

5 Ways to Make the Holidays Happier for Children with Special Needs

Get advice for helping a special needs child through this chaotic time of year.

By Ellen Seidman, magazine editor and the writer behind Love That Max

As parents, you want to make the holidays as jolly as possible for your kids. Keeping children with special needs merry, though, can be challenging. The hubbub of family celebrations and parties can overwhelm those with sensory issues; others might find the break in routine unsettling (and meltdown-inducing). It's also not very joyous for a kid with delays to open up a present that doesn't fit his developmental stage.

Happily, there are plenty of strategies that can help kids with special needs have just as much fun as any kid. Parenting bloggers share the tactics that have enabled their kids to have truly happy holidays -- and peace, too!

1. Help Kids Prepare

"My autistic son thrives on routine and feeling informed, which makes the chaos of the holidays hard for him," says Shannon Des Roches Rosa, mom to Leo, 12, and blogger at <u>Squidalicious</u>.

"A visual schedule helps him understand why and how his routine will change, allows him to focus on the fun to come and lowers his anxiety over being in a different place with different people."

She uses apps like <u>ChoiceWorks</u> and <u>Routinely</u> to create visual schedules, and makes paper ones, too. "We include pictures of the people we'll be seeing," explains Rosa. "We'll also use icons of Christmas trees, presents, and turkey dinner. Then Leo can relax and get into the holiday spirit!"

2. Share a Gift Wish List

"The truth is, it can be difficult to pick the right gift for *any* kid. Add in special needs and things get even more difficult," says Katy Monnot, mom to Charlie, a five-year-old with cerebral palsy, who blogs at <u>Bird on the Street</u>. "I email each set of grandparents a list of suggested gifts. I'll include a tried-and-true one -- something Charlie's seen before and loves or something similar, plus a book because kids needs books, and a gift that addresses one of the goals he's working on."

When one of Charlie's therapists set a goal for him to use both hands during play (since he tends to favor one hand), Monnot requested a box of instruments with a tambourine and cymbals to encourage the use two hands. "This works out great for everyone," she notes. "The grandparents know that at least one of their gifts will make his eyes light up, and I know that at least one of their gifts will encourage him to try new things. It's a win-win."

3. Hire a (Sitter) Elf to Help

"A couple of years ago, when our family was invited to a Hannukah party, the first thing we did was book a babysitter to take along with us," says Jana Banin, mom to 6-year-old Zack, who has autism. "We knew the noise and crowded space would be too much for Zack -- and we wanted to make sure he had a good time and we did, too." Banin, who blogs at I Hate Your Kids (And Other Things Autism Parents Won't Say Out Loud), knew her ploy would help: "The sitter could play with him, make sure he didn't grab a cookie from someone else's plate and make sure he didn't wander out onto the street. The evening was a success! Zack and [the babysitter] checked out all the different food, snacked, curled up on the couch as he played his iPad. Since then, we bring our sitter with us to parties."

4 Teach Other Kids about Your Kids

To help other children understand her daughters Evangeline and Polly, who are both 6 and have Down syndrome, <u>Gillian Marchenko</u> sends out an educational e-mail before the holidays to families they plan on visiting. It includes pointers such as:

- ~Your friend might need more time to answer questions or finish an activity.
- ~Some kids with special needs can be focused on one topic; even though it can get annoying, it makes him feel special when you listen and appreciate the things he loves.
- ~Kids with special needs are often made fun of or bullied. Be brave and defend your friend.

As Marchenko says, "Friends and family are grateful for the advice."

5. Let Go of Your Expectations

"My son Gavin has cerebral palsy and when he turned two, I wrapped every present and couldn't wait for him to open them on Christmas morning," says Kate Gallagher Leong of <u>Chasing Rainbows</u>.

"It was one of the worst mornings of his little life. He has issues with fine-motor skills, and forcing him to use his hands to rip open the paper was more like therapy than Christmas. That's when I realized I shouldn't project my Norman Rockwell Christmas onto my child. The following year, every toy was out of its box and ready to play with, making a bright and inviting display under the tree. The look on Gavin's face as he moved from one toy to the other made it the best morning of *all* our lives!"



These are bills currently in the Massachusetts House and Senate that are relevant for people with disabilities living in our state. Please call Family Connections if you'd like to contact your legislator about any of these but are unsure how. Or go to malegislature.org to look up contact information for your Representative and/or Senator.

