

# Family Connections Center



## A LOOK *at the* BUDGET

### Update for Conference Committee budget release

Disappointing news as the Conference Committee released a 40.2 billion dollar budget for fiscal year 2018. The bill reflects 600 million in adjustments to the FY 2018 budget made due to the tax revenue falling below projections as well the uncertainty of forecasted revenue.

The legislature did minimal trimming of the line items that we have strongly advocated for, such as Turning 22 and Family Support. However, the overall Department of Developmental Disabilities budget has significant cuts. These include a large reduction to Community Residential and Community Day and Work line items (both affecting Turning 22 annualization). We are concerned about those who turned 22 this year and unmet needs of those in the existing services system. State Operated Homes sustained a deep cut as well.

On the MassHealth side, the budget does not adhere to the House provision to protect the Adult Foster Care (AFC) program. The slash will significantly affect services for this cost effective LTSS (long term supports and services) program. The cuts of 6% and 3.7% must be absorbed in the provider's delivery of services, not impact the caregiver stipend. This effectively increases the reduction doubling it in many cases. This compromised budget does not include the specific Mass Health reforms that were presented by the Governor last month.

To see the detailed dollar amounts per line item, please go to <http://thearcofmass.org/update-for-conference-committee-budget-release/>

Advocacy is about persevering, about being ready to go back and not accept the initial outcome. We need to persevere and not accept this initial budget outcome. And you can persevere for what you need at home or elsewhere in your daily life. Whether you or a loved one has autism, Down syndrome, cerebral palsy, or another disability, your stories about how this budget impacts your family member will be needed to share with Health and Human Services, the legislature, and the public at large. Together we will persevere.

# Food for Thought

## Parents: Privacy...Please!

by Kathie Snow, [www.disabilityisnatural.com](http://www.disabilityisnatural.com)

My computer dictionary defines privacy as: "The state or condition of being free from being observed or disturbed by other people; the state of being free from public attention." Privacy is important to all of us, in many different ways.

Most of us, for example, don't want our medical information exposed to every Tom, Dick and Harry. To that end, we're all protected by HIPAA (Health Insurance Portability and Accountability Act of 1996): "The Privacy Rule sets rules and limits on who can look at and receive your health information."

Parents of children with disabilities have further privacy protections for their children in the special ed system: FERPA (Family Education Rights and Privacy Act of 1984) is "a federal privacy law that gives parents certain protections with regard to their children's education records, such as report cards, transcripts, disciplinary records, contact and family information, and class schedules."

Yet the privacy of many children with disabilities is violated 24/7/365 by those closest to them – their parents! The most intimate, personal, and private information overflows on social media, blogs, websites, comment areas, etc.

While the internet has provided valuable opportunities for parents to connect and learn from each other, the detailed sharing of our children's lives has been going on long before the advent of social media. As a presenter in the disability arena for 25-plus years, I've witnessed parents meeting each other at conferences and within minutes, their conversations are focused on their children's diagnoses and problems. This is duplicated in today's "sharenting," as it's now called: parents seldom share anything *positive* about their children with disabilities. When I'm speaking at a conference, it's common for parents to share with me, either in front of the entire audience or one-on-one during a break. About 99 percent of the time, the parents begins the conversation with the

child's diagnosis and a laundry list of problems. I gently interrupt and ask, "What is your child's name?" "Oh – her name is Emma..." Then I ask, "Can you tell me three wonderful things about Emma?" And the vast majority of parents say...nothing. They're unable to readily share anything positive about their children.

It's important to recognize that parents are not being intentionally unkind about their children. We have been "trained" by the disability service system to focus on diagnoses and problems because those are the eligibility criteria for services. Further, seldom do professionals in Early Intervention, Early Childhood, Special Ed services, etc., help parents identify or focus on their children's strengths. So, we, as parents, may inadvertently adopt the deficit-model thinking and talking practiced by professionals. At that point, our children's strengths and abilities become invisible to us!

