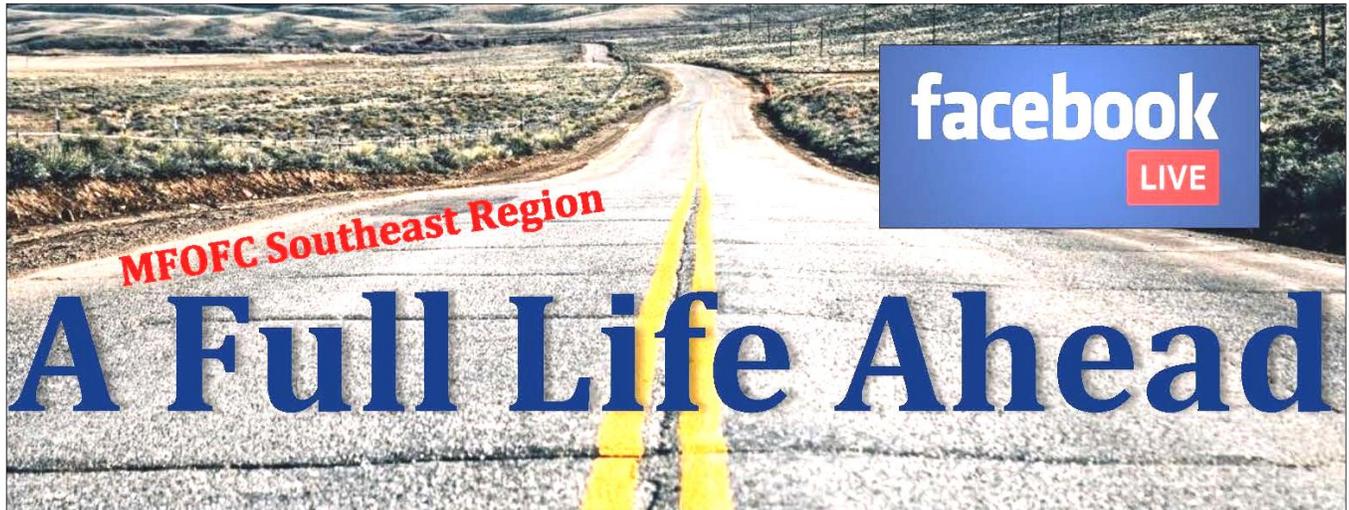


Family Connections Center



This is a series for Parents, Guardians and Support Professionals of Individuals with Disabilities. The series focuses on providing information that will lead to interdependent full lives in the community for people with disabilities.

*Sponsored by Massachusetts Families Organizing for Change
In partnership with the Building Futures Project and
the Family Connections Center of the Nemasket Group*

Connect with us on **Facebook LIVE** as we discuss a variety of topics. Live Stream from the comfort of your home, or on your lunch break.

Like us on Facebook to receive notification.

All Live Workshops will begin at Noon but will be recorded.

Find Us: @familyconnectionscenter

February 14th

Creating a Vision: A Person Centered Approach

March 14th

Leaving the School System – What's Next?



Families return for session two of the 2019 Southeastern Family Leadership Series.

The 2019 Southeast Family Leadership class recently reconvened for part two of a four part series. This year marks the 27th annual series put on in the Southeast, and the first year led by Kathleen Amaral. A graduate herself, she notes the experience as a true cornerstone for families seeking to make a positive change in their lives, as well as the greater community. Part two of the series focused on **Imagining Better** for our loved ones with disabilities, and the importance of thinking outside-the-box, beyond any “service system” to access [what we refer to as] “The Good Things of Life”.

A long time speaker in the series, Dr. Anthony Antosh began his presentation reflecting upon his life and longtime relationship with Emily Nisenbaum, who began the leadership series in the Southeast in 1990. Tony shared with the group that 95% of what he knows- he learned from families- just like our own.