Bills for 190th session (2017-2018)

1. Abuse Registry S 64 / H 80

Senator Mike Moore & Representative Linda Dean Campbell

An Act to establish a registry of caretakers found to have substantiated abuse against persons with intellectual disability or developmental disability.

2. Supporting Individuals with I/DD (OHC) S 1222 / H 1954

Senator Barbara L'Italien & Representative Carolyn Dykema

An Act supporting individuals with intellectual and developmental disabilities to establish training focused on best practices for the treatment and care of individuals with autism and other intellectual and developmental disabilities for medical professionals through a voluntary training and accreditation program

3. Housing (Accessory Apartments) \$ 729 new draft \$2132

Senator Barbara L'Italien

An Act relative to accessory dwelling units. For legislation relative to the development and preservation of affordable housing for persons with disabilities and the elderly; is designed to encourage creation of long-term housing stock for people with disabilities and seniors in the form of 2 bedroom accessory apartments.

4. Dental Therapist Expansion S 1169 / H 2474

Senator Harriette Chandler & Representatives William Pignatelli/Kate Hogan

An Act Authorizing Dental Therapists to Expand Access to Oral Health. This bill would establish the position of advanced dental hygiene practitioner and require training about best practices for people with autism and intellectual and developmental disabilities. The DHP will perform services as tooth extractions and fillings in settings as community centers, nursing homes and schools. The DHP would provide services for individuals who are not able to visit an office.

5. Hospital Training - Autism S 1221 / H 3236

Senator Barbara L'Italien & Representative Sean Garballey

An Act creating Autism teams in hospitals to expand current medical providers' knowledge about autism in order to improve the treatment individuals with autism receive in medical settings. This bill is aimed at expanding medical provider's knowledge about autism and tasks DPH with designing a program to provide specialized training on autism for medical providers and subsequently establishing a pilot program to develop an on call "autism team".

6. Loan Repayment Program for Human Service Workers S 42 / H 116

Senator Jennifer Flanagan & Representative Jeffrey Roy

An Act relative to creating a loan repayment program for human services workers. This bill encourages direct care workers to enter and continue working in community-based human services programs. The bill would help human service organizations recruit and retain a stronger, more qualified workforce.

Bills for 190th session (2017-2018) continued...

7. Criminal Justice Training Regarding Autism H 2276

Senator Jennifer Flanagan Representative Kimberly Ferguson

An Act related to criminal justice training regarding autistic persons. This will require training of law enforcement officers and correction officers in the commonwealth in appropriate interactions with persons on the autism spectrum, and also shall develop guidelines for law enforcement response to individuals on the autism spectrum who are victims or witnesses to crime, or suspected or convicted of crime.

8. Prompting and Cueing S 60 / H 1967

Senator Joan Lovely Representative James O'Day

An Act Relative to Cueing and Supervision in the PCA program. This bill amends chapter 7 of the general law to allow the Personal Care Attendant Program (PCA) program to include cueing and prompting as a covered services for those eligible members who need prompting or cueing in order to perform 2 or more activities of daily living (ADL).

9. Higher Education Opportunities for Students with I/DD S 698/ H 634

Senator Barbara L'Italien

Representatives Patricia Haddad/Sean Garballey

An Act creating higher education opportunities for students with intellectual disabilities, autism, and other developmental disabilities. This bill allows persons with autism or I/DD to access the Commonwealth's state colleges and universities to gain skills necessary to work and live as independently as possible as adults.

10. Supporting Transition to Adult Services (Turning 22) S 288 / H 1953

Senator Barbara L'Italien Representative Mark Cusack

An Act supporting the transition to adult services for persons with disabilities. Expands transition (Turning 22) services and supports to students with disabilities "without adult service agency ties" (688 process). It also updates and expands the types of "habilitative services" that must be provided under the 688 process. It assigns to EOHHS the obligation to monitor and collect data on the extent to which needed 688 services are not being provided, because of shortfalls in appropriations.

11. Prevention of discrimination against adults with disabilities in family or juvenile court proceedings \$ 896 / H845

Senator Barbara L'Italien Representative Paul Heroux

An Act prohibiting discrimination against adults with disabilities in family and juvenile court proceedings". This bill prevents disability used as a sole reason to rule against a person/family on matters in juvenile and probate courts.