How can our children be successful, today or in the future, if we don't identify, believe in, and share their capabilities, talents and potential? They see themselves through our eyes. What do they see?

Adding insult to injury, too many parents broadcast the "bad news" about their children to the world via social media. Again, they don't *intend* to cause harm. Some parents are genuinely trying to learn or share information about therapies, interventions, treatments, and/or strategies that may be helpful for their children. Other parents, however, seem to use social media as a "woe-is-me" platform; competitions about whose life or whose child is "worse" or "better" are common.

Our *intentions* don't matter; *outcomes* matter. Remember the axiom we're all familiar with: "The road to hell is paved with good intentions." So before posting one single word about our children have we considered the outcomes? Posting your child's name and birth date, announcing a birthday party, or sharing about other activities could lead to identity theft or

**You lose your  
privacy, and  
sometimes,  
people don't see  
you as human.**

*Shawn Wayans*

...continued from page 2

knowledge of where your child lives. Photos could be “Stolen” and reposted by pedophiles, by cruel people who make fun of children with disabilities, or even by an unbalanced individual who may identify your child as hers! And a “closed” group is no guarantee: we have no idea what our “friends” may do with our information.

Would you share that your partner recently started taking Viagra or that your burly 16-year-old son still needs a night-light in his bedroom? Can you imagine their pain if you violated their trust? If we agree that sharing this type of information is wrong, why is sharing intimate information about a child with a disability acceptable?

Have we considered that what’s been posted on the internet essentially lasts forever? By the time a young child with a disability is an adult, she might have an electronic footprint that extends far and wide. What might happen when she enrolls in post-secondary education or applies for a job, and her social media presence is reviewed/ What about the possibility that people in the disability service system might search social media for you/your child and discover information that impacts your child’s services now and later?

Have we asked our children for permission to share their lives with the world? What if the positions were reversed? Would it be okay for your child to share your personal, private information or to post questions about “how to deal with a blabber-mouth mother”?

Are our children aware of what we’ve posted about them? Younger children may not so much; but older children? At some point, the child will see and/or hear about what parents/family members have posted. Will your child thank you for revealing her private details to others? When she’s 20, how will she feel about a lifetime of her parent’s blabbing? What can she do to regain her privacy? (Not much, sadly.) If we haven’t asked the child’s permission, we shouldn’t be surprised if the child is deeply hurt, embarrassed, ashamed, and/or angry! Trust between the child and parent may be irrevocably damaged. The benefits of social media to the parent seem to pale in comparison to the harm caused to the child.

In my books, articles, and presentations, I do share lessons from my son’s life that might be helpful

to others, but only if my son has given his permission. When “something new” happens in Benjamin’s life, I ask if I can share it, and if he says no, the story remains private.

That’s the first step parents can take: ask your child’s permission before posting anything on the internet. Would you consider removing everything you’ve posted about your child and then start again with a clean slate? When you ask your child’s permission, if she cannot understand because of age, communication issues, or how the disability affects her, err on the side of caution and assume your child would say no! You may decide to ask again at a later time, but a child’s inability to understand or answer the question doesn’t give us license to carelessly plow ahead.

If you use social media to learn about and/or to share about your child’s diagnosis, condition, or situation, mask your child’s identity to protect his safety and dignity. You should still seek your child’s permission and ensure that whatever you post will not be hurtful to your child at any point in her life.

Perhaps you could use social media only for an introduction to others, then conduct your “business” via email or phone, privately. And if your email signature or other identification is something like

“Linda, mom to Trisomy 13” or “Susan, autism mom,” please, please consider a new moniker that doesn’t reference the diagnosis. Your child does not want to be known by the diagnosis (it’s not the defining characteristic of your child) and she does not want *you* to be known that way, either.

Maybe you’ll decide that social media is taking up too much of your valuable time – precious time that could be spent doing wonderful things with your family, focusing on your child’s strengths and abilities, and making cherished memories. Our children’s childhoods are fleeting and every moment counts.