Dr Antosh shared his belief that disability is just a natural part of existence. He went on to explain how, in his work, he has learned that a predictor of a good life has much to do with how we match people to the “people-places-and things” that match their “nature” (what they like etc..) and that people are a product of their experiences. He quoted studies & statistics, for example children in segregated settings have just 10% of the experiences that other children who are included in regular education have. Within his presentation, he posed a series of thoughtful questions, to help the group think about their own children....“What do you (they) do for fun? How do you (they) occupy their time? He emphasized that “everyone needs a hobby”. And lastly, he emphatically expressed that even the most severely disabled people are PROFOUNDLY more capable that most people first assume. He summarized a quote from Thomas Jefferson, which described that the root purpose of education was to make people good citizens. Ultimately, he inspired participants to remember that school is meant to prepare us for LIFE.



Sandra Heller takes us on a journey of inclusion for her son Craig.

Person Centered Planning was another topic covered during this session, and Ross Hooley, the Director of The [Building Futures](#) Project, shared stories, as examples of what can happen with a person centered approach. Ross enlisted Sandra Heller, co-chair of MFOFC Board and Director of [Family Connections Center](#), to share the story of her son Craig. We completed our time together with Maureen King leading a discussion about [Widening the Circle of Friendship](#) between people with and without disabilities. Maureen helped the group think deeply about how “Life is just Better with Friends”, and what that can mean for our loved ones.

The Southeast group will come back together in March, to continue their leadership journey, and to build personalized visions for their loved ones. To learn more about the series, contact Kathleen Amaral, Coordinator, SE Family Leadership Series, MFOFC, phone: 508-999-4436 ext.133 or email kathleenamaral@nemasketgroup.org

Food for *Thought*

The Power of ONE

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

I'm a 23-year-old college student with big dreams for my life! I also have cerebral palsy, and I use a power wheelchair and other assistive technology devices. I want to get through college and make a difference in the world, I like to stay up late and sleep in, and – well, I'm just a regular person. But you wouldn't know that by how some people behave.

During a recent visit with one of my grandmothers, we ate several meals in her retirement community, and were joined by my grandma's friends. At lunch in the "deli," an older gentleman and I enjoyed a great discussion about today's politics. As we hurried off to another activity, the man asked, "By the way, how long have you been incapacitated?" I *really* wanted to stay and have a *lengthy* conversation about his choice of words – *I am not "incapacitated"* – but there was no time, so I simply replied that I was born with cerebral palsy.

At another meal with my grandma and her friends, the dining room hostess passed out menus to everyone except me. I was busy talking and didn't notice this until I heard my mom say, "He needs a menu, too." Did the hostess presume I couldn't read, or did she think someone else was in charge of what I eat? A few minutes later, when the server came to take our orders, she asked my mom, "What does he want?" My mom said, "I don't know; you'll have to ask him." The server *did* speak to me then, but amazingly, she seemed to "forget" several other times, so my mom and I both reminded her to speak directly to me.

Why does this happen? I don't want to believe that people are intentionally prejudicial or cruel. It seems instead, it's a result of ignorance. Because people with disabilities have, historically, been "hidden away" behind the walls of segregated environments and/or have not participated in the mainstream of society for whatever reasons, many people *without* disabilities have little or no social

interactions with them, so when they do, it seems they simply don't know what to do or how to act!

After the events at my grandmother's, my mom and dad and I talked about these situations. My mom reminded me of similar things that have occurred throughout my life – like when I was very young, sitting in my wheelchair, minding my own business, and people asked my mom, "Can he talk?" (Why would they assume I couldn't?) She had more stories like that: perfect strangers who tried to hug me, pray over me, and/or give me money, as if I was a refugee from the Jerry Lewis Telethon! These actions seem to be the result of pity. At the other extreme are people, like the ones at my grandmother's, who ignored me. And there have been lots and lots and lots of stares, too. (My mom says she could write another book just about this stuff!)

Yes, it must be ignorance, the same kind of ignorance that people of color, women, and members of other so-called minority groups have experienced. The Civil Rights, Women's and other Movements helped to reduce that ignorance, as people from these groups took their rightful places in schools, at lunch counters, on buses, in the workforce, and other settings in their communities.

