

# Family Connections Center

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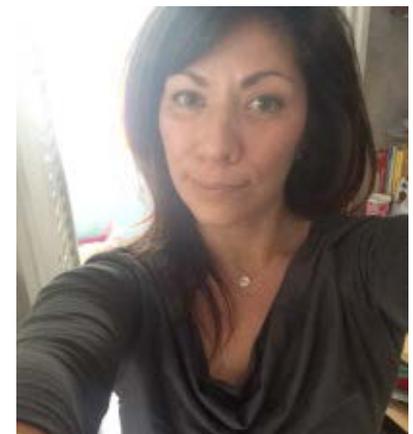
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## Introducing Ivone Rego-Cass Family Connections new family advisor

Greetings all! I am the newest member of the Family Connections Center. I am a mother of two rambunctious kiddos; the Founder of a local Documentary Film Program, Reel Serious; a Family Support Advisor; a grant writer; dog-lover; yoga enthusiast and an amateur Portuguese culinarian.



When I am not trotting around town with my beloveds, or capturing the city's beauty through a youthful lens; I can be found at an IEP meeting with our Portuguese/Spanish speaking families. I believe it is imperative to work with local schools to provide an individualized plan that focuses on giving



kids of *all* capabilities an opportunity to access the general curriculum; as well as the school's community. My son's ASD diagnosis was the catalyst that pushed me to become a better informed and participating parent. I am thrilled to be able to share my experiences and knowledge with you.

# Food for *Thought*

## MODELING: FOR GOOD OR FOR ILL

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

The teenager sees other teens taking drugs and wants to do the same. A ten-year-old sees his father gently removing the barbed hook from the mouth of the trout so it can be released, and the boy learns to do the same. Modeling – the act of imitation – happens all the time. We may model the looks, actions, language, and/or behaviors of others and the outcomes may be positive or negative.

While working in my yard, I wanted to prevent as many weeds as possible. To that end, I decided to tackle the “garden” of weeds growing in the alley behind our home. I didn’t want them creeping through the fence or having the wind blow their seeds into our yard. But there was little I could do about the dense weeds growing in the alley areas of our neighbors. So imagine my surprise later that day when the neighbor behind the neighbor on one side cleared their alley weeds! Did my actions spur them on or would they have done it anyway? I’m not sure.

While going about our daily tasks, at home, on the job, and in other environments, do we consider what impact our actions might have within the disability arena? Let’s consider some scenarios.

A five-year-old with a disability is “held back” in kindergarten because someone determines she’s “not ready” – emotionally, socially, or academically – for first grade. So, it’s believed, a second year in kindergarten will do the trick and help her become more “mature.” Hmmmm. How will being with children who are a year *younger* help her mature? Instead of becoming more like a six-year-old who should be in first grade, she’ll stay more like a kindergartner and will model the behaviors of her peers.

A child with autism flaps his arms and sometimes bites the back of his hand. He’s “placed” in an “autism classroom” where his “needs will be met” (i.e. make him stop doing these “inappropriate

behaviors”). But in this classroom, he’s surrounded by other children with autism who can’t sit still, who persevere, *and* who flap their arms and bit the back of their hands. So he’ll most likely learn that what he’s doing is the “norm,” *and* he’ll learn new “behaviors” from his classmates! Think of other examples.

In his article, “It’s Not What We Teach, It’s What They Learn” Alfie Kohn writes: “...what we do doesn’t matter nearly as much as how kids experience what we do.” And perhaps the same is true for adults.

So it seems important for us to consider what children and/or adults with disabilities are *experiencing* as a result of *our actions*. Our deliberations need to be wide and deep, and should include “minor” issues to “major” situations, *considered from the perspective of the child/adult with a disability*. For example, I might say or do something that seems like a “minor” issue to me, but my son, Benjamin, may experience it as a “major” issue.

So back to modeling. Consider students with disabilities in general ed classrooms. If the classroom teacher treats the student with a disability as an equal member of her classroom, so will the other students in the class (and the student with a disability will make friends and enjoy other positive benefits). On the other hand, if the teacher demonstrates pity, apathy, aversion, etc. (covertly or overtly) toward the student with a disability, the students in her classroom will model that behavior.

In schools where students with disabilities are in self-contained classrooms and are not part of the mainstream of the school in the cafeteria, playground and/or in extra-curricular activities, the main student *experiences* the message generated by the actions of adults in the school (self-containing classrooms): those “sped” kids don’t belong, they’re not like us, etc.

