

FAMILY CONNECTIONS

The Nemasket Group



Issue # 38

May—June 2007

NEWSLETTER

Governor's Budget, House Budget, Senate Budget!!!

Cut, Restore, Cut, Restore... Wait A Minute!

So...here we are...the spring of 2007. Or is it 2006? Wait a minute – I've been here before! It's the annual spring budget dance that families and people with disabilities MUST attend or the dance goes on without us.

Every spring – for longer than I'd like to admit – I watch the budget process. Every year, the same questions are asked. What will the budget look like for people with disabilities and their families? Will there be cuts? What is the best way to advocate? How can we plead our case most effectively?

This year I'd like to ask different questions. Why does this happen every year? Why are cuts made to services for people who can't live without them? Does the administration or the legislature think that massive numbers of children and adults with disabilities shed their disabilities over the past year and no longer need services? Why are people with disabilities and families made to BEG every spring for vital services?

We are not sure where we will be in the budget process when this issue is delivered to you. We know, however, that the need for you to communicate with your legislator does not end with the current year's budget process.

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Governor's Budget, House Budget, Senate Budget!!! (Continued from pg. 1)

Is FAMILY SUPPORT important to you? Do you value the support you get from the staff of Family Connections? Do the flexible funds you receive make a difference to your family?

Most legislators and those in the state's administration do not understand the value of FAMILY SUPPORT – it is not something you can see like the results of someone living in a home or having a job. Only those who receive it can really describe it – or what it can be like to not receive family support while raising a child with a disability.

How about funds for students with disabilities who are “Turning 22”? If you have a child from age 16 to 22, this is important to you! Does your legislator know how important this type of funding is to your family and your child? Do legislators know that without this funding, young people with disabilities have little chance to have a decent quality of life as adults?

What about vocational or day services for your family member? One of the proposals stemming from budget cuts in the Governor's budget is that those receiving vocational/day services be cut from those services one day a week – HELLO! Tell me – does that make a lot of sense?

And what if you and your child look forward to the day when he or she might like to have their own place to live – to have a life in the community that is typical for adults away from his or her family? Does your legislator understand how important this is? Have you spoken to your legislator about this?

There are still institutions open in Massachusetts (unlike our surrounding New England states that have closed theirs) and there is talk that institutions could again be a model of service for people with disabilities – is this what you dream of for your family member? Have you told your legislator how you feel about the use of institutions? If serving people with disabilities and their families becomes financially burdensome in our state, what will prevent the renewed use of institutions as a way to support the people we love who have disabilities?

There is an American Proverb that says, “If you don't have a plan for yourself, you'll be a part of someone else's.” Consider that ~ the budget process has a tremendous impact on your family's life and the life of your family member who has a disability ~ you can be part of that process or you can leave the planning to those who will not understand your life and the needs of your child. So...the decision is yours.

Below is a listing of all the local legislators for the Greater New Bedford area. PLEASE – get to know them. Have them meet your family – help them to understand what your hopes and dreams are for your family member who has a disability – help them to see that decisions they make about the budget for disability services have a huge impact on real people – just like YOU!

“If you think you're too small to make a difference, you've obviously never been in bed with a mosquito.” Michelle Walker

Governor's Budget, House Budget, Senate Budget!!! (Continued from pg. 2)

Action needed NOW -- please ask your state senator to vote in support of budget amendments benefiting people with disabilities. Family Support services are just as important and meaningful as the other services! Remember though, it is your on-going relationship with your local legislators that can make a huge difference – their experience in learning about YOUR family will inform them as they make decisions at budget time!