It seems the solution to reducing ignorance about people with disabilities is the same. So this is a **CALL TO ACTION** to children and adults with disabilities: **get out there're and take your rightful place in society!** The sooner more of us are out there, the more opportunities we have to educate others – *simply through our physical presence* – and the sooner others will learn that people with disabilities are regular, normal, ordinary people, too!

P.S. For proactive strategies on handling awkward situations, see "Humor to the Rescue: What Do You Say When...? And "Why Do We Apologize?" on the family's website, www.disabilityisnatural.com.

AN ACT RELATIVE TO SUPPORTED DECISION-MAKING AGREEMENTS FOR CERTAIN ADULTS WITH DISABILITIES

Sen. Joan Lovely (SD843), Rep. Aaron Vega & Rep. Paul Tucker (HD666)

Supported decision-making (SDM) allows adults, including those with disabilities and elders, to maintain their rights, dignity, and independence by choosing one or more trusted supporters to provide assistance making decisions about their lives.

SDM enables individuals with disabilities or cognitive limitations who may require assistance to make their own decisions with support, instead of having someone else, usually a guardian, make decisions for them. The arrangement is memorialized in a simple written agreement setting out the roles for the supporters (those who provide support) and the individual with the need for assistance (those who make the decisions). SDM has been gaining substantial momentum internationally, across the United States and, since 2014, through innovative pilot projects in Massachusetts.

THE NEED: Too many people are unnecessarily placed under restrictive guardianships when they would be able to make their own decisions if they received individualized assistance from people they trust, allowing them to retain their legal rights and dignity.

THE SOLUTION: Supported-decision making. Five other jurisdictions already have laws that provide clear legal authority and effective processes for SDM arrangements—Texas, Wisconsin, Alaska, Delaware, and the District of Columbia.

Respected **national organizations** and **federal agencies** have recommended and endorse using supported decision-making as an alternative to guardianship, including: American Bar Association, National Guardianship Association, the Arc of the United States, the U.S. Department of Education, U.S. Department of Health and Human Services, and the National Council on Disability.

This bill would establish the legal framework for SDM in Massachusetts. The bill would:

- define SDM and establish roles for those involved
- allow people with disabilities and elders to enter into a SDM agreement with people they trust, or “supporters”
- provide a model SDM agreement form
- create protections against abuse of the model
- require that courts first consider SDM before establishing a guardianship
- establish training for people using the model (supporters and decision-makers)
- ensure all youth turning 18 are made aware of the SDM option at Individualized Educational Plan (IEP) meetings

Passing this bill would **save time and money in probate courts** by reducing the number of guardianship petitions for people who do not need them.

SDM **does not replace guardianship**. It is an additional and less restrictive option.

Supported Decision-Making: Stories of Success in Massachusetts



Cory lives in the Berkshires, where he works with the Advantage Employment Network and in other jobs. Cory is on the Autism Spectrum and at times experiences symptoms from Obsessive Compulsive Disorder and anxiety.

When Cory was approaching 18, guardianship was the only option presented by his school. Cory did need help making decisions about his finances, health, and other issues, but his parents were unable to find any alternative to guardianship.

In January 2015, Cory and his family learned about the Supported Decision-Making Pilot Project run by the Center for Public Representation and Nonotuck Resource Associates and decided to try out this new model of support. Cory identified his supporters and which areas of his life he would need help with decisions. He filled out a SDM agreement reflecting his choices.

On November 17, 2015, a Probate Court judge granted Cory's petition to terminate his guardianship in favor of his SDM agreement. **This is the first time that a MA resident has relinquished a guardianship in favor of a SDM Agreement.**

In Cory's own words:

- "[Ending the guardianship was] very special because I felt my own freedom for the first time."
- "Supported decision-making is really important to me. I love my family and they will always be there to support me."
- "This is **my** journey now." **Amanda** is a young woman who is an avid traveler from the



Berkshires, and who loves the New England Patriots and WWE. Amanda has Down syndrome and at times needs support and clarity in understanding issues before making decisions. Amanda decided to try SDM. Her mother and a long-time friend are among the supporters she chose. One of her supporters, Sandy, believes that SDM is a great option for Amanda who "directs the course of her life and knows when she needs clarity in understanding decisions. [Supported decision-making] has given Amanda the continued opportunity to stay as independent as possible; this is what Amanda and her team both want."