There’s much more to consider that what I’ve detailed in this brief article. Search for “sharenting” on the internet and you’ll find more on this topic to thoughtfully consider.

Under HIPAA and FERPA, parents have legal recourse if their child’s privacy is violated by professionals. What rights do children have when their *parents* are the violators? How do our children *feel* about their private lives being shared publicly? Shouldn’t we care?

**All violations of essential privacy are brutalizing.**  
*Katherine Fullerton Gerould*

# Available *Resources*

## ADVOCACY BOOTCAMP

*Northeast Region of Massachusetts Families Organizing for Change* is delighted to invite primary caregivers of young children (birth to age 10) who have developmental disabilities, chronic illnesses, and/or complex medical needs to apply! Advocacy Bootcamp builds foundational advocacy skills so that participants can empower their children to lead rich, meaningful, and exciting lives!

All application materials must be submitted by **August 1st, 2017**. Space is limited.

Applications and information available in Spanish!

Questions can be directed to O. Sophia Johansson, Northeast Regional Coordinator at [o.sophia.johansson@gmail.com](mailto:o.sophia.johansson@gmail.com) or by telephone at 617-935.2264.

Advocacy Bootcamp is offered to families across the state by the Northeast Region of *Mass Families Organizing for Change*, a statewide grassroots coalition dedicated to individual and family support.



## **Family Leadership Training Opportunity**

Massachusetts Department of Public Health is looking for family members of individuals with special health care needs to take part in a five-part Family Leadership Training. Accepted participants will learn about:

- Making change through a hands-on community action project with support from a mentor
- Personal leadership style and how to use it to make a difference
- Concrete skills such as effective communication, team building and conflict negotiation

For more information and to receive and application, contact:  
[Linda.Freeman@state.ma.us](mailto:Linda.Freeman@state.ma.us)

**Deadline to apply is August 1, 2017.**

# MFOFC Family Leadership Series

The 26<sup>th</sup> SE Family Leadership Series is about to begin! The Series focuses on supporting families and individuals to live in their communities as naturally and typically as desired. Applications from families with children or adult family members **of any age with any disability** who are **Department of Developmental Services eligible** are encouraged.

The **Family Leadership Series** has a three-fold purpose. The first is to offer information about “best practices” for people with disabilities. The second is to assist families in creating a vision for their family member and a process to achieve the vision through leadership and advocacy. The third is to develop family leaders who will advocate at the local and state level to improve the lives of individuals with disabilities. The dates of the **SE Family Leadership Series 26** are: **October 27 & 28, 2017; January 19 & 20; March 9 & 10; and April 20 & 21, 2018**. Each session is two days in length. **Participants are required to attend all four sessions.**

## The Series:

**Initiative and Leadership** – family members are given information on the background of the family support movement, leadership, advocacy and the significance of self-advocacy, how to effectively advocate for change and ways to influence funding and delivery systems.

**Creative, Progressive and Innovative Ways to Provide Support** – how to help our family members and our families to live quality lives. A number of presenters offer their perspectives on a broad range of topics: Inclusion in schools; supported employment; positive practices; community living and family support.

**Creating A Vision** – families are supported to “imagine better” and to create a vision, with and for their family members, that guides their leadership and advocacy. What advocacy is necessary to ensure the visions that are developed and what is effective advocacy?

**Policy Making at the Local, State and Federal Level** – family members receive information on how to develop networks with professionals and families, how to access and control resources that affect family stress and satisfaction and how to use legislative change to procure resources.

**Food and overnight lodging for each family at the Holiday Inn in Taunton is paid for by the Department of Developmental Services.** Respite/child care/nursing for family members is also funded.

Families who have completed the Series have had a tremendous impact on systems change for families and individuals with disabilities in Massachusetts. Family members have been active in policy and decision making locally, regionally and statewide and some have decided to do legislative advocacy work. Some families have been involved in community organizing and advocacy on a local level. Others have used their talents and skills to create change for their child with a disability and/or their families.

