

Family Connections Center

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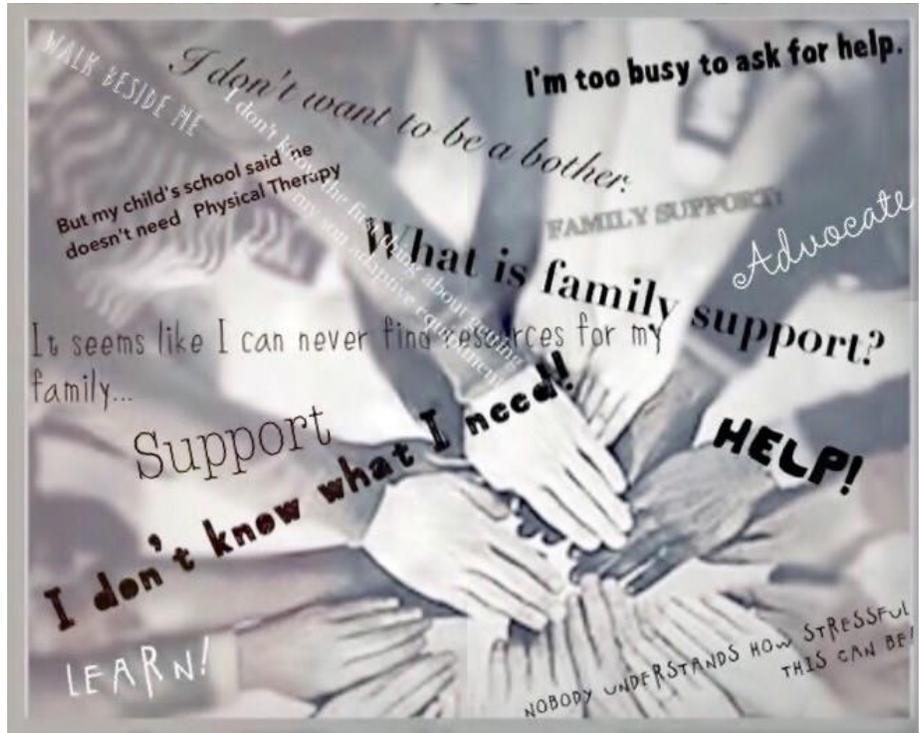
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WHAT IS FAMILY SUPPORT?



The Family Connections Center welcomes you to an OPEN HOUSE

Meet and learn about your Family Support Team

Find out what Family Support is meant to be for you

Wednesday, April 27th

6-8:00 pm

Family Connections Center
56 Bridge Street, Fairhaven MA

Rsvp to Amy Cornell by 4/22

Food for *Thought*

EDUCATED IGNORANCE

From the www.disabilityisnatural.com E-Newsletter by Kathie Snow

On my way home from a recent presentation, my flight was delayed at a large airport. Then delayed again. Then delayed again. You know how it goes: everyone in the gate area is miserable, and misery loves company. So over the next few hours, I spent time talking with some of my fellow passengers. One of them was "Abby," who was in her final year of dental school, and was completing her residency.

We chit-chatted about our travels and ourselves, and when Abby learned that my son, Benjamin, has cerebral palsy, she announced, "Oh, we recently had a Special Needs [dental] course and I learned all about CP kids." Uh-oh. In a friendly way, I told her about the importance of using People First Language (and that it was started by people with disabilities), recommending that she say, for example, "children with cerebral palsy," instead of "CP kids." I also explained that the "special needs" descriptor, while commonly used, leads to low expectations, pity, segregation, and other negative consequences.

Abby looked somewhat bewildered; she apologized for "offending" me. I assured her that I didn't feel offended, so no need to apologize. I added that I simply wanted to share the perspectives of people with disabilities with her in the hope the info would be helpful. "Yes, it is," she said, "and I'm going to take this information back to school and share it with my professors and other students." I told her that was a great idea, and encouraged her to visit my website.

