

Medically Complex Program

Do you have medical supplies in your house that are taking up too much space? We can help!

Do you have things like a wheelchair, bed, stroller, shower chair, diapers etc. that you're no longer using? Send us a picture of any surplus supplies to Shanell Stewart at Shanellstewart@nemasketgroup.org. The Nemasket Group will advertise the supplies in our next Medically Complex newsletter with your email. If you have any questions, email or call Shanell at 508-999-4436 x 161. Thank you in advance.

BACK TO SCHOOL TIME!!!!

School is back in session. Some parents are Yahoo-ing while others are boo-ing. Some students will still be at home learning while others are in school. Did you know that your DDS Service Coordinator, your Family Support Center, and your team here at The Nemasket Group's Medically Complex Program, can assist you in answering common IEP questions and can even attend school meetings including IEP's? If you need us, please feel free to email your advisor so we can help you.

September is Spinal Cord Injury Awareness Month

Spinal Cord Injury Awareness month was established in 2014 by the passing of U.S. Senate Resolution 533. It's been established to go beyond bringing attention to spinal cord injuries and to move toward the ultimate goal of finding a cure for spinal cord damage. In addition, this month seeks to increase awareness about the kinds of mobility issues that individuals may experience after suffering from spinal cord injuries and how to mitigate those issues through specialized care and support.

Medically Complex Program at The Nemasket Group

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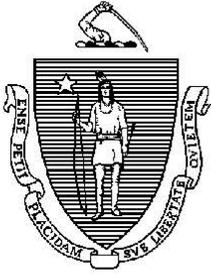
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August 10, 2021

Dear DDS Community:

With the recent policy changes across the country and news about the Delta variant, I know you are wondering how this impacts DDS programs and your loved ones, and what steps we are taking to keep them safe. This week, we are announcing major updates to our congregate care surveillance testing program and also releasing updated guidance for visitation, group homes, and day programs.

First, we will be testing more often and including vaccinated staff in surveillance testing again. Weekly surveillance testing of all staff working in congregate care programs will help us identify cases quickly. As is current practice, any time a positive case is identified, testing will occur right away for all staff and residents. Please note, the current isolation and quarantine policies have not changed.

Second, we encourage masking more often, even for fully vaccinated people. While fully vaccinated residents do not need to wear a mask in their own home, staff will continue to wear masks in day programs and group homes, and we ask that all visitors wear a mask inside programs, even if fully vaccinated. The goal is to not restrict visitation, prevent you from embracing of your loved one, or limit your ability to spend time with them. Masking and testing helps us do that.

Third, we continue to encourage COVID-19 vaccinations for all. You may arrange an [In-Home Vaccination](#) by calling 1-833-983-0485, find a vaccination site near you using the [VaxFinder website](#), or work with a group to schedule a [Mobile Vaccination Clinic](#). If you need help, please contact your DDS Service Coordinator.

On the pages that follow, please find vaccination resources and links to updated guidance for group homes and day programs.

As always, please stay in contact with your Service Coordinator and Area Office and follow the Department on our website (mass.gov/dds) and social media (@ddsmass) for the latest updates.

Take good care,

Jane

Surveillance Testing Program

- ◆ Weekly surveillance testing for all congregate care staff, even if they are fully vaccinated, starting August 12.

Wearing Masks

- ◆ Fully vaccinated group home residents are not required to wear a mask in their home.
- ◆ Individuals served by DDS should follow the public mask guidance in public settings.
- ◆ All staff are required to wear a mask while working in congregate care programs and day programs.

Visitation

We have asked our residential settings to return to their pre-pandemic visitation policies and practices with the following exceptions:

- ◆ All visitors are now asked to wear masks indoors.
- ◆ Continued screening of all visitors for symptoms of illness and COVID-19 infection.
- ◆ Suspended visitation when a resident is isolating due to COVID infection or there is a COVID-19 outbreak at the program.
- ◆ Staff are required to wear masks in group homes, regardless of vaccination status.

Vaccination Update

- ◆ [In-Home Vaccinations](#) are available to anyone with trouble getting to a vaccination site. Call 1-833-983-0485 to schedule your in-home vaccination.
- ◆ Call 2-1-1 to schedule an appointment over the phone.
- ◆ Use the [VaxFinder](#) website to search for appointments at pharmacies, health care providers, and other community locations.

If you need help planning a COVID-19 vaccination for an individual served by DDS, please contact your DDS Service Coordinator.



See, Touch and Try. Assistive Technology Regional Centers are operating in western, central and eastern Massachusetts; visit them to learn about, try out or borrow assistive technology.

Website Massachusetts Assistive Technology Loan Program (MATLP) is an alternative financing program funded through state and federal resources to give people with disabilities and their family's access to low-interest cash loans to buy the assistive technology devices they need.