Amanda says: "[Supported decision-making] is great for me because I get to make my own decisions with help from my team."

Contact your Legislators to support this important bill:
<https://malegislature.gov/Search/FindMyLegislatorwe>



Upcoming *Events*



A Conversation with Fred Misilo

Board President of
The Arc of the United States, Inc.

Thursday, February 14

10:00AM - 12:00PM

Courtyard by Marriott
75 Felton St, Marlborough

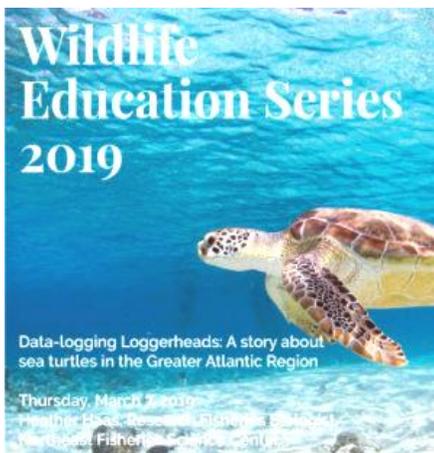
1. Learn about the Federal Legislative Agenda for the 116th U.S. Congress.
2. Learn about The Arc's Position Statements on important policy issues.
3. Share your feedback by participating in an active Question & Answer session.

Fred is Chair of the Trust and Estate Department of the regional law firm of Fletcher Tilton PC with offices in Boston, Framingham, Providence, Worcester and Cape Cod. He and his wife, Sandy, have two adult children. His background includes:

- Chair of the Board of Fallon Community Health Plan, Inc.
- Former Deputy Commissioner of the Massachusetts D.D.S.
- Former Executive Director of Harbor Area Community Services, Inc.
- Past President of The Arc of Massachusetts

Contact Katerina Daley to register at daley@arcmass.org

WILDLIFE EDUCATION SERIES



March 7, 2019 @ 6:00 pm – 7:00 pm

Buttonwood Park Zoo

425 Hawthorn St, New Bedford, MA 02740

Contact: Carrie Hawthorne phone: 508 9916178

Students free with i.d. Members \$8 Non-members \$10

The Wildlife Education Series is a monthly educational discussion covering a wide range of topics pertaining to Biology, Ecology, Marine Biology, Animal Behavior, Veterinary and Conservation Sciences held at the Buttonwood Park Zoo in the evening. The format of the seminars will vary based on the topic and speaker, from lecture to problem based learning, and will be geared to inquisitive individuals who are eager to learn and ask questions.



Save the Date



March 6, 2019 | 10:30AM - 12:00PM

The 41st Annual Legislative Reception Building A Stronger Future: Valuing Our Workforce



The Arc of Massachusetts honoree
Senator Mike Moore



MDDC Honoree
Representative Patricia Haddad

Great Hall, State House

24 Beacon Street
Boston, MA 01233

You are invited to attend our annual legislative reception on March 6. This is an ideal opportunity for persons with disabilities, family members, advocates, state agency heads and their staff, and legislators to interact and catch up on legislative priorities and other important issues.

Invited guests include Governor Charlie Baker, State Senators and Representatives, State Cabinet Secretaries and Commissioners.

Please do set up an appointment with your legislator in advance, in addition to encouraging them to attend the legislative reception.

CART and ASL interpreters will be available.

