

Family Connections Center

INSIDE THIS ISSUE

- Parent Movie Night.....1

FOOD FOR THOUGHT

- Ask and You Shall Receive.....2-3

AVAILABLE RESOURCES

- Disney Sued Over Disability Access Policy4-5

- The Museum of Science Needs Your Help.....5

- New Medicaid Waiver Rules Set to Take Effect.....6

- Free Movie "Companion" Pass.....6

INFORMATION TO SHARE

- Family Connections Center April Sibshop.....7

- 2nd Annual CARE Conference.....8

- 2014 Conference on School Culture, Climate & Positive Behavior Support.....9

- Save the Date: Transition from School to Adult Life.....10

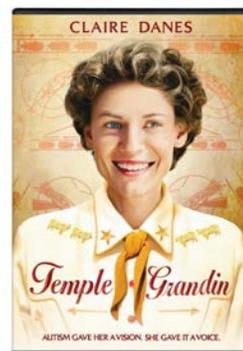
- A Full Life Ahead Workshop Series.....11

- Save the Date: The Nemasket Group 5K Walk/Run.....12



Parent Movie Night

The Family Connections Center invites you to Parent Movie Night!

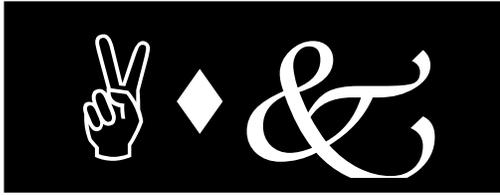


Our feature film:
Temple Grandin

Thursday, May 8th
 Movie begins promptly at 6:00 p.m.
 To be held at The Nemasket Group
 56 Bridge Street
 Fairhaven, MA 02719

If you would like to attend, please rsvp to Jenn at
 508-999-4436 x 115

Food for *Thought*



..... AND YOU
SHALL RECEIVE

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

We all need help. In the best case scenario, we're not afraid to ask for the help we need from family members, neighbors, friends, and even strangers.

Individuals with disabilities may need a little more help throughout their lives. Many are accustomed to receiving help from people in the human service industry. And there's little fear in asking for that type of help since these services are legally-mandated entitlements.

As more children and adults are included in schools, jobs, and community activities, they have more opportunities to interact with "ordinary people" (not just paid providers). And in the best-case scenario, they'll learn to rely on these new friends and acquaintances for help – just the way people without disabilities do. Many, however, may be hesitant or fearful to ask for assistance, or they may not know how to ask for what they need. But this can change!

When my son was very young, he depended primarily on me – his mom – just as most young children do. Because of his disability and his use of a wheelchair, he needed more assistance than other kids. Early on, after absorbing the wisdom of adults with developmental disabilities, I realized I would not always be around. So it was important that Benjamin learn to depend on others, starting at home, of course, with his dad and sister. The rule in our home became: Benj needed to ask for help from whoever was closest to him at that moment. (Isn't that what most people do – grab help from whoever is closest?) So, sometimes big sister, Emily, helped; sometimes it was Dad or Mom.

This rule was transferred and expanded when Benj entered the neighborhood inclusive elementary school. I told my son's teachers, "An adult should

step in and help Benj *only if a child can't do it.*" There was no reason for a teacher or teacher's aide to help Benj if his coat, backpack, and many other things. Kids help each other all the time!

But I realized there's more to successfully assisting someone than meets the eye. It's important that the person who needs assistance knows how to ask for the help he needs – and Benjamin taught me this valuable lesson!

For years, I helped Benj get dressed every morning before school. My husband, Mark, left for work before the kids were up. One Saturday morning, Benjamin (age 8 or 9) decided he wanted Daddy to help him get dressed on the weekends. *Yippee* – I could live with that! But my joy was short-lived as I heard Benjamin screaming and crying and his Dad yelling back! Rushing to the bedroom, I discovered my son angrily venting his frustration because my husband wasn't following the "dressing routine" Benj and I had followed for years.

When I asked Benj why he just didn't tell his Dad how to do it the "right" way, the tears continued to flow as he replied, "I didn't know *how!*" Point taken. Right then and there, we helped Benj figure out how to tell someone the best way to help him.