Equipment: Choose to reuse your D M EDM equipment.org offers free gently-used, refurbished wheelchairs and other DME to people who need it. Delivery is available. Search for available items [here](#).

Go To Get AT Stuff. MassMATCH is happy to announce the establishment of Get AT Stuff Massachusetts, a new Assistive Technology Exchange website. Here visitors can shop for used equipment or advertise what they are no longer using.

Back-to-School Tips for Parents of Children with Special Needs

By: [Reading Rockets](#)

Our Top 8 back-to-school tips for parents emphasize communication, organization, and staying up-to-date on special education news.

A new school year means a new grade, new teachers, new goals, and maybe even a new school! In order to help you and your child with special needs be as successful as you can be, we've put together a list of eight helpful back-to-school tips that we hope will make the transition into a new school year a little easier for you and your child.



Organize all that paperwork

In the world of special education, there are lots of meetings, paperwork, and documentation to keep track of. Try to keep a family calendar of school events, special education meetings, conferences, etc. Setting up a binder or folder to keep your child's special education documentation, meeting notices, and IEPs in sequential order can also help you stay organized.

Start a communication log

Keeping track of all phone calls, e-mails, notes home, meetings, and conferences is important. Create a "communication log" for yourself in a notebook that is easily accessible. Be sure to note the dates, times, and nature of the communications you have.

Review your child's current IEP

The [IEP](#) is the cornerstone of your child's educational program, so it's important that you have a clear understanding of it. Note when the IEP expires and if your child is up for reevaluation this year. Most importantly, be sure that this IEP still "fits" your child's needs! If you're unsure, contact the school about holding an IEP review meeting.

Relieve back-to-school jitters

Just talking about the upcoming year and changes can help reduce some of that back-to-school anxiety! Talk to your child about exciting new classes, activities, and events that they can participate in during the new school year. If attending a new school, try to schedule a visit before the first day. With older students, it is sometimes helpful to explain the services and accommodations in their IEP so that they know what to expect when school begins.

Keep everyone informed

It's important that routine that will happen once school starts. You can even begin practicing your new schedule, focusing on morning and evening routines, and begin implementing them well in advance of the first day of school.

Stay up-to-date on special education news

Being knowledgeable about your child's IEP and their disability can help you become a better advocate for your child. Try to keep up-to-date on new special education legislation, news, and events. The more you know, the more prepared you will be to navigate the world of special education and successfully advocate for your child!

Attend school events

Take advantage of Open House, Back-to-School Night, and parent-teacher conferences to help you and your child get a feel for the school and meet the teachers, other staff, students, and families. Share the positives about working with your child, and let the teacher know about changes, events, or IEP concerns that should be considered for children in special education.

For more information about starting the year off right, please visit [Reading Rockets' back to school section](#).

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.



APPLY NOW FOR THE 2021-2022

FAMILY LEADERSHIP SERIES

The voices of families are a powerful tool for creating system-wide change. For over 30 years, the Family Leadership Series has helped grow family leaders who create positive change within their families, communities, across the state and beyond every day.

ABOUT THE SERIES

The Family Leadership Series focuses on supporting families and caregivers to develop a Vision for their loved ones with disabilities to live an enviable life in their own community. This includes understanding advocacy as a means to create possibilities. Applications from families and caregivers of a loved one who meet eligibility from the Department of Developmental Services are encouraged to apply.

GET READY FOR A SIX MONTH, LIFE-CHANGING CRASH COURSE IN:

- Advocacy & Leadership
- Creating a Vision
- Policy-Making
- Self-Care

DATES

The Series includes overnight lodging at area Hotels and virtual sessions.

Northeast: November 2021 - April 2022

Southeast: October 2021 - April 2022

Central: November 2021 - April 2022

West: February 2022 - April 2022

Metro dates to be announced

"I feel strengthened, hopeful and energized to make a difference for myself, my son and other people with disabilities. The Family Leadership Series has changed my life."

LEARN MORE

massfamilies.org/family-leadership-series/



MassFamilies

leadership training for a world where everyone belongs

This opportunity is funded by the Department of Developmental Services and unrestricted funding from MassFamilies.

To stop a controversial electric shock therapy, the disability community is owed better alternatives

The FDA banned the treatment, but the courts have overruled the agency. There has to be a better way.

A student wearing an electrical shocker device on her leg lines up with her classmates after lunch at the Judge Rotenberg Educational Center in Canton, August 2014. Many students at the school, who were born with autism and development disorders, wear shocking devices to control violent behavior.

The Judge Rotenberg Center, once again the center of national controversy over its use of painful electric shocks to treat intellectually or developmentally disabled patients, is a place of last resort. Desperate parents and guardians from all over the country send students to the Canton facility when nothing else has worked: when their loved ones have been kicked out of or rejected by other programs, hospitalized for weeks at a time, or subjected to medications that left them unresponsive.

