

Medically Complex Program

Now that we have connected for half a year, most of us feel bonded. We have had some laughs and some tears in this short amount of time. Our physical year runs from July 1st to June 30th. We will be starting to do as many in home visits as possible within family's comfortability limits. We will be bringing over some Family Support Plans to be reviewed and signed. These plans are the things that we will be working on with you on this upcoming year. We may also have an expenditure plan to be signed if you got any funding from us within the last 6 months. If for some reason we are unable to meet in person we will mail these things out to you and do a phone call or zoom to go over these items so you know what you are signing and can mail back in a self-addressed stamped envelope. If you have any questions about any of this or would like to schedule an inperson visit please reach out to your advisor. If you don't know who it is or if it was Ana please reach out to Shanell at Shanellstewart@nemasketgroup.org or 508-999-4436 x161

With that said as we are moving into the beginning of our new year, and we are looking for some information we may not have gotten. This information can help us help you through this journey. I know we have spoken to most of you and have a great idea of your wants and needs but let's make it official, so we know everything that will let you get the best out of us. If you can please fill out this survey (it's on google forms) we will be very grateful. Once this is done we will have enough information to put together some ideas on how to help with our future. This should not take you more than 5 minutes to complete. For your time we are holding a **\$25 visa gift card raffle** for taking your time in filling this out. The raffle winner will be told by July 30th. If you have any questions at all please contact ShanellStewart@nemasketgroup.org 508-999-4436 x 161

<https://docs.google.com/forms/d/e/1FAIpQLSdNGsbNmkjVdTloc9bXx5VZ4a-QLaeJZwAfqlSrj0KGEJ12rw/viewform?vc=0&c=0&w=1&flr=0>

Medically Complex Program at The Nemasket Group

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Real Stories from People living with Cerebral Palsy

<https://www.cdc.gov/ncbddd/cp/stories.html#>

Sandy's Story

Sandy is the parent of a child with cerebral palsy and the Board President of [Gio's Garden](#)^{external icon}, a non-profit organization in Wisconsin whose mission is to nurture and strengthen families with special needs children by increasing their access to services. Before becoming a full-time mother and advocate, Sandy worked for 14 years in depression research.

"Every aspect of our lives is shaped by the over 1200 hours a year it takes to take our daughter with cerebral palsy to her more than 200 appointments with 9 doctors and 5 therapists; deal with insurance; find needed equipment and services; do therapy with her at home; address her behavioral issues; spend extra time on her school work; supervise almost everything she does to maintain her safety and maximize her independence; and make the extra time for her to do things other kids do so quickly and easily. It means staying where we have supportive family and have learned how to navigate systems; giving up my career because of my family's needs; and becoming an advocate for families with children with special needs. It has forced us to acquire new skills and re-focused our lives. It has made us intentional parents who constantly think about how we can keep our daughter's needs from taking over our family while making sure her brother's needs are also met. It has brought us closer together as a family, taught us the value of family and community, and helped us learn to cherish every little thing about both of our children.

Although cerebral palsy is a disorder that can impact any and all aspects of a person, it does not define who that person is. He or she still wants a high quality of life and parents of kids with cerebral palsy want the same thing for and to do the same things with their kids that other parents want." Having a child with special needs changed everything; because I now know the effect raising a child with special needs has on the entire family and how hard it is to learn about and access the multitude of needed services, I feel compelled to help other families through this process any way I can. My husband and I have all the advantages a parent of a child with special needs could hope for—supportive family and friends, relevant education and training, a good income, and good insurance—yet we have still experienced challenges. If we have not had an easy time of it, how do families who are not as fortunate as we are do it? And how could I sit back and watch that happen when the focus of the career I gave up for the sake of my special needs family had been resilience, stress, and coping?

Cynthia's Story

"Is this hopeless?" Cynthia Frisina Gray asked upon learning about her daughter's diagnosis of cerebral palsy in 2001. Cynthia knew there was a possibility that Cathryn could have problems—she was born prematurely—but she never imagined the difficulties that lay ahead.

Though she seemed fine at first, after several months, Cynthia began to notice that sometimes Cathryn seemed very floppy, almost like a rag doll. Other times, she seemed to stiffen. "I knew she wasn't hitting the same growth and motor milestones like my older daughter," said Cynthia.



Several doctor's appointments later, she finally received a diagnosis of cerebral palsy. Cynthia immediately went to the Internet searching for anything and everything about cerebral palsy. She felt frustrated by the limited information she could find that specifically addressed the needs of parents.