**People were not what they said. They were not what they thought. They were not what they promised. People were what they did. When the final tally was done, nothing else mattered.**

*James Lee Burke*

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That experience can shape the minds of these students *for the rest of their lives* and no doubt contributes to the continuation of pervasively negative attitudes about people with disabilities in our society, in the employment arena, community activities, religious entities, education, and more. Children *without* disabilities who have not grown up alongside children with disabilities will, as adults, simply model what they experienced as children (unless there's an intervening occurrence, like becoming the parent of a child with a disability). This example represents the macro. What about the micro?

How many times have we heard or seen ourselves in one of our children – our words, tone of voice, body language, or something else? We're most likely proud of – or even giddy – about the "good mimicry that we see or hear; we may be horrified by the "bad." *And both are the result of what a child learned from our actions.*

**Nothing is so contagious as example; and we never do any great good or evil which does not produce its like.**

*Francois de La Rochefoucauld*

Whether you're a family member or are employed in the field, you may try to teach this-or-that to a child or adult with a disability but do they see *you doing these things*? As an example, perhaps you're trying to teach a math lesson via traditional pencil and paper means, but you, personally, use your smartphone's calculator and everyone knows it. Regardless of your belief that the child/adult "needs" to learn math the way you're trying to teach it, your efforts will probably be unsuccessful because you're not modeling the actions or behavior you espouse. (To wit: do you try to get someone to stop yelling by yelling at the person?) Sit and ponder other scenarios that have happened today or yesterday or last week.

Staying on the micro level, and back to Alfie Kohn's example of how others "experience what we do," a parent may be doing what she thinks is best when she enrolls her child for years and years of therapies (physical, occupational, speech, behavioral, etc.). But how does the child experience the therapy sessions? Yes, the therapists may be lovely, caring people, and the child might indicate that she "has fun" at therapy. But sooner or later, the unspoken – and

devastating – message of traditional therapy ("You're not okay the way you are; we want you to be different/better," as told to me by countless adults with disabilities) is recognized. The child will model and internalize the actions of others, believing he's not okay and not good enough. What does that do to a person? (Note: There are many alternative ways of assisting a person that doesn't send negative messages, see "The New and Improved Therapeutic Landscape".)

In this day and age of reality TV shows where losers are ridiculed and school bullying is on the rise (think there's a connection?); where internet anonymity emboldens people to spew garbage they would never express in a face-to-face encounter; and where trust in leaders and traditionally-revered public and private institutions is eroding, the consequences of modeling – for good or ill – needs our attention more than ever.

None of us need to try to be perfect; that would be unachievable and a foolish waste of time. But we can be more thoughtful, more aware, more careful, and more deliberative about our words and actions, knowing that what we do and say, every minute of the day, can influence the lives of others (i.e., a person may model our words/actions *or* someone may "experience what we do" in a way we didn't intend) and can also influence our society as a whole.

Do our words and actions generate inclusion and equality for our brothers and sisters with disabilities? Or do they indicate that people with disabilities are not "good enough" so they need to be "fixed" and "placed" in "special" environments?

I don't have a disability – yet. But if I live long enough, I *will*, through an accident, illness, or the aging process. *The same is true for you.* Not being able to walk or talk wouldn't be such a big deal to me; assistive technology devices could help me move and communicate. But what would I *experience* from the actions of others? Would I enjoy the equality and inclusion I take for granted today? Or would I encounter what many people with disabilities experience: pity, segregation, exclusion, and more? What do you and I need to do to generate positive change?

# Available Resources

## IMPORTANT! MassHealth update on PCA overtime

On September 1, 2016, MassHealth put in place new rules to manage PCA overtime. MassHealth has been working with PCA consumers and other stakeholders since then about managing PCA overtime. Based on the feedback we received, MassHealth has made important changes to the PCA Overtime Management rules including increasing the number of hours a PCA can work before an overtime approval is required to 50 hours per week as well as updating the overtime approval criteria along with other initiatives. The complete list can be viewed here:

<http://www.mass.gov/eohhs/docs/masshealth/memlibrary/pca-omu.pdf>.

The changes will take effect on January 16, 2017. This information supersedes and replaces information in letters, sub-regulatory guidance and FAQs on PCA overtime management issued prior to this date.