We've continued this practice over the years, with great results! For years, Benj stayed close to me while shopping at "superstores." As time went by, he started feeling more secure about exploring on his own. I explained how to go up and down the aisles looking for me if he felt he was lost. Imagine my surprise when a voice over the store intercom announced, "Would Kathie Snow please come to register six?" Benj couldn't find me, but he figured out how to ask for help!

...continued on page 3

One of our shopping routines was to grab sodas out of the refrigerated case by the check-out stand to drink on the way home. Emily and Benj routinely begged for Mountain Dew, but I restricted them to a non-caffeine soda. By this time, Benj was 12 or 13, and he roamed the video department while his sister browsed in clothes and I shopped for food. During one of these adventures, I told my kids to meet me at 5:00 PM by the check-out stands. At the appointed time, Emily showed up, but there was no sign of Benj. I was prepared to page him, then he wheeled up, face aglow. "Guess what?" I drank a Mountain Dew," he proudly announced. Shocked, I asked him if he got it out of the refrigerated case by himself. He nodded yes. "How did you get it open," I asked (Benj can't unscrew bottle tops). "Well, I found a really nice lady to open it for me," he said, with an even bigger smile.

I looked for the bottle in his wheelchair basket, but found none. "What did you do with the bottle," I asked. "Well, I found another nice lady to throw it away for me" he replied – beaming – and then added, "Are you proud of me?" How could I resist? I said I was very proud of him for finding the help he needed, but reminded him that he had not paid for the soda before he drank it, and that he had essentially stolen it! Fear washed over his face until I said I would pay for the soda and he could pay me back.

If we hope children and adults with disabilities will be interdependent and included in ordinary activities in our communities, they need to be able to seek help from anyone: a classmate, a coworker, store clerk, neighbor, or even a stranger. In addition, they need to know how to ask for the help they need. And, again, they may need assistance in learning how to ask.

It's common for those who are closest to a person with a disability (family members, service providers, etc.) to "know" what the person needs by a look, a phrase or sound, or even by the circumstances. And sometimes, the person with the disability doesn't even need to ask for help – again, if we feel we "know" what the person needs, we just do it. But this may not be helpful in the long run since the person doesn't learn how to ask for help.

So one way to really help is to stop helping so much! In other words, don't automatically "do" for

the person; wait and/or encourage him to ask for help. This will, in the long run, be one of the most important skills a person will acquire: the ability to speak up for himself!

For specific situations (shopping, in school, at work, etc.), we can talk things over with the person and suggest ideas, role play, and/or encourage the person to just do it, knowing that practice makes perfect. I wasn't with Benjamin when he asked those two nice ladies to open his soda and then dispose of the evidence! I have no idea how he asked for the help he needed, but it worked – and it's something we never specifically practiced. I assume the "asking for help" experiences Benj had at home and in school prepared him for the Sneaking-the-Mountain-Dew episode!

Many parents and professionals worry, worry,

worry about what will happen to a person with a disability when she's "in the community." They worry how the person will survive, if others will take advantage of her, and more. In fact, many children and adults with disabilities are prevented from participating in ordinary activities in inclusive settings because of these worries. If, however, the person learns to ask for what she needs and to speak for herself (using whatever form of communication is most effective),

we need not worry.

The world is full of good people – people just like you and me – who stand ready to help. When we're sharing space with nameless strangers, we may not feel we're surrounded by potential sources of assistance. But when we ask for what we need, and when we're specific, a nameless stranger can become a friendly acquaintance in the blink of an eye.

And consider how society's perception of people with disabilities might change. Many who only see my son wheeling through a store may have negative, even pitiful, perceptions of him. But I feel sure the two ladies who helped him that day with his Mountain Dew came away with a positive perspective of him and, perhaps, of others with disabilities. And his good manners – he's great with "please" and "thank you" – surely impressed them! The same can be true for others.

Ask and you shall receive. And in many cases, you may receive even more than you asked for!

