, October 20th at 2:00 p.m.** on Zoom to meet your Family Support Advisor. We would like to welcome Patrick Russell into his new position as a Family Support Advisor. Patrick has work for the Nemasket Group for over 5 years and brings a wealth of experience to his new job. In that time he has worked in several positions including being a direct support worker and team leader in our Job Paths Program. To contact Patrick, please call 508-999-4436 ext. 106.



Sandra Heller



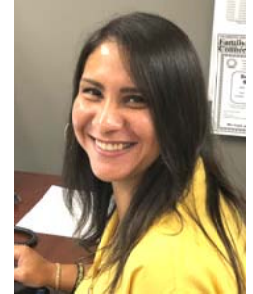
Heidi Pina-Barnes



Shanell Stewart



Patrick Russell



Ana Colon

Join Zoom Meeting: <https://us02web.zoom.us/j/82124824001?pwd=SFZEZTNoU0JaSGYvY2dIVjhREl3dz09>

Meeting ID: 821 2482 4001

Passcode: 847279

One tap mobile +13126266799, (Chicago)

+16465588656 (New York)

Questions? We've Got Answers!

Join us **every Monday at 1:00 pm** on Zoom with your questions: Feeling stressed that school is virtual/hybrid AGAIN? Want to talk it out with other parents? We are here to talk about everything from virtual schools to what resources you used to help get through the first time. Sometimes a good therapist is a sounding board of people that are going through the same journey.

Join Zoom

<https://us02web.zoom.us/j/86905126646?pwd=WnZZZ1RCRjFZaXFla3I5czB0OEZBUT09>

Meeting ID: 869 0512 6646

Passcode: 689319

One tap mobile +13126266799 (Chicago)

+16465588656, (New York)

The Nemasket Group is looking for family members to join our Advisory Committee

We are looking to get together a fun group of people to help facilitate things that are going on at The Nemasket Group that may be able to help families. **Join us on September 11th at 2:00 p.m.**

Join Zoom Meeting:

<https://us02web.zoom.us/j/85950708567?pwd=OGNJYTRWZEFJOzBLZXlQd3lnd0VKZz09>

Meeting ID: 859 5070 8567

Passcode: 814977

One tap mobile +13126266799 (Chicago)



Join us for Zoom Bingo on **Saturday, September 19th at 1:00 p.m.** Email ShanellStewart@nemasketgroup.org for your bingo cards.

Join Zoom Meeting

<https://us02web.zoom.us/j/86462845540?pwd=d1ZYeDVXRvFhFUzQ0UzZ4aTVadkZoUT09>

Meeting ID: 864 6284 5540 Passcode: 949387
One tap mobile +16465588656

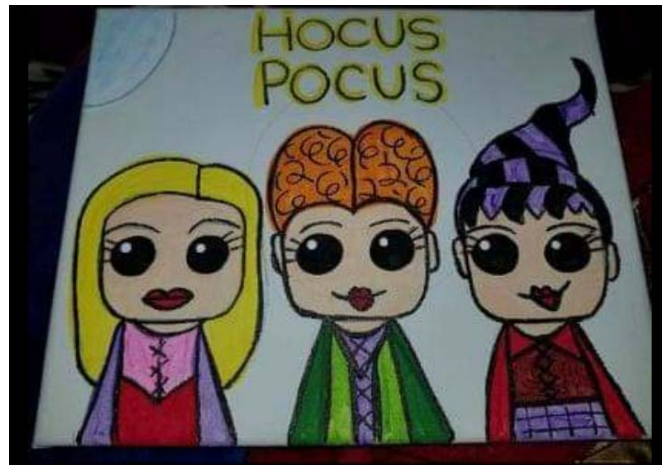
Let's Paint With Casey's Fun Faces!

Please join us on Zoom on **Saturday, October 3rd at 1:00 p.m.** for a Hocus Pocus Paint Day!

Hi Everyone! I'm Casey from Casey's Fun Faces! Join me while I teach you a step by step canvas painting of the Hocus Pocus witches.

You will need the following supplies:

- 9x12 canvas or larger (if you do not have a canvas, white copy paper will work)
- A cup to make 3 circles for the witches heads
- A pencil
- An eraser
- A black permanent marker
- Acrylic paint in white, orange, green, red, yellow, purple and black
- 1 small paint brush
- 1 cup of water (for cleaning paint brush in between colors)
- Paper towels (to dry paint brush)
- 1 Paper plate (to put paint colors on)



No paint? No problem! Crayons, colored pencils and markers work too!

Please be on time. We start at 1:05pm the latest! We can't wait to paint with all of you :)

Join Zoom Meeting

<https://us02web.zoom.us/j/86462845540?pwd=d1ZYeDVXRvFhFUzQ0UzZ4aTVadkZoUT09>

Meeting ID: 864 6284 5540 Passcode: 949387
One tap mobile +16465588656

scavenger hunt

Looking for something fun to do outside? We invite you to take part in our Selfie Scavenger Hunt Fall Edition! Look for one, two, or all of the items in the scavenger hunt and send us a selfie! Post your selfie to <https://www.facebook.com/familyconnectionscenter> or email ShanellStewart@nemasketgroup.org.