All official information about PCA Overtime management, including the attached documents, has been posted on the MassHealth website at <http://www.mass.gov/eohhs/consumer/insurance/masshealth-member-info/pca>.

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## Exceptional Lives How-to Guides

At Exceptional Lives you will find Guides designed to walk you through challenging processes. For example, our Guides can help you figure out how to set your child up with a good IEP, apply for SSI, navigate guardianship, or make the most of your health insurance coverage. Whether you have a new diagnosis or are an expert in your child's situation, we want to meet you where you are. We can help you move toward greater peace of mind, organization, and knowledge.

Exceptional Lives' Guides are developed and reviewed with subject matter experts, based on the latest research and best practices. Visit our website to read more about our experts and partners.

We've had over **10,000 parents and professionals** use our free online Guides since we launched them in November.

Visit [exceptionallives.org](http://exceptionallives.org) to check out our guides: Create an effective IEP, Access special education, Apply for SSI benefits, Optimize health insurance, Navigate guardianship



# Disability Portrayals on TV At Record High

by Michelle Diamant | Disability Scoop November 7, 2016

The number of characters with disabilities on prime-time television is on the rise, with a new report finding such representation nearly doubled since last year.

Among series regulars appearing this season on scripted prime-time programs on ABC, CBS, The CW, Fox and NBC, 15 are expected to have disabilities.

By contrast, there were just eight portrayals of disability on network shows last season.

The findings come from an analysis released this month by GLAAD, a media advocacy organization for the gay and lesbian community. The annual report assesses representation of minority groups on television including people with disabilities.

For the 2016-2017 season, the report found that characters with disabilities account for 1.7 percent of all series regulars on network shows, the highest percentage recorded since GLAAD started tracking disability representation on TV in 2010. There are five characters with disabilities appearing on Fox shows, four on NBC, three on ABC, two on CBS and one on The CW, the report found. GLAAD included any condition that would qualify under the Americans with Disabilities Act.

"As noteworthy as these numbers are, in comparison with previous tracked seasons, they lack far behind the actual representation of people with disabilities found in our communities nationwide," Jennifer Laszlo Mizrahi, president of the nonprofit RespectAbility, said in the report. "The only way to create authenticity within entertainment television is if characters with obvious and hidden disabilities are included within every script and storyline, just as they are found within the diversity of our everyday lived experience."

Network shows expected to feature disability portrayals include "Empire," "24: Legacy" and "Rosewood" on Fox; "Superstore," "Taken," "Trial & Error" and "This is Us" on NBC; "Grey's Anatomy," "How to Get Away with Murder" and "Speechless" on ABC; "NCIS: New Orleans" and "Scorpion" on CBS and The CW's "The 100."

Meanwhile, on cable, Freeform's "Switched at Birth" and "Pretty Little Liars" and Showtime's "Shameless" will include representations of disability, the report said. Streaming series include Amazon's "One Mississippi" and "Transparent" and Netflix's "Wentworth" and "DreamWorks' Dragons" with disabilities by investigating approaches that address variations in student learning styles within the range of online learning options.



Micah Fowler, right, who has cerebral palsy, stars as JJ on ABC's "Speechless." (Eric McCandless/ABC)

## Movie Showings for Guests & Families Living with Autism or Other Special Needs

AMC is proud to partner with the Autism Society to bring you unique movie showings where you can feel free to be you! We turn the lights up, and turn the sound down, so you can get up, dance, walk, shout or sing!

We've expanded our Sensory Friendly Film program to four showings per month.

- The second and fourth Tuesday and Saturday
- Family-friendly movies continue to show on Saturday mornings
- Films that may appeal to older audiences now show Tuesday evening
- Check the AMC Theatre/Dartmouth for specific listings



# Family Connections Center Hours Have Changed!

We are excited to share that beginning December 6<sup>th</sup> Family Connections Center will be holding late hours. Our center will be open Tuesdays until 7pm, by appointment only.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
CLOSED	9am-4:30pm	9am -7pm	9am-4:30pm	9am-4:30pm	9am-4:30pm	CLOSED

Please remember to call or email to schedule appointments, as staff is often out in the community supporting families.

## Research Study ~ Online Survey

Wandering by children with ASD and other developmental disorders is a significant safety concern. It is estimated that more than **250,000 children** with disabilities wander away from adult supervision each year. Few researchers have looked at this major issue, and there has been little focus on **prevention measures** and the **impact** that wandering concerns have on families.