Somehow, the conversation led to my saying something about "when Benjamin wore braces..." Abby interrupted: "You mean braces *on his teeth*?" "Yes." "You're talking about your son, Benjamin, the one who has CP?" I nodded yes, and she exclaimed, "*He had braces on his teeth?*" "Yes..." And it became a slow-motion moment: Abby's eyebrows raised up almost to her hairline,

her eyes were popping out and were unblinking, her jaw dropped, her mouth was a perfect O, and she was speechless. I looked at her and said, "What? *What?* Why are you looking at me like that?" She took a breath, shook her head from side-to-side, and said, "I can't believe that. CP kids-I mean kids with CP-cannot wear braces!" It was my turn to be stunned and I asked, "Why couldn't they wear braces?" "Because," she explained, "they can't tolerate them!" I asked, "What does that mean? Why couldn't they 'tolerate' them? And who told you this?"

Abby explained that this is what she and her fellow dental students are taught at the university. I laughed and asked what century her professors

**Prejudice is the
child of ignorance.**

William Hazlitt

were living in. I told her that some children with cerebral palsy (or any other condition) may not be able to "tolerate" wearing braces, just as there might be some children with

no disabilities or diagnoses who could also not "tolerate" wearing braces for whatever reason. I shared my opinion that this is the danger in believing you "know" about a person just because you know the person's diagnosis.

Our aircraft finally arrived and we took off. I then spent the next few hours on the flight home mulling over this situation. I thought about how many adults with cerebral palsy I've met who have very crooked and/or missing teeth. It's hard to keep crooked teeth clean, this can result in tooth decay, and that can result in losing one's teeth. I wondered how many parents considered braces for their children, but were told, unequivocally, "No, children with cerebral palsy [or whatever] can't tolerate wearing braces." And no further efforts were made: no parents questioned this nonsense and the orthodontists didn't even try.

I continued musing on the long flight. When my son was an infant and receiving numerous occupational and physical therapy sessions each

...continued from page 2

week, I also stepped in if baby Benj started to cry; I comforted him and told the therapists to do something that wouldn't generate tears. They weren't always happy about this, but they complied. I was saddened, however, by the other very young children receiving therapy in the large room who were often wailing and screaming. I spoke to several of the therapists about this, saying I didn't think children were learning anything from therapy when they were crying and in distress. I couldn't understand how therapists could keep working on a child who was screaming and wailing, making no efforts to comfort the child and/or change what they were doing. Their response? "You don't understand! We know – *we've been taught* – that children with disabilities as young as six-months learn to be manipulative and cry just to get out of therapy!" It seemed they had no common sense and no compassion; they didn't consider that a child might cry because he was in pain, afraid, tired, wet, hungry, or something else.

Next, I recalled an enormous mistake I made before my son entered a general ed first grade class: I gave the teacher a book about "children with cerebral palsy" to read over the summer. I hoped the information would be helpful, and she later reported that it *was* very helpful: she knew that Benjamin would do "such-and-such" and "this-and-that." I told her Benjamin *didn't* do those particular things. Unfortunately she learned a great deal about CP and *nothing* about my son. I then asked if she could forget everything in the book! (Thankfully, she did, by learning directly from my son and from me.)

It was a profound lesson: just because a person knows the medical diagnosis assigned to my son and/or the characteristics of the diagnosis, doesn't mean she knows *anything* about Benjamin. The same is true for others. So when a parent, for example, says, "I have a question about my child who has [fill-in-the-blank]," I ask the parent to tell me about her *child*, not the diagnosis. And what about, for example, books about "how to teach children with Down syndrome to read?" *Really?* Are we to learn that all children with Down syndrome learn in the same way?

I've shared a few examples of educated ignorance, and I'm sure you can think of some, too. A person may be highly educated and yet may remain very ignorant. We don't know what we don't know. And because *we think we know*, we don't question.

Going back to Abby, will knowing that my son could "tolerate" wearing braces despite having CP make a difference? Will she be able to influence the thinking of her professors? I would hope so, but I doubt it. Do most professors think they can learn anything from their students? When Abby opens her dental office one of these days, will she make adjustments in her thinking and how she practices dentistry? Perhaps; I hope so.