For questions or an application, please contact:

Emily Murgo Nisenbaum at the Nemasket Group, 508-999-4436, email: [emilynisenbaum@nemasketgroup.org](mailto:emilynisenbaum@nemasketgroup.org) or Kathleen Amaral, 508-999-4436 email: [kathleenamaral@nemasketgroup.org](mailto:kathleenamaral@nemasketgroup.org)

*“The Leadership Series not only educated me, it made me think differently. It was great to leave with our visions – I am convinced that there will be a better future!”* FLS Graduate

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The Nemasket Group provides generous support to the SE FLS  
<http://nemasketgroup.org/>

The SE Mass Family Leadership Series invites you to a conference...

# Interdependence: The Route to Community

Strategies and tools to promote more opportunities  
for social inclusion and community engagement for  
people with disabilities in their local communities

**October 14, 2017  
10:00 AM to 3:00 PM  
Taunton Holiday Inn  
700 Myles Standish Blvd.  
Taunton, MA 02780**

## Presenter

**Al Condeluci, Ph. D.**

National Leader and Consultant on Human Services and Community Issues;  
Author of numerous books on Culture, Community and Social Capital and  
CEO of CLASS, a major disability agency of Western PA

**Check out Al's website: [www.alcondeluci.com](http://www.alcondeluci.com)**

## GOALS OF THE CONFERENCE

- ❖ Conference attendees will learn about effective approaches to helping their family members develop meaningful relationships within their communities
- ❖ Conference attendees will take away specific strategies and tools so that their family members can be assisted in establishing community connections
- ❖ Conference attendees will have the opportunity to ask questions and share helpful stories about their experiences in promoting social inclusion and community engagement

***Light refreshments and lunch will be served...***

This conference is free of charge for SE Mass Family Leadership Series graduates  
Others are welcome for \$20.00 (payable at the door)

To register: call or email Amy Cornell at 508-999-4436 or [amycornell@nemasketgroup.org](mailto:amycornell@nemasketgroup.org)

# Doug Flutie, Jr. Foundation for Autism Accepting Applications for Family Support Programs

The goal of the Doug Flutie, Jr. Foundation for Autism is to help families affected by autism live life to the fullest. Through its programs and partnerships, the foundation helps people with autism get access to care, lead more active lifestyles, and grow toward adult independence.

To that end, the foundation is accepting applications from organizations and schools in three focus areas:

1. **Access to Services:** The foundation provides funding for community organizations and schools that are providing vital resources and actively assisting children with autism spectrum disorder and their families through education and technology, advocacy programs, diagnostic and clinical services, direct family support, safety equipment, emergency care, respite services, and other opportunities that will enhance the quality of life for those affected.
2. **Active Lifestyle:** The foundation provides support for recreational and sports programs, aquatic programs, social skills training, family events and summer camps for all individuals on the autism spectrum.
3. **Adult Community-Based Services:** The foundation supports opportunities in the areas of job training, vocational skills programs, employment, housing, transportation, and healthcare delivery for adults on the autism spectrum.

To be eligible, applicants must be recognized as tax exempt under Section 501(c)(3) of the Internal Revenue Code. In addition, applicant organizations must provide services in one or more of the following geographic regions: Massachusetts, New Hampshire, Maine, Rhode Island, Connecticut, New York, New Jersey, Southern California (San Diego County, Los Angeles County, Orange County), Central Florida (Marion, Volusia, Sumter, Lake, Seminole, Orange, Osceola, Brevard counties), and select Canadian cities (Toronto, Vancouver). The foundation will also consider national educational and advocacy programs.

Grant amounts will range up to \$20,000.