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Cynthia expressed her frustrations to Cathryn's orthopedic surgeon, who connected Cynthia with another parent of a child with cerebral palsy: Anna Marie Champion. Cynthia and Anna Marie set out to understand how they could help educate other families about prevention and treatment. But they weren't sure where to start. They read about spina bifida, a disabling birth defect of the spine, and about the discovery that folic acid can help reduce it. "That's what we want—our 'folic acid'—something that could help prevent cerebral palsy," Cynthia said. "We found out that we can't prevent and treat cerebral palsy without understanding the root causes of it." Tracking the number of children with cerebral palsy is the first step to understanding the characteristics and finding the root causes.

"Watching Cathryn go through the pain of two major orthopedic surgeries at such a young age is hard, but we know it's necessary to help her walk," said Cynthia. Today, Cathryn is thriving but her mother knows there will be many challenges ahead. "Like all parents, I hope and dream about my daughter going to college and having a fulfilling life," said Cynthia. "I also hope that one day we know what causes cerebral palsy so that we can help others."

Dalila's Story



"I have mild spastic diplegia. My cerebral palsy (CP) made me the person I am today. It has shown me that there is strength in the weak and a world full of outsiders.

Since I grew up unaware of my CP diagnosis, my younger self was only conscious of the fact that my stiff muscles made it taxing for me to walk straight and for long distances, to wear certain shoes, and to participate in vigorous activities. I now realize that these difficulties were strongly magnified by the negative emotions they produced. Feeling as though I did not fit in and devoting energy to try to mask that very fact caused more pain than the tangible, physical aches. I did not fully

understand why my body could not move the way most kids' could, and my confusion only worsened my perception.

As a coping mechanism, I ignored my responsibilities to stretch my leg muscles. I hoped that if I didn't acknowledge my complications, then maybe one day they would just evaporate. I am certain that I would not have increased flexibility in my muscles without my family's support and their reminders to stretch. My mother took me to physical therapy sessions every week and my older brother, Christopher, helped make my assigned stretches become part of my routine. Christopher, an athlete, understood the benefits and rewards reaped from exercising and targeting particular muscles in order to strengthen them. He and I would watch television in our living room regularly; he would use the time to stretch and invited me to do so too. At the time, I felt as if my condition had already defeated me and, so, completing the stretches seemed pointless. But, for a long while, there in that living room alongside my older brother was the only setting where I felt comfortable doing my assigned stretches because it was the only place where I did not feel alone in my journey. Christopher gave me exactly what I needed then— the courage to work on myself.

After discovering I am part of the CP communityexternal icon, I learned that CP does not look the same on every diagnosed person. "Cerebral Palsy" is a broad term used to describe various conditions. For example, those with quadriplegia are affected in both arms and legs; those with hemiplegia have only one side of the body affected; and those with diplegia are affected in both legs. Further, there are different types, like, spastic CP which describes tight muscles, dyskinetic CP which denotes spasms, and ataxic CP which describes shakiness. I would recommend that family members of those with CP use available resources, like the Centers for Disease Control and Prevention (CDC), to

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remain educated on the most recent statistical findings and utilize that information for the benefit of their loved one. Equally as important, however, I also suggest they do what my brother did for me: simply be *there* in any way they can.

I started the Young Professionals Committee (YPC) within the Cerebral Palsy International Research Foundation (CPIRF) to be an example for other young adults who may not realize that CP is an idiosyncratic condition. Discovering my CP helped me realize that I am strong. I hope my work for the YPC helps others affected by CP find their strength and courage as well. I am continuously inspired by the possibility of making a difference, and potentially improving the lives of others with CP. I hope for a day when people with CP are understood and embraced by not only those who are somehow connected to it, but also by the general public."

Sam's Story

In 2011, a severe ice storm hit the Midwest, leaving Mary and her family without power, heat, or a reliable car. Mary's son, Sam, has spastic quadriplegia cerebral palsy. Cerebral palsy is a group of disorders that can affect a person's ability to move and maintain balance and posture. Sam requires a specialized wheelchair and a wheelchair-accessible van in order to move from place to place. But during the ice storm, Mary's van was damaged, keeping her from taking her son to a place where he could receive proper medical attention in a safe environment.



Mary quickly turned to her local community for help. "I called the sheriff's office on that day, and was told to take him to the hospital," she says. She soon realized that there was not an emergency plan in place to provide transportation for people in wheelchairs to help them get to shelters or the hospital. Without transportation, Mary and Sam were left stranded in their home. Mary encourages families with a child with a special health care need who could face similar emergencies to have an escape plan in place. **"Have a set plan for transportation and a place that is safe and able to take care of your child."**



MassFamilies

*leadership training for a world
where everyone belongs*

REAL TALK: BLACK & BROWN CONVERSATIONS

Join MassFamilies for a six parts series where we will explore the different kinds of family make-up in our communities via the lens of Black and Brown family leaders. It will highlight the knowledge and experiences of those caring for and/or providing services to someone with special needs. Please come explore and share with us how you have nourished your family network!