12. Act to promote health equity \$600

Senator Michael Barrett

The Act will establish an Office of Health Equity (OHE) within EOHS to focus on reducing health disparities among minorities, people with disabilities and other populations that experience health disparities.

Go to malegislature.org to look up contact information for your Representative and/or Senator.



Systemic change doesn't always filter down to real change in the personal lives of people with disabilities, so we need Community Leadership for INCLUSION

by Kathie Snow, www.disabilityisnatural.com

Change. We all want it – and we want it now! We want children and adults with disabilities to have better lives. Because many of us believe that improvements in the system will result in a better quality of life for individuals with disabilities, our advocacy is directed toward legislation, increased funding, more programs and services, and so forth. There's something wrong with this picture, however.

The United States already has more laws, programs, and services than any other nation. Billions of dollars are spent on federal and state programs and services. Even so, the unemployment rate for people with disabilities has remained at 70-75 percent for many, many years. Students with disabilities are still excluded in schools. And community inclusion and living real lives remain unfulfilled promises for most children and adults with disabilities. So while changes in public policy are important, changes in the system cannot guarantee the precious elements of life most needed by individuals with disabilities: inclusion, participation, friendships, and living natural lives as citizens in their communities.

I believe the best way to effect longlasting change in order to achieve our goals is through positive, enthusiastic, creative leadership in our communities. Many may dispute this notion as "pie in the sky" thinking, and I understand the criticism. I, too, once believed that systemic change would provide all the answers. But I have found (as have millions of others) that systemic change doesn't always filter down to *real change* in the personal lives of people with disabilities.

I don't need research to prove this point; you probably can describe your own experiences that illustrate this fact. The

unemployment rate and the high number of children still excluded from regular ed classrooms, despite laws and programs to address these issues, provide stark testimony about millions of others.

In this nation of plenty – plenty of laws, programs, and services – why is inclusion so hard to find? Because, like love, we're looking for it in all the wrong places! We look to the system instead of where inclusion actually takes place: in the community!

When we change the hearts and minds of people in the community, we'll see real change – long-lasting change – that will go beyond what is mandated by laws and policies. Now, before you roll your eyes and say to yourself, "What a Pollyanna!" read on.

If you're a parent, a professional in the field, or a person who acquired a disability, what did you know about people with disabilities before you "entered the field?" The answer, in most cases, is absolutely nothing!

Before the birth of my son, I could have been a Scout leader who said, "Oh no, we don't take kids with disabilities." You could have been a regular ed teacher who refused to include a child with a disability in your classroom or an employer who didn't believe adults with disabilities could be competent employees. Yet today I know better and so do you. Why? Was it laws and policies that changed you? I don't think so. Your heart and mind were changed by your personal experience with disability.

When we provide community leadership and influence with hearts and minds of people in our communities, real lives and inclusion for

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people with disabilities will become a reality. And consider this: as a citizen of my community, I can create change faster and more effectively (insider influence) than any law or program (outsider influence) can. Put yourself in the shoes of someone in your community. Would you respond more willingly to the friendly request of a fellow citizen or to the long arm of a government mandate? This isn't rocket science, folks! It is, instead, common sense.

The first step on the road to community leadership is your *presence and participation*. You've got to be there! No one can know what you need unless they know you! Many of us complain that the community "isn't ready" to include people with disabilities. But this is simply hogwash! People in the community *are* ready and willing, but they can't do a thing until they know what's needed, and how can they know until we tell them?

The second step is to use your existing connections. You probably already have many contacts in the community so star there. If

you're not connected now or if you don't like the connections you have, make new ones, Volunteer, go to community

events, tag along with a friend, or do whatever it takes to meet new people.

The third step involves *reciprocity* – give and take. Community is all about reciprocity. You help others: others help you. If you're out there and people know you by your helpful actions and participation, you'll discover how easy it is to ask for help when you need it. Friends help friends.

The fourth step requires you to *state what you need* for yourself or for the person with a disability in your life. You don't need to beg, nor do you need to get angry and threaten. Both are counterproductive to achieving dignified inclusion and citizenship. Instead, be specific and positive and provide the details about how to accomplish what you need. Don't leave it up to someone else to figure everything out – you're the expert!