**The race of mankind
would perish did they
cease to aid each other.
We cannot exist without
mutual help. All
therefore that need aid
have a right to ask it
from their fellow man;
and no one who has the
power of granting can
refuse it without guilt.**

Sir Walter Scott

Available *Resources*

Disney Sued Over Disability Access Policy



By Michelle Diament April 8, 2014

The mothers of 16 kids and young adults with developmental disabilities are suing Disney alleging that the company is failing to accommodate their children who cannot tolerate long wait times for theme-park rides like “It’s a Small World.”

Disney is facing allegations of discrimination, with a lawsuit charging that modifications to the company’s policy for accommodating people with disabilities at its theme parks violate the Americans with Disabilities Act.

The lawsuit filed last week by mothers of 16 kids and young adults with developmental disabilities from across the nation accuses Walt Disney Parks and Resorts of failing to accommodate their children’s special needs and of actively dissuading their presence at the company’s theme parks.

The move comes after Disney made sweeping changes to its policy for accommodating park visitors with disabilities last fall. For years, Disney had offered individuals with special needs a pass that often allowed them and their guests to skip to the front of long lines for park attractions.

Now, however, visitors to Walt Disney World and Disneyland can obtain a Disability Access Service Card which allows them to schedule a return time for rides based on current wait times. The system prevents those with disabilities from having to wait in line, but only allows visitors to schedule one attraction at a time.

Disney said the changes — which took effect in October — came after its existing system was “abused and exploited.” In their suit, however, the families allege that there was no abuse, but rather that the company wished to “cleanse its parks of what Disney views as the anti-Magic of such persons’ stimming, tics and meltdowns.”

The 180-page complaint filed in the U.S. District Court for the Central District of California details long waits and unhelpful interactions with employees at Disney parks. Moreover, the suit alleges that Disney won’t discuss accommodations with families until they have invested significant sums of money to arrive at a park.

...continued from page 4

In the suit, a mother known as M.B. alleges that she waited in line for an hour and a half to receive a Disability Access Card for her 6-year-old with autism who is referred to in court documents as A.B. Even though she offered park officials medical documentation about her child's inability to tolerate waits, the mother says she was given no choice but to schedule a return time at "It's a Small World" which A.B. wanted to ride repeatedly. After riding twice, A.B. faced another hour-and-fifteen-minute wait and entered a "full-fledged meltdown," the lawsuit alleges.

In a separate case, the suit indicates that a mother known as L.C. tried to take her 7-year-old with autism, referred to as J.C., to Disney World several times since the new policy took effect. L.C. said her child has had multiple meltdowns after learning of wait times to ride "Peter Pan" and "Winnie the Pooh," with J.C. falling to the ground or jumping up and down with arms spinning around. As a result, L.C. is no longer taking her child to Disney parks and does not plan to renew the family's annual passes.

"Until recently, parents of developmentally disabled children universally adored Disney, because of the way Disney caringly accommodated their children," said attorney Andy Dogali who is representing the families. "No reasonable mind could ever conclude, after investigating these facts and spending extensive time with these families, anything other than Disney willingly abandoned them."

The lawsuit also alleges that Disney has a secret offering known as the "Magic List" whereby the company extends to select individuals five passes to gain immediate access to rides without even obtaining a Disability Access Card.

The families are seeking damages and are looking to compel Disney to alter its policies and practices.

In a statement to Disability Scoop, Walt Disney Parks and Resorts stood by their existing policies.

"Disney Parks have an unwavering commitment to providing an inclusive and accessible environment for all our guests. We fully comply with all ADA requirements and believe that the legal claims are without merit," the company said.

The Museum of Science Needs your Help!

The Museum of Science, Boston is committed to the inclusion of people with disabilities and strives to create an environment that is inviting, engaging, and accessible for everyone. To work toward achieving this goal, there are times throughout the year when the Museum seeks people with a variety of abilities and disabilities to help improve the accessibility of our Museum. Hearing from people with disabilities expands our knowledge about the museum experience and informs how we design museum offerings, such as exhibits and programs, in the future.

We are now seeking visitors with a range of disabilities (including, but not limited to, sensory, physical, and cognitive disabilities) who would like to be contacted to test new exhibit prototypes and explore the museum. Interested participants will come to the Museum of Science to interact with exhibit prototypes or explore other existing museum experiences. Testing could last anywhere between 30 and 90 minutes and will always include free admission to the Museum of Science exhibit halls for the day and free parking in the Museum's garage.