This series will happen over a zoom platform and zoom Credentials will be emailed closer to the conversation date.

Jul 14, 2021 Time: 2:00 pm - 3:00 pm

Jul 21, 2021 Time: 2:00 pm - 3:00 pm

Aug 4, 2021 Time: 2:00 pm - 3:00 pm

Aug 18, 2021 Time: 2:00 pm - 3:00 pm

Register today by visiting:

<https://massfamilies-org.zoom.us/meeting/register/tZMkdeCuqTwqH9F0N51mkC6R33mi5q122mF8>

FREE Estate Planning for Special Needs



Webinar with a Massachusetts' based special-needs law firm.

July 20, 2021

10 a.m.

Free. Learn why some wills do not work, even when drafted correctly, the necessary steps to protect your home from future nursing home expenses, and how to reduce estate death taxes.

Topics include:

- How to protect your property, and reduce estate taxes
- Why up-to-date health care proxies and powers of attorney are now crucial
- How the new SECURE Act (of December 2019) can impact your estate planning
- Why a HIPAA release is essential in obtaining medical information
- How to keep your family out of probate
- How to obtain a free virtual estate planning meeting

Once you register, you will receive an email with simple instructions for connecting to the webinar.

* The speaker will be Tax Attorney Michael T. Lahti.

To RSVP or for more information visit www.fletcherilton.com/seminars-events or contact 508.459.8000

Epilepsy Support: Seizure First Aid & Recognition



Webinar with the Epilepsy Foundation New England.

July 22, 2021

To RSVP or for more information, visit

<https://epilepsynewengland.org/events> and scroll down to your desired event, or contact 617-506-6041 or email info@epilepsynewengland.org.

Do you know someone with epilepsy? Would you know what to do if they had a seizure with you?

- ❖ This is a one hour, online class.
- ❖ Learn about different types of seizures and what to do to help and keep someone safe.

Epilepsy Foundation New England is a 501 c 3 nonprofit organization whose mission is to help people and families affected by epilepsy in New England. They serve the Maine, Massachusetts, New Hampshire, and Rhode Island communities affected by epilepsy.

2021 SUMMER LEADERSHIP INSTITUTE

JULY 12 – 14 • A VIRTUAL EVENT

As we emerge from a year of disruption and challenges, there's no better time to prepare for the road ahead and make sure you're prepared for the future.

Our virtual 2021 Summer Leadership Institute provides the chance to learn from cutting-edge experts and fellow peers and engage in meaningful conversations with your fellow professionals.

SLI offers a high quality conference for not for profit leaders, with many diverse sessions at an affordable price point.

Here's a sneak peek at some of the hottest sessions:

Get It Right the First Time! Asking Better Questions

Alonzo Kelly | Kelly Leadership Group

Being explicit in our inquiry provides clarity, reduces mistakes, increases role clarity, and establishes accountability. Alonzo Kelly will introduce attendees to the art and skill of asking better questions to achieve better results.



Being the Change: Intersections of Race, Disability, and Allyship

Faith Tiemann & Renata J. Williams | The Arc Otsego & IncludED Perspectives

How can we work as agencies and individuals to create more inclusion and break down systemic barriers to that inclusion, and how do racism and allyship intersect with the biases around ability?



5 Peer-to-Peer Fundraising Fails (And How to Avoid Them)

Karrie Wozniak & Kelly Velasquez-Hague | OneCause

What makes one fundraising campaign more successful than another? This session will expose some clear fails many of us are committing when structuring ours.



DSP Boost Program: Our Answer to Solving the DSP Crisis

MaryEllen E. Jones & Bitta DeWees | Stone Belt

The Direct Support Professional (DSP) workforce is a national crisis. Preparing students for the workforce is another important subject. The DSP Boost Program addresses both.



Policy Update From Washington, DC

The Arc's national policy staff | The Arc of the United States

This session will outline our legislative priorities for the 117th Congress and the new administration. It will address where we have made progress and where we are heading. Key points will include HCBS and the American Recovery Act.