The fifth step is being willing to *negotiate*. You may not get everything exactly the way you need or want it. The other person may be unable (not necessarily unwilling) to meet the exact need. Being flexible and working through details to reach a mutually agreeable

arrangement can make the difference between success and failure.

The sixth step – and perhaps the most important – is to expect inclusion. Many of us have had painful experiences, we're angry, and we expect to be excluded. We wear our anger like a badge of honor and enter a new arena ready to fight. Arming ourselves with the law, and before taking the time to educate or negotiate, we assault or ambush the unsuspecting person and turn a potential ally into a true adversary. We shoot ourselves in the foot so often, it's a wonder we have any toes! When we leave our anger behind and enter a new situation with hope and an open mind, wonderful things can occur.

Consider that the experiences you have will impact the lives of other people with disabilities in your community. When a person, business, or organization has successfully included an individual with a disability once, they'll know they can do it again! We can truly blaze new trails that will open new frontiers of

inclusion in our communities. Typical preschools, park and rec activities, churches, employers, and every other entity can be

the beneficiaries of our influence. The sky's the limit!

The most important step

is to expect inclusion!

A recent situation in our family's life illustrates how community leadership can enable people with disabilities to lead real lives. Our 16-year-old daughter, Emily, is enrolled in dance class at the Starr Mountain Performing Arts Studio in our small town in Colorado. When a drama class was added, 15-year-old Benjamin was interested in enrolling, since his goal is to become the first James Bond who uses a power wheelchair!

The folks at Starr Mountain knew me, since I made it a point to be involved in my daughter's dance experience: helping with recitals, talking to the teacher when I had concerns, and so forth. I enrolled Benjamin in the drama class and after paying for the first month's tuition, told the instructor (Jonathan) that because of Benjamin's cerebral palsy, he would need scripts in large print. I added that these should be easy to enlarge on Jonathan's computer, but I volunteered to do it to on our home computer if that would be helpful.

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Jonathan replied he would provide this accommodation.

Each time we took Benj to and from the weekly classes, we casually chatted with Benj and his instructors (Jonathan and Jenn) about how things were going. Through this friendly process, we realized we needed to send a tape recorder with Benj to each class so he could have a record of the lessons (the other students took handwritten notes). Benj and his dad began transcribing the recordings to our home computer, and all the lessons went into Benj's drama notebook.

Soon, we learned the class would have a performance at our city-owned Cultural Center.

A leader is a

dealer in hope.

Napoleon

Since my daughter had performed in ballet recitals in this building, I was familiar with it and realized the stage was not wheelchair accessible.

About eight steps led from the seating area to the stage. Oops!

How would our budding actor perform in a real play in the community if he couldn't get on stage?

After carefully considering several strategies, my husband and I decided on a plan. I called a couple of Eagle Scout troops in our community, told the leaders we might need help building a ramp to the stage, and asked if this sounded like a good Scout project. (You do know that Scouts, Kiwanis, and a wide variety of organizations in your area routinely engage in community projects, right?) One Scout leader said no; the other said yes. This was to be our back-up plan in the event the folks at the Cultural Center said they didn't have the money, time, or resources to ramp the stage. An additional piece of this back-up plan was for me to solicit donated materials from the neighborhood do-it-yourself store.

I called the manager of the Cultural Center and made an appointment for a meeting, simply stating that I wanted to speak with her about using the Cultural Center. I did not say one word about my son or accessibility. The Cultural Center is regularly rented out (for a fee) for various events, so it was easy for the manager to assume I was interested in using the Center for a future event.

My husband, Mark, and I brainstormed how we wanted the meeting to go: what we would say and how we would say it, and we tried to anticipate the manager's objections and what our responses would be. We vowed to keep it positive and to use "compliance with the Americans with Disabilities Act" only as a *last resort*. Furthermore, we decided to take Benj with us so he could participate and learn how to do this form himself in the future, and so the manager could see we were talking about *a real person*.

When the appointed time came, we drove to the Cultural Center with positive attitudes and a picture of success in our minds. The outcome – an accessible stage – was our guiding light. We were determined to not only be successful, but to also develop an ally in

Mary, the Cultural Center manager.