If you would like to help the Museum of Science become more accessible by providing feedback during an upcoming testing session, please contact Stephanie Iacovelli, a Research and Evaluation Assistant, at 617-589-4438.

Information to *Share*



Sibshops are workshops that provide opportunity for brothers and sisters of children with medical and developmental needs to obtain peer support and education within a highly recreational context. Organizers and families appreciate that the workshops take a wellness approach and the siblings who attend them appreciate that they are fun and engaging. Siblings are often the family member to have the longest relationship with the brother/sister with special needs and although they are not therapy, Sibshops prove to be therapeutic for some children.

Our Sibshop program now has two different age ranges. On the days listed below, we have a young sib group from 4:30-6:00 for 6-9 year olds and a group from 6:00-7:30 for our 10-14 year old sibs.



Monday, April 28th

Young Sibs meet from 4:30-6:00pm
Sibs Ages 10-14 meet 6:00-7:30pm

Sibshops are held at the Nemasket Group
56 Bridge Street
Fairhaven, MA 02719
**entrance through Front Door **

For more information and to sign up
Contact: 508-999-4436
Kathleen Amaral x133 –or- Jennifer Newcomer x118

Space is Limited

Registration is Required



Are you a family caregiver for a loved one with special needs, a chronic illness, or a disability?

Friday, May 9, 2014

2nd Annual **CARE** Conference

Connecting and Advocating Respite for Everyone

TIME: 8:00am to 3:00pm
WHERE: Best Western Royal Plaza Hotel
181 Boston Post Rd W
Marlborough, MA 01752
THEME: 3 R's of Respite – Refresh~Reflect~Recharge

The MLRC is excited to offer this **FREE** conference for any family caregiver in Massachusetts. Keeping with this year's theme, 3 R's of RESPITE, workshop offerings will include both experiential topics like yoga and expressive art as well as informational topics like estate planning and advocacy.

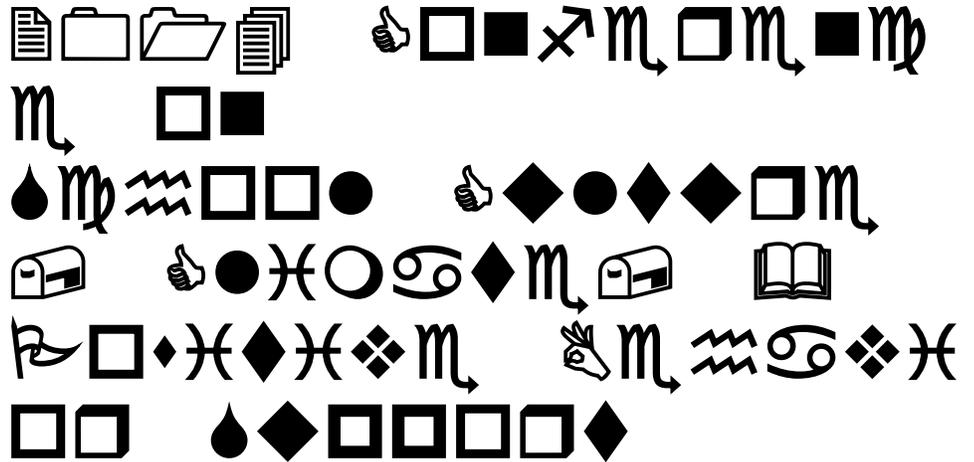
We are fortunate to have Lon Kieffer, nationally known as DOC, Defender of Caregivers, as the keynote speaker.

Some financial assistance to cover respite expenses while you attend the conference is available. Request an application when you register!

Registration now open!

VISIT – www.massrespite.org

Email Questions to conference@massrespite.org



Conference Overview

The 2014 Conference on School Culture, Climate, and Positive Behavior Support will take place on August 20-21, 2014 at the SERESC Event & Conference Center in Bedford, NH.

Schools and communities continue to face obstacles to addressing behavior, climate, safety, and academic achievement. Establishing a safe school environment using a multi-tiered system of support is related to improved outcomes for all students.