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Senator Joan Menard

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Representative Antonio F.D. Cabral

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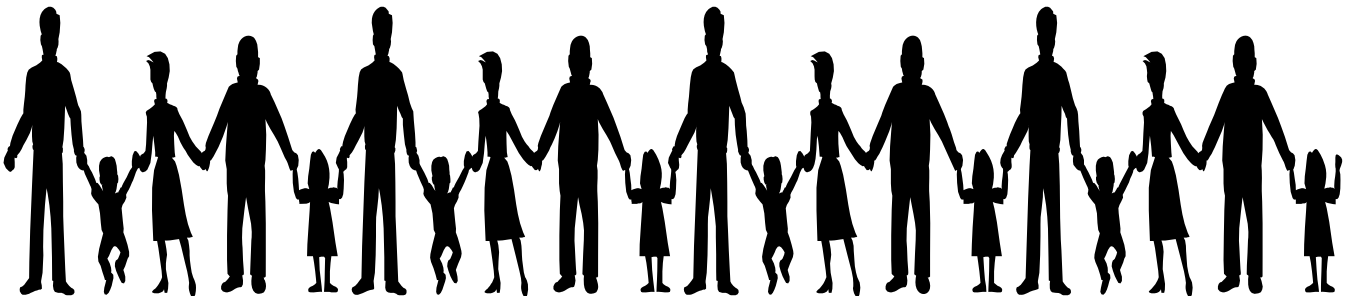
Rep.AntonioCabral@hou.state.ma.us

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Great Expectations

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

Have you heard this tale about a school teacher? On the last day of school, a weary, worn-out teacher entered the principal's office for one last visit before the summer vacation. "Please," the teacher begged, "give me better students next year—I can't handle another year like this past one!" Three months passed, and on the first day of the new school year, the teacher eye-balled her class roster with growing excitement. She read, "Susan Jones-135, Lolo Brown-140, Maria Lopez-144..." and so on. "Geniuses" she thought, "I have a class of geniuses!" That school year was wonderful—for the teacher and her students!

On the last day of school, the teacher came across the class roster in the bottom of a drawer. It was wrinkled and torn in a few places, but she gazed at it fondly. At the end of the day, she stopped by the principal's office. "Thank you for the *best year ever*," she gushed, waving the class roster like a flag. "This made all the difference—my class of geniuses!" Puzzled, the principal took a quick look at the paper and said, "I don't know what you're talking about—these numbers were their locker assignments!"

Learning that she had mistakenly assumed the numbers were her students' IQ scores didn't change a thing: the teacher *still* had the best year ever! At the beginning of that school year, she believed the best about her students, had high expectations for them, and was excited! In turn, her students lived up to—and even exceeded—her expectations. None actually had a "genius IQ," but in *her mind* they did, *and that's what mattered!* Her *attitude*—not the students' actual academic abilities—made the difference! The teacher learned a great lesson. Can we learn from this, too?

The "Low Expectation Syndrome" (LES) attached to people with disabilities—whether they're toddlers or middle-agers—can be a greater barrier to success than the person's actual disability diagnosis. The double-whammy many parents receive (from physicians, educators, service providers, etc.) essentially goes something like this: "Your child has (fill-in-the-blank), so don't expect much." While the medical diagnosis of autism, Down syndrome, cerebral palsy, or other condition may be an accurate fact, the LES verdict is only someone's *opinion—about as valid as a fortune-teller's vision in a crystal ball!*

Nevertheless, the LES descriptor usually sticks to the person like a powerful glue: parents may believe it, along with educators, service providers, therapists, and others throughout the person's life. The outcome? Children and adults with disabilities are often denied the ordinary experiences which could lead to their success. When the low-expectations-mentality prevails, the self-fulfilling prophecy is fulfilled: people with disabilities—like those *without* disabilities—will most likely live up (or down) to our expectations.