Once we arrived, we introduced ourselves and enthusiastically described our daughter's participation in ballet recitals at the Center and our excitement over Benjamin's upcoming

performance. Then we detailed the purpose of our visit: have the city build a ramp to the stage so Benj could take his place alongside his drama classmates during rehearsals and the performance. Immediately, Mary stated that a ramp wasn't necessary since there was a garage door in the rear of the building that was on the same level as the stage. "Your son can use the garage door," she said.

I explained that it wouldn't be effective or appropriate to expect Benj to get to the stage that way, while his classmates would be able to get to the stage from inside the building. I painted a picture of a rehearsal: instructor on stage with a small group of kids while the others watched from the audience area, then the actors trading places and so forth. How could Benjamin truly participate if he constantly had to go in and out of the building through the garage door in the back?

I added that during rehearsals and for the actual performance, it would be almost impossible to expect Benj to use the garage door numerous times during any one timeperiod, considering the cold and snow on the ground in the middle of a Colorado winter. I politely reiterated that a ramp to the stage from the seating area was the only solution.

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And then I shut up and waited for her reply. (I really can shut my mouth when I need to!)

With a momentary tightness around her eyes and mouth, and after a long pause, Mary answered that a permanent ramp could not be built because some people who rented the Center needed every square foot of space and the ramp would take up a lot of room (and she was right – it would be big!)

My husband jumped in with ideas for a portable ramp. We walked over to the stairs and began discussing different options, specifically a ramp made of piping, similar to the ones used by hotels when they build a temporary stage and ramp during large meetings. I added my hope that a ramp would encourage other people with disabilities to participate in our town.

As we batted around different ideas, the light bulb went off in Mary's head. "You know," she gushed, "if we had a portable ramp, others could use it, too. We've had some groups who wanted to have beauty

pageants here and they needed a runway from the center of the stage out into the audience. If we had a portable ramp system, there are lots of ways we could use it!" I had to resist jumping for joy, but my big smile matched hers.

Mark and I continued our efforts, knowing if you want something done right, you do it yourself! So we asked Mary about the process of actually getting the city to purchase a ramp and she gave us the details. "Tell them I sent you," she added, as we headed over to city hall.

The ramp isn't a reality yet, but it will be. Because of changes in Benj's drama class, the performance has been postponed until the spring, giving us all a little more time to investigate which type of ramp will be best.

Some advocates who wield rights and laws like baseball bars may criticize this method, feeling we shouldn't have to ask or negotiate for access which my son and others with disabilities

are entitled to under the ADA. And yes, angry demands may have gotten the ramp. In the process, however, I might have made enemies would despise me and my family, as well as every person with a disability who came along after us. Is there a time when rattling our sabers is appropriate? Of course. In our family, however, we choose that method only if all other efforts fail.

One day, when my son performs on the accessible stage at our community Cultural Center, his participation will demonstrate that our community is inclusive and that people with disabilities are competent, contributing, participating fellow citizens. And if I look into the future, isn't it highly likely that the contacts made through my son's drama experience will lead to potential employers seeing him as a

competent young man when he's ready for a part-time job as a 16-year-old? The positive outcomes are unlimited.

I'm hopeful and excited about the possible ripple effect this may have on people who attend the

performance. Won't audience members (who represent a wide cross-section of folks in our community) recognize that people with disabilities can be easily included? And how many families of people with disabilities will realize they, too, can take advantage of the wonderful opportunities in our town?

What can you do to provide positive, proactive leadership in your community to ensure people with disabilities enjoy the precious benefits and enriching adventures of citizenship? And what methods will you employ that will ensure success and develop allies at the same time? What attitude, which words, what body language, and what efforts will you bring to the table? Always remember that your actions will impact others with disabilities in your community, for better or for worse. What legacy will you leave?

When I'm getting ready to reason with a man, I spend one-third of my time thinking about myself and what I'm going to say, and two-thirds thinking about him and what he is going to say.

Abraham Lincoln



Funding Resources Available

A Wish Come True, Inc.