See the Flutie Foundation website for complete program guidelines and application instructions:  
[www.flutiefoundation.org/](http://www.flutiefoundation.org/)



On June 30, 2017 the U.S. Department of Education published final regulations under Parts B and C of the Individuals with Disabilities Education Act (IDEA) in the Federal Register. The final regulations make technical conforming changes needed to implement statutory amendments made to the IDEA by the Elementary and Secondary Education Act (ESEA) as amended by the Every Student Succeeds Act (ESSA), and can be found at the Federal Register's public inspection site.

To learn more about the Every Student Succeeds Act in Massachusetts, visit:  
<http://understandingessa.org/state/massachusetts/>

## Person Centered Transition Planning Webinar for Educators and School Administrators

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**August 29, 2017 | 10:00-11:30 AM**

**\$60**

This webinar will focus on the use of Person Centered Planning in creating seamless transitions to adult services for students ages 14-22. Participants will look back at the historical perspectives of student planning, learn why a person centered approach makes sense and view methods of person centered planning. This workshop will provide examples of student outcomes and highlight best practices.

**Presented By:**



**Pat Pakos, MS**

**Kerry Mahoney, The Arc of MA**



Please go to:  
[www.thearcofmass.org](http://www.thearcofmass.org)  
Search "Webinar"

Financial assistance is available. Contact [Kerry Mahoney@arcmass.org](mailto:Kerry.Mahoney@arcmass.org)



The Disability Law Center (DLC) is the Protection and Advocacy agency for Massachusetts. DLC is a private, non-profit organization responsible for providing protection and advocacy for the rights of Massachusetts residents with disabilities. DLC receives federal, state and private funding but is not part of the state or federal government.

**Call for Assistance: (800) 872-9992 (617) 723-8455**

# 85 MUSEUMS & CULTURAL EVENTS 5 FRIDAYS. 100% FREE FREE FUN FRIDAYS!



## JULY 28

JFK Presidential Library and Museum  
Commonwealth Museum  
Arnold Arboretum  
The Eric Carle Museum Berkshire Theatre Group Historic Deerfield  
Cape Cod Museum of Art  
Wenham Museum  
Tower Hill Botanic Garden

## AUGUST 4

Commonwealth Shakespeare Company  
Old State House  
The Greenway Carousel  
Fort Devens Museum  
Children's Museum at Holyoke  
International Volleyball Hall of Fame  
The Old Manse, The Trustees  
JFK Hyannis Museum

## AUGUST 11

Franklin Park Zoo  
Fuller Craft Museum  
Cape Cod Maritime Museum  
Worcester Historical Museum  
Griffin Museum of Photography  
Fitchburg Art Museum  
Jacob's Pillow Dance  
Smith College Museum of Art  
Naumkeag

## AUGUST 18

The Institute of Contemporary Art/Boston  
Old Sturbridge Village  
Freedom Trail® Foundation  
Buttonwood Park Zoo  
Cape Cod Children's Museum  
Concord Museum  
Berkshire Museum  
Emily Dickinson Museum

## AUGUST 25

Boston Harbor Islands National and State Park  
USS Constitution Museum  
Plymouth Plantation  
MASS MoCA  
Nantucket Whaling Museum  
The Children's Museum of Greater Fall River  
Museum of African American History  
Cape Cod Museum of Natural History  
Heritage Museums & Gardens

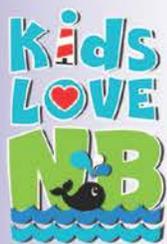
Please visit [HighlandStreet.org](http://HighlandStreet.org) or call 617.969.8900 for more information.



The Boston Globe

WCVB 5 abc





# Free Family Fun

a small historic city full of fun adventures, sightseeing treasures and hours of exploration, new bedford is a perfect place to bring the kids!

## Harbor Walk

Walk across the city's hurricane barrier, and look out upon where Buzzards Bay (East Beach) meets historic Fort Taber, beyond to Fairhaven's Fort Phoenix, West Island, and noted points of interest like Butler Flats Lighthouse. East Rodney French Boulevard.