Before going further, let's tackle one of the barriers to expecting more: the "false hopes" issue. On a regular basis, parents are told not to get their hopes up, so they won't be disappointed later. In turn, parents may pooh-pooh their children's hopes and dreams in order to protect *them* from disappointment. What we're really talking about is the *fear* of disappointment. First, we can't *know*

Great Expectations (Continued from pg. 4)

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

we'll experience disappointment, so why do we waste even one moment worrying about something that may not happen? Second, on a daily basis, we experience actual disappointment: the bathroom scale seems stuck, a pay raise doesn't come through, a loved one dies, and much, much more. Have any of these actual disappointments made our lives unlivable? No, we survive, and in many cases, disappointment leads to enlightenment, wisdom, and maturity, and can even spur us on to greater things! Real disappointment is often a blessing in disguise.

What is life without hope? A living death. And isn't all hope essentially "false," since no one can predict the future? Calling something "false hope" simply represents a difference in opinion and perspective. A pessimist sees false hope; an optimist sees possibilities.

In addition, some will say, "But this person will never [fill-in-the-blank]," and *they're right!* Joe probably won't ever get a job and Mary Ann may never go to college, not because they have disabilities, *but because we don't believe it can happen!* Conversely, when we believe it can happen, we start doing the things to make it happen—and the hope becomes reality! We generally operate from the perspective of, "I'll believe it when I see it." But we need to reverse this to, "I'll see it when I believe it." The belief has to come first, followed by action.

So what if we made the choice (*and it is a choice*) to have great expectations for children and adults with disabilities? What if we chose to be *excited and passionate about possibilities?*

We must first go beyond expectations related to the disability. Traditionally, we've looked at what a person with a disability cannot do, and then write goals to address the "problem." This, we think, is the right approach: try to make a child walk, talk, behave, write her name, tie her shoes, or whatever! For adults, focus on meal preparation, bedmaking, etc. We don't seem to be able to think bigger until these goals have been achieved! But some people may never walk, tie their shoes, or achieve other functional skills. How dare we hold them hostage to the "able-bodied standard," limit their opportunities, and prevent them from living the lives of their dreams?

When my son, Benjamin, was diagnosed with cerebral palsy at the age of four months, the doctor delivered his low-expectation: "Take him home and do the best you can..." We rejected that nonsense, electing to have the same expectations for our son as for our daughter: that he be successful in school, have friends, go to college and/or enter the workforce. Luckily, we had learned (from adults with disabilities) that walking, holding a pencil, and other "normal" skills were *not* prerequisites to Benjamin being successful! So we stayed true to our greater expectations instead of the puny functional skills favored by many professionals! We also provided Benjamin with a power wheelchair, laptop computer, voice recognition software, and other tools, accommodations, and supports he needed. Today, he's a successful college student. High expectations paid off, and *our belief in Benjamin enabled him to believe in himself!*

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Great Expectations (Continued from pg. 5)

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

The same is true for Dylan, an 18-year-old with Down syndrome. He just started reading last year, but he's always been included in general ed classrooms, where he's learned "his way." He's leaving high school with the other seniors, will have a summer job (paid), and will attend college in the fall (auditing many classes). Again, the high expectations of his parents paid off. There's never been any question that Dylan would go to college, following in the footsteps of his older brother and sister.

What's more important? Writing your name with a pencil or learning how to use a computer so you can be successful at school and on the job? Spending your childhood in therapy to learn to walk (or talk) or using a power wheelchair (or communication device) so you can "be" the age you are, learn and grow, and get on with your life? Learning to follow a recipe book or figuring out how to throw something together in the kitchen the way most of us do? Put your thinking cap on and consider other scenarios—there's a ton of traditional low expectations and paltry goals that need to be examined and permanently discarded!

We can reject the Low Expectation Syndrome, and choose to be like the teacher and "believe the best." It's time to get excited and passionate—it's time for great expectations!

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2007 Family Leadership Series

Several people from the Greater New Bedford area were in attendance at the 16th SE Mass Family Leadership Series. Pictured to the right in front of the State House in Boston are (left to right), Sandy Kinney, Deb Cornish, Anna Tolentino, Jesenia Barahona, Trina Bigham, Gloria Villalobo and Natina Smith. Sandy, Trina, Gloria and Natina provided support to families at the Series ~ Deb, Anna and Jesenia were participants in this year's Series along with 25 other family members from throughout the Southeast region of Massachusetts.