The vast majority of children and adults with disabilities are surrounded by many, many people who exert control and influence over their lives, 24/7/365, cradle-to-the-grave. You might be one of those people: a parent, therapist, service provider, teacher, etc. How many policies, practices, and every-day actions are based on myth, the status quo, conventional wisdom, etc.? Are your actions in the person's life based primarily on what you've been trained to do and/or based on what you think you know about the person's diagnosis? Or are your actions based on what you've learned

from the person?

Perhaps therein lies the problem. Just as Abby's professors may feel there's little they could learn from their students, many professionals may think there's nothing to be learned from children/adults with disabilities and/or their families, and many parents may feel they would learn little from their children. I don't know who came up with "children with cerebral palsy cannot tolerate wearing braces," but it's not true. Perhaps if just one dental scholar had personal experience in learning from a person with cerebral palsy who *did* wear braces, this myth would be put to rest. (Consider similar situations.)

My son has quashed many myths in his 29 years. We've learned from him; others have, too. Many parents have shared stories when their beliefs (or those of professionals) were changed by reality.

Perhaps therein lies the solution that can eliminate educated ignorance: to be skeptical of conventional wisdom and to learn from children and adults with disabilities. They are the true experts.

**Nothing in the all the world
is more dangerous than
sincere ignorance and
conscientious stupidity.**

Martin Luther King, Jr.

Available *Resources*

Congress May Consider Tweaks to ABLE Accounts

Disability Scoop by Michelle Diamant | March 22, 2016

Even before ABLE accounts are available to consumers, federal lawmakers are already proposing enhancements to the program. Federal lawmakers are already looking to expand the eligibility and capabilities of a new type of savings account for people with disabilities.

A package of three bills introduced this month in Congress would offer extra flexibility to individuals with disabilities using accounts created under the Achieving a Better Life Experience, or ABLE, Act. The savings vehicle established under federal law in 2014 will for the first time allow those with disabilities to save up to \$100,000 without jeopardizing Social Security and other government benefits. Medicaid eligibility will not be affected by any level of funds accrued in the accounts.

Currently, states are working to establish regulations and implement the new offering and ABLE accounts are expected to start becoming available sometime this year. Even before the first accounts are opened, however, the bipartisan group of lawmakers responsible for the ABLE Act is working to tweak the new program.

Under the latest proposals, people with disabilities who are employed would be able to allocate extra money each year to their ABLE account. Beyond the existing annual cap of \$14,000, those who are working could also deposit their earnings up to the federal poverty level – currently \$11,770 for a single person. In addition, eligibility for the accounts would be expanded to include people with disabilities that onset by the age of 46, an increase over the current requirement that conditions must exist prior to age 26. Finally, the lawmakers want to allow families to be able to rollover money they've saved for an individual with a disability in a 529 college savings plan to an ABLE account.

“The ABLE Act broke through the glass ceiling for thousands of individuals with disabilities by giving them the ability to plan and save for their futures,” said U.S. Rep. Pete Sessions, R-Texas, a sponsor of the bills. “While the ABLE Act was a critical first step, today’s package will bolster our efforts and strengthen the law to ensure individuals with disabilities, like my son, Alex, have the opportunities they need and deserve to achieve a bigger, brighter future.”

The bills known as the The ABLE to Work Act, The ABLE Financial Planning Act and The ABLE Age Adjustment Act are sponsored by U.S. Sen. Richard Burr, R-N.C., and Sen. Bob Casey, D-Pa., in the Senate and Rep. Ander Crenshaw, R-Fla., Rep. Chris Van Hollen, D-Md., and Rep. Cathy McMorris Rodgers, R-Wash., in addition to Sessions in the House of Representatives.

Supporting Families

If family support were truly supportive, what would it look like?

In 2008, MFOFC led a campaign, *You Are Invited*, intended to bring insight and knowledge about the joys and challenges of raising our sons and daughters in our communities and how Family Support benefits us all. Every year individuals and families advocate tirelessly for increased funding. This year MFOFC has joined other statewide organizations to substantially increase funding for families who are supporting individuals with disabilities in their homes.

Supporting Families is a collaboration of:

- Massachusetts Families Organizing for Change
- The Arc of Massachusetts
- Association of Developmental Disabilities Providers
- Advocates for Autism of Massachusetts
- Autism Speaks
- Massachusetts Down Syndrome Congress
- Massachusetts Developmental Disabilities Council

We need your story!