- Selfie in front of a fall, colorful tree
- Selfie in a pile of leaves
- Selfie in front of a political sign
- Selfie with a pumpkin
- Selfie with a scarecrow
- Selfie with acorns
- Selfie with a school bus
- Selfie with a backpack on
- Selfie in your favorite fall sweater
- Selfie with Halloween decorations



BOSTON CENTER FOR INDEPENDENT LIVING

Virtual Housing Workshop

Join us on the first and third Wednesday of every month to learn more about and how to apply for affordable housing options in your area. Our knowledgeable staff will answer all your questions and put you on the path to finding the housing that is right for you.

Beginning **OCTOBER 7TH FROM 10:00 AM - 12:00 PM**

This workshop will teach you about:

- Types of housing available in the Boston area
- Navigating subsidized and affordable housing
- Conducting a housing search
- Communicating with housing authorities, agencies, and landlords
- Completing applications for state voucher programs
- How to request reasonable accommodations for your disability



Each workshop will include a period when you can ask questions.

To register: email Amanda at abernard@bostoncil.org with your full name and phone number. You will receive a confirmation email from Amanda that will include the Zoom link and meeting password.

To request reasonable accommodations, please let Amanda know when you register.



Registration Open! eLearning at Healthtrax

This program is open to Healthtrax Members and Non-Members!

We know eLearning from home can be challenging, and parents that need to continue to work and manage the household may be looking for additional academic support for their children. Healthtrax offers a dedicated eLearning space complete with separate outside entrance, private bathroom, and an academic support advisor.

Full-day eLearning is available Monday - Friday (part-time options available) include activity breaks in the gym including yoga, art projects, movement and more! Students will need to bring their own eLearning devices (iPads, lap tops, tablets) as well as snacks and meals. Space is limited to 7 participants to ensure proper physical distancing can be maintained.

eLearning Program is available Monday-Friday 7:30am – 3:30pm.

Options and Rates:

*sibling discounts available

- 5 days/week - \$250/week
- 3 days/week - \$180/week
- 2 days/week - \$140/week

Additional eLearning Services (do not have to participate in the day program to register for the additional services):

*Extended day - \$15 per hour

*Youth Small Group Training programs also available (P.E. session) - \$20 per day -
Take a break from screen time!

To register, or for more information, please call 508-999-2171 and ask to speak with Deb or Diane. You can also email Deb Gidley at dgidley@healthtrax.net

THE GREAT BLIZZ SPECIAL ICE HOCKEY

A 501©3 Non-Profit Public Charity

NO HOCKEY PLAYER LEFT BEHIND

ICE HOCKEY FOR PEOPLE WITH INTELLECTUAL, COGNITIVE AND/OR DEVELOPMENTAL DISABILITIES

Last Saturday, The Great Blizz completed it's first-ever year! When we first took to the ice on September 7 last year, who would have imagined all the ups and downs of life we have experienced in the past 12 months.

Despite COVID, we were able to:

- Have our first autowash at King Collision in October - generated \$800+
- Have our first and hugely successful Boston Bruins Alumni Game while showcasing our team members on the SELECT team vs the Bruins and our coaches, mentors and Great Blizz players during a halftime shootout
- Invite David Silk, member of the Miracle on Ice 1980 Olympic Gold team, to our March 7 practice and have pics taken with his shiny medal
- Get back on the ice on July 11 with lots of pre-cautions to finish the season



In all, 34 practices and one amazing Bruins Alumni Game (and we play them again Feb. 27, 2021)!

Some 15 players on our current roster, a huge start for a special hockey team. And players who never skated before are vertical and skating!

We continue to grow in so many ways.

Please refer any special people in your life to us...

*Weekly Practice/Games every Saturday 7-7:50 am at Bog Arena in Kingston, MA

*Season #2 begins September 19, 2020

*All hockey equipment will be loaned to registered players

*Registration fee of \$300 for September to May season

*No skating or hockey experience required – we teach skating

*Not Sure? We Allow a three-practice free trial period

*We will play other New England teams and travel to national tourneys

* On- and off-ice volunteers welcome – we'd love for you to join our program!

* Corporate sponsorships and charitable donations needed and appreciated!

FOR MORE INFORMATION:

Coach Nearms - The Great Blizzards of Massachusetts Special Hockey

on Phone - 508-202-0218

by email - thegreatblizz@yahoo.com our website - <https://thegreatblizz.sportngin.com/>

on FaceBook - The Great Blizzards of Massachusetts Special Hockey Inc or @thegreatblizz

Proud member of the American Special Hockey Association and USA Hockey