This year's conference theme is **What Works: Effective Strategies within Multi-Tiered Systems of Support** and will include presentations by national leaders, New Hampshire educators, youth, and community partners with opportunities for teams to work together, and instruction on cutting-edge strategies for school improvement.

Join other educators, administrators, parents, youth, community members, and service providers and learn to work on making our schools and communities safe while supporting the social, emotional, and behavioral health of all children and youth.

Keynote Presenters:

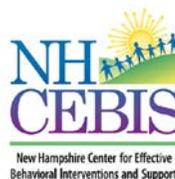
George Sugai, Ph.D., Professor and Carole J. Neag Endowed Chair, Neag School of Education at the University of Connecticut

Hank Bohanon, Ph.D., Director, Center for School Evaluation, Intervention and Training (CSEIT)

This conference is a collaboration between the UNH Institute on Disability, the New Hampshire Center for Effective Behavioral Interventions and Supports (NH CEBIS) at SERESC, Strafford Learning Center, the New Hampshire Department of Education, and Youth M.O.V.E. New Hampshire.

Sign up to be among the first notified of new conference details and when registration opens.

Event Partners





SUPPORT  **brokers**
helping people thrive in their community

SAVE THE DATE

TRANSITION FROM SCHOOL TO ADULT LIFE

A statewide all-day conference for families

SATURDAY, SEPTEMBER 20, 2014

*The Hogan Campus Center
College of the Holy Cross
1 College Street
Worcester, MA*

A statewide all-day conference for families, introducing state-of-the-art, best practices around Transition, covering topics focused upon creating seamless, successful transitions into the adult world. Workshops will cover education in the school system, employment, post-secondary education, community involvement, self-determination, independent living skills, financial and legal considerations, eligibility for services and many others.

In the coming months, we will be announcing conference details including information about workshops and speakers.

Funded by The Arc of the United States and the Walmart Foundation



217 South Street, Waltham, MA 02453-2710 T: 781.891.6270 F: 781-891.6271

Achieve with us.

www.arcmass.org

the
nemasket
group



Massachusetts Families
Organizing For Change

A network in support of
individuals with disabilities
and their families



A Full Life Ahead ~ Workshop Series

Massachusetts Families Organizing for Change (MFOFC) in partnership with Building Futures and the Family Connections Center of the Nemasket Group is sponsoring “A Full Life Ahead” ~ a series of monthly workshops for parents and guardians of young adults with a disability. The series focuses on transition, employment, housing, friendships and other topics that will lead to interdependent, full lives in the community for young people with disabilities.

Please join us... Wednesday, April 30, 2014

6 – 8 PM

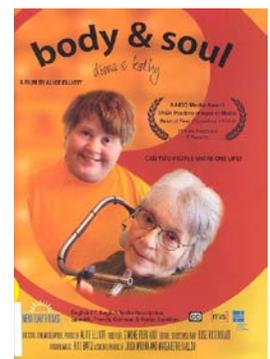
**The Nemasket Group
56 Bridge Street
Fairhaven, MA 02719**

Advocates in Action

“Through their experiences... listening to people with disabilities”

Join us for a viewing of the film:

The 2007 documentary film ***Body & Soul: Diana & Kathy*** chronicles the lives of a tireless and dynamic pair of lobbyists and activists in the disability movement.



Following the film, **Deanne Gagne** will deliver an inspirational speech entitled, **“Services Survivor, What it’s Like to Receive Services”** Deanne is the Coordinator of Advocates in Action RI – Leadership Series.



the nemasket group

NON PROFIT
ORGANIZATION
US POSTAGE PAID
NEW BEDFORD, MA
PERMIT NO. 651

Family Connections Center

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



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



THE NEMASKET GROUP 5K WALK/RUN

~~SATURDAY, MAY 17, 2014~~
AT THE NEMASKET GROUP
56 BRIDGE ST., FAIRHAVEN, MA

REGISTRATION 8:00 AM
TIMED RUN STARTS AT 9:15 AM
WALK STARTS AT 9:20 AM

FOR MORE INFORMATION CONTACT: WalkRun@NemasketGroup.org