We need your help. We know that families across Massachusetts are struggling to meet the needs of their loved one with a disability. We know that many families do not receive enough financial support, and how this can create substantial financial and emotional hardship. **We know this, but our legislators do not**, which is why five statewide organizations have launched a campaign to substantially increase funding for families who are supporting individuals with disabilities in their homes.

There is a crisis facing many of the eighteen thousand families who support their loved ones at home. The families who face difficulty do not have adequate funding through the Department of Developmental Services (DDS). We can and will provide facts and figures that justify this expenditure, but **the most powerful thing our legislators can hear are the life experiences of families like yours**. Together, we can communicate the critical need to invest in families, and the incredible potential that will be unleashed when we do.

We are asking you to think about this question: "If family support were truly supportive, what would it look like?" It is important to capture what your life looks like now and what it could look like with more financial support from DDS. Some families have said they could get a job if they had more family support funding; some families say they could pay someone to take over during the night so they could get a full night's sleep; other families have said they would buy adaptive equipment that would radically change the quality of their loved one's life.

We need your story so that we can communicate the real challenges faced by real families, and the real impact that increasing family support can have on our families and our communities.

We will be using these stories to raise awareness in the general public and in our legislature. You can choose to have your identity remain anonymous or public, and we will fully respect your choices of how we may use this information.

Please send us your story! Go to The Supporting Families web site: <http://thearcofmass.org/supporting-families>

OR you can also complete the survey at: <https://www.surveymonkey.com/r/8D2GGK9>

Together we can make a difference!



Fellowship Opportunities

2016 Barbara Wilensky Gopen Memorial Fellowship And The 2016 Allen C. Crocker Family Fellowship

Now Accepting Applications

The Gopen Fellowship is a one year, part-time work and learning opportunity for an individual with a developmental disability. It allows an individual to work on a self-designed project and learn about disability policy, services and advocacy. Massachusetts residents with developmental disabilities who have finished school are eligible to apply.

The Crocker Fellow will design and implement a project of their choice that embraces the values and work of Dr. Crocker. Activities will be based on the Crocker Fellow's interest, and may include grassroots advocacy, public policy analysis, research, and other initiatives to improve the quality of life for people with developmental disabilities and their families. Family members of individuals with developmental disabilities are eligible to apply for the Crocker Fellowship.

The application deadline for both opportunities is April 28.

For more information and application details: <http://www.mass.gov/mddc> and click on **Fellowship Opportunities**

PBS Show to Feature Boy with Autism

An 11-year-old on the spectrum will appear on a brand new PBS children's show in an episode focusing on inclusion.

The show "Mack & Moxy" will debut on many PBS stations across the country starting April 1. Aimed at kids ages 3 to 7, each episode includes two segments exploring a different cause.

Charlie Owens, who lives in the St. Louis area, will appear on an episode called "A Spectrum of Possibilities" about the importance of inclusion. Owens, who has autism, was recommended by Easter Seals to be on the program.

"Mack & Moxy" includes a mix of 3D animation, live action puppets and celebrity role models like Hank Azaria, Josh Duhamel, Eva LaRue and Rachael Ray in addition to guests like Owens.

A St. Louis-area boy with autism will appear on "Mack & Moxy" in an episode titled "A Spectrum of Possibilities" where the characters meet a little bird who has the developmental disorder. (Mack & Moxy)

In each episode, a moose called Mack and a raccoon named Moxy help kids learn about various issues. "Mack & Moxy is the first kids' show to focus exclusively on introducing children to important causes like hunger awareness, autism or emergency preparation," said Brahm Wenger, the show's executive producer and creator. "The characters Mack and Moxy are fun, enthusiastic heroes eager to help and learn, just like our kids today."



FAMILY CONNECTIONS CENTER ANNOUNCEMENTS

FAMILY CONNECTIONS HOSTS SIBSHOPS

Watch for more information or call Family Connections at 508-999-4436 x 118 or x 133



Enjoy coffee or tea?