Cohen Children's Medical Center of New York is conducting **a major national study** about wandering, and we very much want you to participate.



It takes just a few minutes to complete the **anonymous, online questionnaire**. If enough families complete our questionnaire:

We will have the most representative study done to date - giving voice to as many families as possible

We can help guide families like yours about what prevention strategies seem to be most effective

We can document the impact that wandering has on families in terms of activities and household stress

Go to [www.WanderingResearch.com](http://www.WanderingResearch.com) to take the survey, request a copy of our results, and be contacted regarding a follow-up research project related to wandering.

We thank you in advance for your kind cooperation.

Laura McLaughlin, Research Assistant

On behalf of: Andrew Adesman, MD, Chief, Developmental & Behavioral Pediatrics, Cohen Children's Medical Center of New York

Professor of Pediatrics, Hofstra Northwell School of Medicine

Northwell Health

Visit us at [Northwell.edu](http://Northwell.edu)

# 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 go to <http://thearcofmass.org/supporting-families/> to find out how you can share your story.

# Information to *Share*



**Boston  
Children's  
Hospital**  
Until every child is well™

Children's Advocacy  
Network

**MLRI**  
Massachusetts Law Reform Institute

Please join the Office of Government Relations and the Massachusetts Law Reform Institute for our quarterly discussion.

## Breakfast on Benefits

### Focus on Medicaid Managed Care

Legal experts from MLRI will join BCH leadership to review recent federal and state changes to Medicaid managed care including the development of Accountable Care Organizations (ACO) and fixed enrollment.

Come and get your questions answered.

*Light Refreshments Will Be Served!*



Wednesday,  
December 14, 2016  
10:00-11:00 a.m



**Vicky Pulos**  
Staff Attorney  
Massachusetts Law Reform Institute



Garden Conference Room  
300 Longwood Ave.



**Josh Greenberg**  
Vice Pres. Government Relations  
Boston Children's Hospital



Please RSVP to Jamie Gaynes at  
[jamie.gaynes@childrens.harvard.edu](mailto:jamie.gaynes@childrens.harvard.edu)



**Kevin Pawl**  
Enterprise Director of Patient Access  
Boston Children's Hospital



Can't be there in person?  
Check out our live stream at  
[meeting.childrens.harvard.edu/landl](http://meeting.childrens.harvard.edu/landl)



Guest Speaker: **Patti Menzel**

Please join the New Bedford Training Committee

**Wednesday, January 18, 2017**

**10:00 am – 12:00 pm**

**The Nemasket Group**

**109 Fairhaven Road, Mattapoisett MA**

Patti is an eloquent speaker and is able to give her unique perspective on living with autism.

To register contact Amy Cornell ([amycornell@NemasketGroup.org](mailto:amycornell@NemasketGroup.org))

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## **Planning A Life:**

### **Making the Most Out of High School For Students with Disabilities**

If you have a child with a disability who is approaching the age of 14 to 21, this transition conference is an important opportunity for you. Begin the transition planning process early and stay on schedule. Strategize now and prepare for a full productive life during and after high school.

Two action-packed days (Friday and Saturday) are filled with information and resources that will support you to understand your role, rights and responsibilities in the transition planning process. Registration fees for this 2-day conference are \$125 per person, or \$175 per family or professional. FCSN's Planning A Life conference is open to families of students with disabilities, educators and other professionals. Scholarships are available.

Planning A Life is offered on: Friday and Saturday from 8:30am-4:00pm.

**Pre-registration is required.**

**Choose from upcoming dates:**

**February 3rd and 10th 2017:** Federation for Children with Special Needs TWO Fridays The Schrafft Center 529 Main Street, Suite 1M3, Boston, MA 02129

**For more information contact The LINK Center at 617-236-7210 or email: [info@fcsn.org](mailto:info@fcsn.org)**

**To register and learn more, please visit our website at: <http://fcsn.org/linkcenter/pal>**

# 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)  
109 Fairhaven Road  
Mattapoisett, MA 02739  
Phone: 508-999-4436  
Fax: 508-997-9239



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

*With warm wishes for love, peace and many  
moments of joy during this holiday season!*

*We are so grateful for our relationship to  
you and the opportunity to be of service!*

*We look forward to continuing our  
work with you in the New Year!*

*Sandy Jorge Kathleen Jennifer Ivonne Julia*