A Wish Come True, Inc. is a local nonprofit organization founded in 1982, granting wishes to medically qualified children ages 3 through 18 who have a life-threatening illness and live in Rhode Island and areas of southeastern Massachusetts.

http://www.awish.org/

Phone: 401-781-9199 Email: awish@awishcometrue.org

Catastrophic Illness in Children's Relief Fund

The Catastrophic Illness in Children Relief Fund (CICRF), as payor of last resort, helps families with costs associated with the care of children with special health care needs and disabilities. It provides financial assistance for Massachusetts families with children experiencing a medical condition requiring services that are not covered by a private insurer, federal or state assistance, or any other financial source.

www.mass.gov/cicrf

Consumer Empowerment Funds Program

The Massachusetts Developmental Disabilities Council may reimburse expenses up to \$250 for individuals with developmental disabilities and/or a family member or guardian of an individual with a developmental disability to attend conferences or other events in Massachusetts or another state. *Applications must be received and approved before the event.*

Contact Harold Lieberman

Phone: (617) 770-7676 ext 115 Email: Harold.Lieberman@state.ma.us

Easter Seals-Massachusetts Assistive Technology Loan Program

The Massachusetts Assistive Technology Loan Program, operated by <u>Easter Seals Massachusetts</u>, is an alternative financing project that gives people with disabilities and elder's access to low interest cash loans to purchase assistive devices and services. The program has many options that can help — even for people who don't think they would qualify for a loan.

www.massatloan.org

Phone: 1-800-244-2756 ext. 428 or 431 Email: info@massatloan.org

Edwin Phillips Foundation

The Edwin Phillips foundation provides bi-yearly grants to individuals for prosthetic appliances, wheelchairs, beds or other forms of physical or educational assistance, provided there are no other funds, public or private, available for the needs of such individuals. It is financially based and for individuals in Marshfield, MA and Plymouth County, MA.

http://fdnweb.org/phillips/ Email: grants@epfgrants.org

First Hand Foundation

Provides funding to children with special healthcare needs who are under 18. The funding has to be relevant to the healthcare of this child. The funding would be toward clinical procedures, medicine, therapy, wheelchairs, assistive technology equipment, care devices, hearing aids, lodging, food, gas, parking and transportation (for families of seriously ill children who must travel during treatment) and vehicle modifications.

www.firsthandfoundation.org Phone: (816) 201-1569

Pass It On

They have recycled adaptive equipment. Call for details.

Phone: (508) 477-6966 Email: passitoninc@comcast.net

www.passitonforkids.org

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Fuel Assistance

Massachusetts Low Income Energy Assistance Program

Call LIHEAP Fuel Assistance Phone: 800-632-8175 to ask about your local contact.

Home Modifications Loan Program

The Home Modification Loan Program provides low- and no-interest loans to modify the homes of elders, adults and children with disabilities. Such home modifications allow individuals with disabilities to remain in their homes and live independently in their communities. Any homeowner who has a disability or has a household member who has a disability, or rents to an individual with a disability may apply for this loan.

www.mass.gov/mrc/hmlp

Contact: Susan Gillam at (617)-204-3739 Email: Susan.Gillam@MRC.state.ma.us

Help A Little One Foundation

The mission of the H.A.L.O. Foundation as listed on the website is to enhance the quality of life for children with neurological impairment. H.A.L.O. fulfills requests that enrich or make life easier for children in pediatric nursing homes and supports families who care for their children at home.

http://www.halo.org/

Kaileigh Mulligan Program

This is a program for severely disabled children. The program grants the individual child MassHealth Standard coverage, including assistive technology with no premiums and a Care Coordinator to coordinate benefits and services

Phone: 1-800-408-1253 then ask for Kaileigh-Mulligan intake.

Knights of Columbus - Massachusetts State Council Grant funding

470 Washington St. Suite #6, Norwood MA 02062

Phone: 781-551-0628 Email: State.Office@masskofc.org

getATstuff-AT Exchange in NEw England/ MassMatch

Mass Rehab Commission

Phone: 866 682 9955

http://www.massmatch.org http://www.getatstuff.org

Ralph Braun Foundation

The Ralph Braun Foundation was created for a simple purpose: to assist those with mobility needs. The foundation periodically gives out funding to help with the purchase of accessible equipment.

http://ralphbraunfoundation.org/apply-for-a-grant/

On facebook for updates: http://www.facebook.com/pages/The-Ralph-Braun-Foundation/209800352394493

Make-A-Wish Foundation

Make-A-Wish® Massachusetts and Rhode Island grants wishes for children with life-threatening medical conditions to enrich the human experience with hope, strength, and joy. According to information from the Centers for Disease Control and Prevention, approximately 500 children in Massachusetts and Rhode Island are newly diagnosed with life-threatening medical conditions every year. Our vision is to grant wishes for *every* medically eligible child annually. http://massri.wish.org/