Those parents are now the center's most passionate defenders, and they're speaking out as the Food and Drug Administration considers whether to ban the center's use of the electric shock devices. As ghoulish as the treatment seems, some parents insist that it's necessary for patients exhibiting self-injurious or aggressive behavior like biting themselves and head-banging. One father whose son has been at the center since 1988 told the Globe that his son blinded himself in one eye before the electric shock device enabled him to verbalize more, dress himself, and visit his family more often. Unlike some other programs, the center virtually never rejects or expels a student.

The plight of those parents underscores how few options they have. The FDA suffered a setback in its effort to stop the center's use of so-called contingent skin shock when a federal appeals court overturned the agency's ban. That March 2020 prohibition followed a four-year review that found that the treatment's risks, including depression, anxiety, and post-traumatic stress, outweigh the benefits. But if the FDA appeals the ruling or establishes a more categorical ban, the government also needs to create more viable alternatives.

"Nobody wants to use contingent skin shock," the center's director, Glenda Crookes, told the Globe during a tour. But ever since its founding in Rhode Island in 1971 as the Behavioral Research Institute, the center has used "aversives" — physical punishments that originally included spanking, pinching, and forced ammonia inhalation — for behavioral correction when other treatments fail. The center eventually moved to Massachusetts and renamed itself in honor of Ernest Rotenberg, the Bristol County probate judge who halted an attempt by state authorities to ban aversives in 1986, following the death of a 22-year-old autistic man, Vincent Milletich, at one of the center's group homes.

Around 1990, the JRC moved on to a new generation of aversives, including electric shocks. The shock device consists of batteries worn in a backpack or fanny pack that power electrodes in constant contact with the wearer's skin. It can be triggered remotely by the center's staff. While representatives of the school compare the shocks to bee stings, former student Jennifer Msumba called the feeling "a terrible pain" that led her to attempt escaping the center twice. The center's founder, Matthew Israel, himself stated, "It has to hurt enough" to modify behaviors.

At times, however, the center has taken "treatment" to extremes. In 2002, for example, a student named Andre McCollins was shocked 31 times in just under seven hours, initially for refusing to

remove his jacket and consequently for tensing up and screaming between shocks. McCollins was hospitalized for 37 days, and his mother settled a lawsuit against the school in 2012.

Currently, 52 of the center's 280 students wear an electric shock device with parental or guardian consent and court approval. They are all adults deemed "treatment refractory" after alternative therapies failed. The center sets a maximum of 10 shocks per day before a clinician must approve further "applications" and claims that, on average, students receive less than one application per week.

Regardless of the policies surrounding its use, many medical experts argue that the device does not fundamentally reform behavior. "There was some data that people did learn faster, but the point was that once the negative goes away, the old habits come back," said Catherine Lord, a psychiatry professor at UCLA's medical school, of aversive therapy. The Judge Rotenberg Center's director of clinical services, Nathan Blenkush, published findings that while electric shocks did reduce the frequency of targeted behaviors by up to 97 percent, less than 30 percent of patients observed over 20 years have been successfully removed from the device without recurrence of target behaviors.

Blenkush argues those numbers don't indicate a treatment failure, though, and uses the term "prosthetic" to liken the electric shock device to other permanent medical devices that meaningfully improve quality of life. Advocates counter that using permanent threat of pain to modify behavior is inherently inhumane. In 2010, the United Nation's Special Rapporteur on Torture called the center's practices "torture."

The continued reliance on such controversial practices is at least a partial consequence of the nation's inability to provide better alternatives. "It's a failure of our services that people feel that this is their only option," Maura Sullivan, director of government affairs for advocacy group The Arc of Massachusetts, told the Globe. Families of Judge Rotenberg Center patients and disability advocates, often at odds, agree on these failures.

First among those failures is a shortage of medical experts and care staff qualified to manage the complexity of autism and other developmental or intellectual disabilities. Through her own experience as a mother of two sons with autism, Sullivan has seen firsthand the limited number of specialists with the expertise to manage self-injury and aggression. This scarcity manifests in the over-medication and prolonged hospital stays that many JRC parents have experienced. Many residential facilities also suffer from high staff turnover, which is particularly disruptive to patients with developmental or intellectual disabilities who benefit from continuity of care.

Second, too little is known about successful interventions for complex behavioral challenges. A select few schools, like Melmark New England and the New England Center for Children, are pioneering models of evaluation and intervention that use medical, psychological, educational, and environmental approaches to positively modify behavior. Although these schools publish their results, the body of research and experience is still limited, resulting in too few programs capable of supporting the most complex cases — cases where students end up on electric shock devices instead.