The Series began in October and ended in April – family members of children/adults with developmental disabilities met for a total of 8 days in 4, two-day Sessions. Session I of the Series focused on initiative and leadership. Family members were given information on leadership, its relevance to the life of families and the implications of using leadership to effect positive change in one's life. Session II of the Series focused on creative, progressive and innovative ways to support our

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Family Leadership Series 2007 (Continued from pg. 6)

family members and our families to have quality lives. A number of presenters offered their perspectives on a broad range of topics: Inclusion in Schools, Community Involvement, Supported Employment and Family Support. Session III of the Series focused on creating a vision for the future of our children and family members; families received a graphic depiction of their vision.

The focus was also on the advocacy necessary to ensure that vision and how to effectively advocate on behalf of our families and family members. Finally, the focus of Session IV of the Series was on policymaking at the local, state and federal level. Families also learned a variety of strategies to decrease stress in their lives and to better care for themselves.

A comment from one of the family member's who attended this year's Series, "The Family Leadership Series was so meaningful...the connections, the friendships, knowing we are not alone, and more, that we are a much larger group than we knew. The Series was a big investment of time but we gained back tenfold!"

Watch this newsletter for notice of the next Family Leadership Series due to begin in October, 2007!

The Assistive Technology Exchange

The Assistive Technology Exchange in Massachusetts is designed to facilitate simple, easy transactions between Massachusetts residents who can benefit from assistive technology devices and those who have assistive technology devices that are no longer needed. It is not for vendors or distributors to buy equipment, although vendor participation through donations of equipment or posting equipment for loans is welcomed.

To post an item or to look at items available go to www.getATstuff.org. You can also look at items available from the other neighboring states.

The goal of the Assistive Technology Exchange in New England is to put AT equipment that is not currently being used into the hands of someone who can benefit from it.

The Assistive Technology Exchange in New England is primarily for New Englanders, although we do accept entries from neighboring states. The program is designed to facilitate equipment exchange between individuals and is not for vendors or distributors to buy and sell equipment. Vendor participation through donations of equipment is welcomed.

Once on the website, use the buttons to navigate the Assistive Technology Exchange in New England. You may browse our listings anonymously (without having an account or being logged in), however to view contact information and/or post your own items you must be a registered user and be logged in.

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The Assistive Technology Exchange (Continued from pg. 7)

Categories of devices listed on the Assistive Technology Exchange in New England are:

- Vision
- Hearing
- Speech Communication
- Learning, Cognitive, Developmental
- Mobility, Seating & Positioning
- Daily Living
- Environmental Adaptations
- Transportation and Vehicle Modifications
- Computers and Computer-related
- Recreation, Sports, and Leisure
- Other

Futures Planning, Trusts and Legal Alternatives

Presenter: Attorney Theresa Varnet, MSW, JD

Theresa Varnet has been an advocate for persons with disabilities for over 30 years. In addition to being a certified teacher, licensed social worker, and graduate of DePaul University College of law, she is the parent of a daughter with a disability. Her experience includes providing training to families, special educators, and other professionals. She specializes in legal and financial planning for people with disabilities.

This workshop (full day and 1/2 day) will address the unique needs that families have in planning the financial and legal future of their relative with a disability. It will include:

- Explanation of government benefits
- Estate planning options
- Guardianship and less intrusive alternatives
- Negotiating the social security maze (SSI/SSDI, DAC benefits)

Cost: (full day) \$35 per person, \$20 for Arc members.

Cost: (1/2 day) \$25 per person, \$15 for Arc members.