Join other Moms raising children with disabilities for some time away and a chance to chat at a local coffee shop



Watch for more information or call the Family Connections Center at 508-999-4436

We currently have open a part-time Family Advisor position.

Family Connections Center at The Nemasket Group creates a network of family support for individuals with developmental disabilities and their families. Family Connections has an exciting job opportunity available. Applicants should be highly organized, self-motivated, and responsible (bi-lingual Portuguese speaking is preferred).

Job duties include providing families information and referral to a variety of community and statewide resources, educational planning and support, community and systems advocacy, and in-home assistance or consultation to provide support and information to a family or an individual who has a disability to develop and expand their strengths and abilities. Assist individuals and families to more establish their presence in the community by strengthening and building relationships to fill valued social roles. Serious inquiries only please.

Competitive benefits package available. Person is required to have their own reliable transportation and be available to begin immediately.

Please forward resume & cover letter to SandyKinney@NemasketGroup.org

Information to *Share*



Join us for a webinar on Special Education Law: Children with Autism Spectrum Disorder

Thursday, April 7th, 2016
7:00pm-9:00pm

Presented by Leslie Hughes

Public Information Specialist, Massachusetts Advocates for Children

This workshop is about the special education legal requirements and the unique learning needs of children with autism spectrum disorder (ASD). It will address legal standards, evaluation rights and procedures and some court cases. It will also explain that under the law, children with ASD are entitled to receive educational opportunities which assume competency and potential.

This presentation is intended for parents and professionals working with children on the autism spectrum who would like to have a better understanding of:

- The legal obligations of a school district in educating a child with ASD
- The role of the service provider in providing educational opportunities which reflect competency and potential of children with ASD
- Then need for intensive, coordinated services and programs often required for students with ASD to make effective progress

The cost of attending is \$20.00. Once you make your payment, you will be receive an email with a link to the webinar registration.

If you have questions or need any accommodations please contact:
Shalene Gupta (sgupta@massadvocates.org)



A Full Life Ahead

Massachusetts Families Organizing for Change (MFOFC) in partnership with Building Futures and the Family Connections Center of the Nemasket Group presents

A series of monthly workshops designed for parents and caregivers as they plan for the future of their loved one with a disability. Various workshop topics such as friendships, transition, employment, housing and financial planning are offered. The workshops and resources provided in this series will help lead to interdependent, full lives in the community for people with disabilities.

LOCATION

The Nemasket Group - 56 Bridge St., Fairhaven, MA 02719

TIME

6:00 - 8:00 PM

Please RSVP to: Amy Cornell: amycornell@nemasketgroup.org or 508-999-4436

~ Space is Limited ~

Wednesday, April 20, 2016

Planning for Two Generations

Special Needs Financial Planning is planning for two generations. Many adult children with a disability must be supported their entire lives, even long after their parents have died. Our approach reaches beyond the limited boundaries of Wills and Trusts to provide you with a road map to address your own Special Needs. Planning for Two Generations centers upon our Special Needs Planning Timeline™ which highlights the various planning pressure points relating to their child's benefits, legal and financial issues. The primary focus is to help parents avoid common mistakes and pitfalls in their own planning.

Presenter: Alexandria Nadworny, CFP Special Needs Financial Planning

Wednesday, May 25, 2016

Turning 22: Adult Services - What should I be thinking about? What are the options?

Providing opportunities for students to explore different jobs, obtain paid employment and to think about post-secondary education is a key component to having a successful transition. This workshop will discuss different college resources and activities your child should be participating in to ensure they are fully prepared for when they leave the school system.

For more information: <http://www.mfofc.org/events/afla/index.html>

the nemasket group

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Family Connections Center

Joint Project of The Nemasket Group and
DDS (*Greater New Bedford Department of Developmental Services*)
56 Bridge Street
Fairhaven, MA 02719
Phone: 508-999-0077
Fax: 508-997-9239



Creating a network of family support
for individuals with developmental
disabilities and their families

Register now for our 2016 5K Walk/Run

April 30, 2016



Join us for a great morning of fun as we make our way through Fairhaven with family, friends and neighbors while raising awareness and support for The Nemasket Group. For more information and to register, please visit our website at www.NemasketGroup.org and follow us on Facebook.