See the full schedule at a glance. We have an impressive three days of programming planned just for you. With over 30 sessions, this is one event you don't want to miss. [Register now!](#)

I would love to see you there and if you have any questions, please contact events@thearc.org

July 2021

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1 ASD Fit Boston 5:15-6:15pm (602 Oak St, East Bridgewater)	2	3
4	5	6	7	8 Sing, Explore, Create 1-3pm (28 Webster St, Rockland) ASD Fit Boston 5:15-6:15pm (602 Oak St, East Bridgewater)	9	10
11	12	13	14	15 Sing, Explore, Create 1-3pm (28 Webster St, Rockland) ASD Fit Boston 5:15-6:15pm (602 Oak St, East Bridgewater)	16	17
18	19	20 Family Skate Night 6-8pm (1055 Auburn St, Whitman)	21	22 Sing, Explore, Create 1-3pm (28 Webster St, Rockland) ASD Fit Boston 5:15-6:15pm (602 Oak St, East Bridgewater)	23	24
25	26	27	28	29 Sing, Explore, Create 1-3pm (28 Webster St, Rockland)	30	31

ACTIVITIES & EVENTS!



**Plymouth County
Family Support Inc.**

FOOD PANTRY

Our food pantry located at 118 Long Pond Rd in Plymouth, Suite #100 is open for walk in access Monday-Friday 9am-4pm

Walk In Center

We are a "walk-in" center and welcome you to stop by any Monday-Friday 8:30-4:30



JUNE 17TH – JULY 22ND
THURSDAYS 5:15-6:15

Get Moving This Summer with Ryan Feeney & Friends!

PCFS is excited to announce the start of a new 6-week exercise & movement program with Ryan Feeney of ASD Fit Boston! Ryan is Adaptive Training Academy Certified and a Certified Autism Fitness Instructor, owner & founder of ASD Fit Boston. Those who participated in our first ASD Fit session, LOVED IT and cannot wait for this one to start! Join your friends in movement, exercise & physical development & have fun while doing it! Sign up today by calling Catherine at Plymouth County Family Support!



**Plymouth County
Family Support Inc.**

602 OAK STREET
EAST BRIDGEWATER,
MA

1:1 SUPPORTS
WELCOME

EVERY THURSDAY
FOR 6 WEEKS

SIGN UP TODAY TO
SECURE YOUR SPOT!

CALL CATHERINE @
508-927-4520
EXT. 107

THANKS TO GENEROUS
FUNDING FROM DDS, THIS
PROGRAM IS **FREE** FOR
PARTICIPANTS!

PCFS

118 LONG POND ROAD,
PLYMOUTH, MA

508-927-4520

JOIN US FOR FAMILY SKATE NIGHT!

TUESDAY, JULY 20TH 6-8PM LOCATED AT
1055 AUBURN STREET, WHITMAN MA

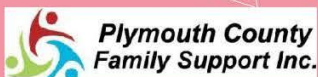
All Are
Welcome!

Skates will be provided
& Skate Mates
available for rental.

2 Pizza Slices & a
Drink Included!



Call Anne @ 508-927-4520 ext. 104 to sign your family up today!



This
event is
being
generou



**South Shore Beach: 125
South Shore Road, Little
Compton, RI 02837**

**All ages welcome but
space is limited!**

**Please sign up by
calling 508-927-4520
ext. 107 before June
30th, 2021**

SAVE THE DATE! 8/21/2021 SURF CAMP WITH GNOME SURF



**Sign up for a day of surfing & activities with Chris Antao and his
team at Gnome Surf!**

Gnome Surf is a Surf Therapy Organization focusing on creating a culture shift
towards happiness, kindness, love and acceptance for all kinds of abilities!

Join Gnome Surf at Happy Camp this Summer!

No equipment required; all surfboards provided by Gnome Surf. If your child
needs a life jacket, please reach out and we will see what we can do! Otherwise,
just bring yourself, a towel and a positive attitude!

**"Surf Therapy combines the
therapeutic elements of the
ocean with the adventure of
surfing to impact the physical
and mental well-being of
individuals worldwide
positively!"**

**Hosted by P.C.F.S, big
thanks to DDS for their
generous funding of
this event!**

TIME TBD



118 Long Pond Road, Suite 100

Plymouth, Ma 02360

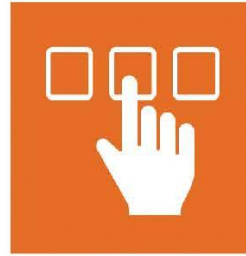
SELF-DIRECTION PROGRAMS



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:

7/13/21 10:00am to 11:30am

7/28/21 4:00pm to 5:30pm

8/10/21 10:00am to 11:30am

8/25/21 4:00pm to 5:30pm

9/14/21 10:00am to 11:30am

9/29/21 4:00pm to 5:30pm

Offered via WEBEX

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