(Cost includes continental breakfast and bag lunch)

(Scholarships available – contact your local Arc office)

Register and pay on-line: www.arcmass.org/trainingeducation.html or

Mail or fax form to: The Arc of Massachusetts 217 South Street, Waltham, MA 02453

For further information, contact: Beth Rutledge PH 781 891-6270 x101 Fax: 781 891-6271

Email: arcmass@arcmass.org

June 16, 2007 Plymouth Library, 132 South Street, Plymouth, MA 10:30a.m. – 3:00p.m.

Host: The Arc of Gr. Plymouth (508) 732-9292 **Contact:** Michelle Jean

Asperger's Syndrome & ADHD: The Education Challenge

A Conference at GORDON COLLEGE - Wenham, MA - June 29 & 30

A Special 2-Day Event - Featuring Internationally-known Author and Educator:



RICK LAVOIE

JUNE 29-30 2007

Sponsored by GORDON COLLEGE and SUMMIT ACADEMY SCHOOLS

Residential Packages Available - includes food & lodging on campus Friday & Saturday

REGISTER NOW - space is limited.

We are very excited to be bringing you a special education event that's designed to offer valuable information for teachers, school administrators, parents, counselors and other professionals who work with special-needs students. Our 2-day event - The Education Challenge: Asperger's Syndrome & ADHD, will focus on offering the tools, techniques and inspiration that will enable you to help these children find success in the classroom and at home as well.

Featured Speaker: Rick Lavoie, Author of IT'S SO MUCH WORK TO BE YOUR FRIEND, and creator of HOW DIFFICULT CAN THIS BE? THE F.A.T. CITY WORKSHOP video, he has been featured on ABC NEWS, THE CBS MORNING PROGRAM, GOOD MORNING AMERICA and PBS. An administrator of residential programs for children with special needs since 1972, Mr. Lavoie's presentations on Friday and Saturday will focus on helping children with learning disabilities find social success, as well as effective classroom techniques for reaching these students.

ADDITIONAL SPEAKERS INCLUDE:

Janet S. Arndt, Ed.D, assistant professor of Education at Gordon and a former classroom teacher, counselor and principal, will present on "Social Competence: The Forgotten Component of School Success." Her session will discuss the social issues that interfere with learning, and review strategies that will help students develop a positive outcome for learning.

Joseph J. Bove, director of Therapeutic Martial Arts and Outdoor Experiential Education at Summit Academy Schools, will outline successful therapeutic activity programs for students with ADHD and Asperger's. The program he currently manages has been integrated into the curriculum at Summit Academy Schools, where it is currently used to help over 1,700 students.

The conference will offer unique insights into related special education issues, as well as a number of information and product exhibits. Gordon College is a leading higher educational institution in programming that offers on-going professional support and development to teachers of children with disabilities.

Asperger's Syndrome & ADHD: The Education Challenge

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LOCATION: GORDON COLLEGE CAMPUS - JUNE 29 & 30, 2007

255 Grapevine Road Werham, MA 01984 CEU / PDP CREDITS AVAILABLE.

TUITION: FULL (RESIDENTIAL) FRIDAY & SATURDAY RATE: \$300

for full conference package; including on-campus accommodations Friday and Saturday night, lunch & dinner on Friday, breakfast/lunch/dinner on Saturday, and breakfast on Sunday.

COMMUTER RATE: \$90 for FRIDAY \$140 for SATURDAY \$230 for BOTH DAYS

Includes conference attendance plus lunch and dinner.

REGISTER BY PHONE: (978) 867-4575

M-F 9AM - 3PM EST. Please have credit card information available

REGISTER BY FAX: 1-330-670-8280 with credit card payment

For CEU - PDP Credit information: Call Dr. Gerald Horak (330) 670-8470 x 6509

MORE CONFERENCE INFORMATION AT: www.summitacademies.com/conference

QUESTIONS? Contact conference coordinator, Karla Pingeton at (978) 867-4575 or via e-mail at: karla.pingeton@gordon.edu

the
nemasket
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Family Connections

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Creating a network of family support

For individuals with developmental

Disabilities and their families