Phone: 617-367-9474 Email: boston@massri.wish.org

<u>ACT Today</u>

Act Today! SOS is a program dedicated to supporting the immediate and imperative needs of those impacted with autism. ACT Today! Grant Programs established in 2005 do provide access to vital and effective treatments for autism through our quarterly grant cycles. **We recognize that some individuals diagnosed with autism who are in immediate personal danger or harm are unable to wait up to 12 weeks for a response to their request**. The ACT Today! SOS Program is <u>designed to provide immediate support for these families</u> based upon need and the program funds available.

http://act-today.org/SOS/

Louis Nisenbaum Memorial Scholarship Fund

The Louis Nisenbaum Memorial Scholarship Fund is available to family members of children/adults with disabilities. The goal of the Scholarship Fund is to grant family members the opportunity to attend conferences in which the central theme is inclusion/living in community. Applicants can submit a request to attend either national or international conferences.

For an application, interested individuals and families should visit www.nemasketgroup.org, click on the Services link and then Family Support; scroll to the bottom and click on Louis Nisenbaum Memorial Scholarship Fund. (Please note there is a limit of two family members who will receive funding to go to a requested conference.)



Lou's passion and commitment for people with disabilities were woven into the fabric of his being. He was fascinated by people and he truly believed we are our brother's keeper. He absolutely loved connecting people, looking for resources and sharing ideas. He also enjoyed challenging all of us to imagine better! The world he wanted to live in, and worked to create, was really all about community. It was about being there for each other. He often said, "Everyone needs someone in their lives to be unreasonable on their behalf." Lou willingly took on that role for so many people as do so many other family members.

Lou considered himself fortunate to work throughout the state, nationally and internationally. He humbly sought ideas and shared ideas always believing that he had so much to learn. He was besotted by the idea of family support and the potential of families to create change. He was instrumental in the development of our system of family support here in Massachusetts. Lou would be delighted to know that through this scholarship fund he will provide other family members the opportunity to "partake of learning" which might enhance the lives of their family members, others living with disability and our fellow community members.

Donations for this Scholarship Fund are gratefully appreciated. Please write the check to The Nemasket Group, 109 Fairhaven Road, Mattapoisett, MA 02739 with *LN Scholarship Fund* on the subject line.

"We all know that community must be the center of our lives because it is only in community that we can be citizens. It is only in community that we can find care. It is only in community that we can hear people singing. And if you listen carefully, you can hear the words: "I care for you."

~John McKnight



TASHCONFERENCE

DECEMBER 13-15

TASH ORG/CONFERENCE 2017

ABOUT THE TASH CONFERENCE

Each year, the TASH Conference brings together a diverse community of stakeholders who gain information, learn about resources, and connect with others across the country to strengthen the disability field. This year's conference theme, "Still We Rise for Equity, Opportunity, and Inclusion," shows the resilience of individuals with disabilities and their families across the lifespan. Conference attendees will celebrate their passion for disability rights, civil rights, and human rights while exploring inclusive communities, schools, and workplaces that support people with disabilities, including those with complex support needs.

TASH ON COMMUNITY LIVING

All people have the right to live in and participate in the community with the supports they need. We believe it is a basic human and civil right for people with disabilities to have full and equal participation in society as called for in the Americans with Disabilities Act and the United National Declaration of Human Rights.

- Children with disabilities belong with families.
- Adults with disabilities have the right to pursue the same range of lifestyles and opportunities as other members of the community.
- And TASH believes public policy should support these rights.

TASH is committed to expanding person-centered, long-term supports and individualized choice for community living for people with intellectual and developmental disabilities.

#2017TASHCONF

Conference Highlights:

- 1 Research Symposium
- 3 Half-Day Wednesday Workshops
- 5 Poster Presentations
- 20+ Breakout Sessions

Hot Topics:

- HCBS Waiver
- · Community Building
- Community Inclusion Tools
- Self-Determination
- Person-Centered Planning
- Communicating with Policy Makers
- Olmstead Decision
- Long-Term Services & Supports
- Independent Living & Home Ownership
- Healthy Relationships & Abuse Prevention