*If you require other accommodations,
please contact us no later than February 18, 2019.*

Growing Older Forum: How Best to Support Older Caregivers of Adults with Disabilities

- What matters most
- What is working
- Barriers faced

Tuesday April 9th, from 10-12 p.m.
121 Campanelli Drive, Middleboro MA

Can't make the forum? We still want to hear from you!
Contact Sandra Heller

Tel: 508-999-4436 or Email: Sandykinney@NemasketGroup.org



Leading by Example | 2019 GALA



The Arc of Massachusetts

March 27, 2019 | 6:00PM
Boston Marriott, Newton

Please plan to join The Arc of Massachusetts on Wednesday, March 27, 2019 for our Annual Gala. Our theme is **Leading by Example**. We will be recognizing several special people with intellectual and developmental disabilities who are making a difference: teaching the next generation of doctors; advocating at the State House for much-needed services and funding; and educating the community. They have overcome challenges themselves and their stories will inspire you. To kick off our evening, guests are invited to enjoy a cocktail reception and to bid on fun silent auction items. This will be followed by a seated dinner, program, and live auction. Emceed by WBZ's Chris McKinnon, with comedian Jimmy Tingle serving as auctioneer for our truly exciting live auction.

Visit www.arcofmass.org to buy tickets



Like us on 

SAVE THE DATE

SATURDAY, MAY 4, 2019

Fort Phoenix State Reservation
 Fairhaven, MA

Registration	8:00 AM
5K Run	9:00 AM
5K Walk	9:05 AM

Join us for a great morning of fun as we Walk or Run through Fairhaven with family, friends and neighbors while raising awareness and support for The Nemasket Group.

The first 125 registered adults will receive an event T-Shirt
All registered children (under 12) will receive an event T-Shirt

For more information and to register, go to our website at www.NemasketGroup.org ...

Did You Know

Show Us What You Love About Your Direct Support Professional!

We are raising awareness of the importance and value of Direct Support Professionals. Let's celebrate their contributions! Share your stories with us.

Create a 1-3-minute video to capture:

- What does your Direct Support Professional (DSP) mean to you and your family member(s)?
- What are some activities that the DSP does with you or your loved one(s)?
- What is an example of when your DSP has gone above and beyond his/her staff assignment?
- How have you or your loved one(s) benefited from the DSP's assistance?
- What do you wish more people knew about the work of DSPs?



If your video is selected, you will receive a \$50 gift card!

Visit arcmass.org/dsplove for rules and eligibility.

All submissions due February 14, 2019.

DID YOU KNOW?

THAT 60% OF INDIVIDUALS SERVED BY DDS ARE CARED FOR BY FAMILY MEMBERS

Across the state, more than 20,000 Massachusetts citizens are caring for a family member with an intellectual or developmental disability. While these families represent 60% of the individuals served by DDS, family support funding for caregivers is only 3.5% of the DDS budget.

Source: IN THEIR OWN WORDS: THE NEED FOR FAMILY SUPPORT SERVICES

INSPIRING QUOTE

"A life that hasn't a definite plan is likely to become driftwood".

~David Sarnoff



Find Caregivers When and Where You Need Them!

www.RewardingWork.org



Qualified caregivers available!

Individuals and families throughout Massachusetts use Rewarding Work's online directory and job board to find and hire caregivers. Rewarding Work job candidates are available to support children and adults with disabilities—at home or in the community. Respite care is also available.

RewardingWork.org subscriptions are free with DDS eligibility

Individuals and families served by DDS get a free subscription when they register with the DDS access code: **ddsconnect**

Try our FREE Job Board

The job board makes it easier and faster to connect with qualified workers. Write a short description of your hiring needs, and post it free of charge. Responses from interested applicants go directly to your email.

Get started today!

It only takes a few minutes to register and subscribe. Please see our tips on the reverse side to get started.



How it works:

- Search for workers or post ad on job board
- Subscribers post ads for free
- Responses go directly to your email
- Thousands of qualified candidates
- RewardingWork.org subscriptions are free with DDS eligibility
- Paid subscriptions to RewardingWork.org are also available (1 month at \$10; 3 months at \$25—call for additional rates.)

Contact us!

Email: Info@RewardingWork.org
Tel: 866-212-9675

Rewarding Work
CONNECTING TO CARE

 An Affiliate of
Toward Independent Living and Learning, Inc.

RewardingWork.org is sponsored by the Commonwealth of Massachusetts, Department of Developmental Services (DDS)