## AHA! Nights

(Art, History and Architecture) These themed family-friendly cultural nights are held every second Thursday from 5pm-9pm and involve over 60 downtown museums, galleries, arts organizations, merchants, and restaurants. [www.ahaneewbedford.org](http://www.ahaneewbedford.org)

## The Bay Learning Center

A free environmental exploration center located in downtown New Bedford's Historic District. The Bay Learning Center is home to a variety of unique, informative and interactive exhibits that help guide your discovery of Buzzards Bay. Buzzards Bay Coalition, 114 Front Street.

## Self-Guided Dock Tours

Pick up a brochure containing information and maps highlighting several points of interest along the piers of the city's working waterfront. Fisherman's Wharf/Pier 3.

## Fort Taber Park

Over one mile of walking, jogging or biking paths, natural areas, a beach for swimming, a pier for fishing, a playground, community boating, and picnic areas offering panoramic views. S Rodney French Boulevard.

## Fort Taber-Fort Rodman Military Museum

On display are artifacts from every major American War, the evolution of Clark's Point to Fort Rodman, as well as photos and stories of local men and women that have served our nation over each conflict. Open daily from 1:00PM to 4:00PM. 1000 S Rodney French Boulevard.

## Paths and Trails

Explore nature at the Flora B. Peirce Nature Trails on New Plainville Road, the Ross C. Mathieu Trail at Pulaski Park, and the Ricketson Nature Trail at Brooklawn Park. [www.newbedford-ma.gov/parks-recreation-beaches/](http://www.newbedford-ma.gov/parks-recreation-beaches/)

## NB Fishing Heritage Center

Located in New Bedford's Seaport Cultural District, the Fishing Heritage Center invites visitors of all ages to try on foul weather gear; explore the wheelhouse; and race the clock while donning a survival suit. 38 Bethel Street.

## NB Whaling National Historical Park

Take a narrated walking tour of this 13-block area of cobblestone streets and whaling era buildings, daily during July and August. 33 William Street.

## Seaport Art Walk

Ten to twenty sculptures are temporarily installed along New Bedford's Working Waterfront (MacArthur Blvd, the City and State piers, in the city's Seaport Cultural District). Exhibition duration: June – October.

## The New Bedford Bay Sox

A nationally-ranked summer collegiate baseball team. Kid Tickets (6 and under) free, Kid Tickets (16 and under) \$3, Adult Tickets \$5. Paul Walsh Field, 230 Hathaway Boulevard. [www.nbbaysox.com](http://www.nbbaysox.com)

for select dates when admission is free to additional city attractions and events visit:

Destination  
**New Bedford.org**

# Information to *Share*

Come explore what's available in your community  
& shop Art, Craft & Specialty item vendors!

5<sup>th</sup> annual

## Southeastern Ma Community Resource & Craft Fair

Sunday October 22nd, 10a-3p,

Dartmouth High School

555 Bakerville Road, Dartmouth, MA

Resources include (not limited to):

- Social/Emotional
- Community
- Therapeutic
- Educational
- Health Wellness
- Recreational
- Safety

This event is FREE to the public

Smoking is not allowed on school grounds

For more information, email:  
[dartmouthsepac@gmail.com](mailto:dartmouthsepac@gmail.com)



**MYSTIC  
AQUARIUM**

August 10, 2017  
5:30pm-8:00pm

**REGISTRATION IS  
REQUIRED**

**2017 Free Evening Event for Families with  
Children on the Autism Spectrum**

# Save the Date!

## Summer Sizzler



**Date:** August 17, 2017

(rain or shine)

**Time:** 5:00 – 8:00 p.m.

**Location:** Mattapoisett YMCA  
38 Reservation Road  
Mattapoisett, MA



Bay Club

Save the Date

Monday, August 28, 2017

The Louis Nisenbaum Memorial Golf Tournament  
to benefit The Nemaasket Group