As a hub for health care and medical innovation, Massachusetts ought to be an incubator for humane, effective behavioral therapies. Decades of effort to #stoptheshock at the Judge Rotenberg Center in court or through regulatory processes have failed, overcome by tenacious families who see it as their only hope. Instead, the most effective path to eliminating shock treatments would be to render them obsolete.



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





Special Needs Trusts: Planning For Your Future

Webinar

September 8th, 2021

Carroll Center for the Blind in Newton, MA.

For Parents, Family members, Professionals, and Individuals who think they could benefit from a Special Needs Trust themselves.

- ◆ Special Needs Trust allows money to be set aside for a person with a disability.
- ◆ The trust is intended to help preserve funds for the sole benefit of the person with a disability, enhance the person's quality of life, while protecting his or her eligibility for public benefits, such as Medicaid and Supplemental Security Income (also known as "SSI").
- ◆ Join PLAN of MA & RI for an informational webinar to learn about what Special Needs Trusts are and how they can help you to plan for your future.

WHAT YOU'LL LEARN

- ◆ Information about the different types of Special Needs Trusts
- ◆ Why a Special Needs Trust is beneficial to you
- ◆ Unique features of PLAN as a Professional Trustee

SPEAKERS

JOAN MCGRATH, EXECUTIVE DIRECTOR – Joan has more than 25 years of experience in professional accounting and finance and has been with PLAN of MA & RI since 2009. Prior to assuming the role of Executive Director, Joan was the Director of Finance at PLAN.

KATHY VITELLO, LSW, DIRECTOR OF OPERATIONS – Kathy is a Licensed Social Worker with more than 35 years of experience working with seniors, people who are physically challenged, and chronically ill. She has broad experience and insight—drawn from her work in hospitals, in skilled nursing, rehabilitation, and psychiatric facilities, and in-home care and hospice settings.

To register or for more information visit <https://carroll.org/events/special-needs-trusts-planning-for-your-future/> or contact jason.laffer@carroll.org.



IEP para minha criança

Webinar

12 de setembro, 2021

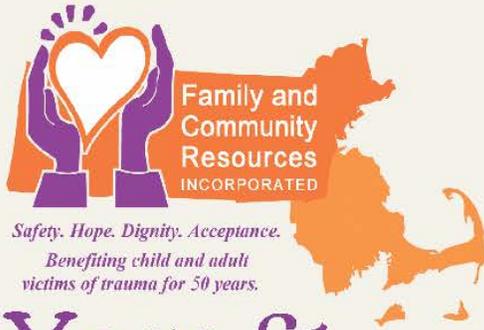
Com a Federação para Crianças com necessidades especiais em Massachusetts.

Informações sobre as leis e procedimentos da educação especial.

* Participe dos Cursos em Português Domingos às 5 p.m.

- 8/29 – Direitos Básicos em Educação Especial
- 9/12 – IEP para minha criança
- 9/19 – Comunicação Efetiva
- 9/26 – Intro à Transição
- 10/3 – Clínica do IEP
- 10/26 – E estratégias para reunião do IEP

Registrar https://docs.google.com/document/d/1bdVTjzAfkG_y36x_r0CXMPdsixE8U0nT/edit contato ou contato Aceriane Leal aleal@fcsn.org



Yoga & Mindfulness Class

With Certified & Trauma Informed Instructor

Andrea Hobkirk

First Class is
Saturday, October 2, 2021

8:30 am - 9:30 am

This class is a free bi-weekly zoom class for survivors of domestic violence.

All are welcome.

A reminder will go out the day prior with a link that you can click on and attend from the comfort of your own home.

Join in at any time - even if you are a few minutes late!

There are calming modalities that can help you feel centered, balanced and at peace with life.

Mediations and journaling may take place from time to time so feel free to bring a notebook.

For registration & inquiries contact:

Sarah.Bloom@fcr-ma.org

Tel: 508-583-6498



www.fcr-ma.org



CapeCodCAN
together with
**Barnstable
Recreation**
present



SATURDAY ART CLASSES for Adults and Teens

CapeCodCAN invites you to join us either online or at Cotuit Center for the Arts to explore a new form of art each week with in-person art classes led by local professional artists. Create and have fun in this inclusive, supportive environment. All supplies will be provided.

Times:

- 9:00-10:00AM online via Zoom or
- 10:30-11:30 in person at Cotuit Center for the Arts (Schoolhouse building)

Fee: \$30/3 classes

Register and pay online at artsonthecape.org/cape-cod-can

Class Dates:

September 11th

Create some fun fall art with Jennifer

September 18th

Donna will lead you in a fall leaf project

October 2

Create gorgeous paper sunflowers with Barbara



Cape Cod Collaborative Arts Network (CapeCodCAN) provides opportunities for inclusion and active participation in the arts for people with unique talents and all abilities on Cape Cod.

Reserve your spot today! artsonthecape.org/cape-cod-can

Questions? Email capecodcan@gmail.com or call 508-681-0239