THE NEMASKET GROUP

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INSIDE THIS ISSUE

Already-depleted DDS Family Support & Respite Program faces New Cut of \$10 million in FY13 budget.....1-2

FOOD FOR THOUGHT

•	Everyone Needs to be
	Needed

Fatherhood Without Fear.....4

INFORMATION TO SHARE

- 2012 Gunnar Dybwad Leadership Award......5
- Massachusetts Alliance for 21st Century Disability Policy......6
- TSA Helpline for Travelers with Disabilties......8

Free Attractions......7

U.S. Department of Education Issues Resource Document that Discourages Restraint and Seclusion.....8

AVAILABLE RESOURCES

- Austism Spectrum Support Group......9
- 101 Creative Uses for the Ipad Camera to Support Individuals with Disabilities.....10
- Save the Date: 2012 Summer Sizzler.....11
- Save the Date: 11th Annual Charity Golf Tournament......11
- Save the Date: Lose the Training Wheels Conference....12
- Building a Home Conference....13
- Save the Date: 21st Annual Holiday Bazaar.....14

Already-depleted DDS Family Support & Respite Program Faces New Cut of \$10 Million in FY13 budget

Family Support & Respite programs are effective and cost-efficient. This program, administered by the Department of Developmental Services, give the families of individuals with intellectual disabilities are access to respite services, adaptive equipment, and medical supplies.



This past January, the Commonwealth issued a report based on data from 1300 Massachusetts families, outlining the overwhelming need and outstanding success for this program.

Fiscally-speaking, DDS Family Support & Respite is an effective and efficient program that allows families to avoid costly residential placements for their loved one.

Family support is 75% to 80% less expensive than out-ofhome placement, and is the service that can have the greatest impact on reducing more expensive residential demand.

... continued on page 2

Family Connections Staff

Sandy Kinney. Program Director / Associate Executive Director

Jorge Pagan, Family Advisor

Jennifer Newcomer, Family Advisor

Sherry Amaral-Lopez, Family Advisor

Kathleen Amaral, Family Advisor

Emily M. Nisenbaum,

Sr. Associate Executive Director

Dustin Green. **Executive Director** ...continued from front page

- Families readily take on their role as caregivers, and require comparatively small amounts of support to help them continue.
- These modest funding amounts support the enormous unpaid contribution of caregivers and supplement the long term care service system in Massachusetts.

If this Line Item is cut \$10m (as proposed in the Senate budget), then 4200 families will lose this vital service. If, due to this cut, 4200 individuals with disabilities had to be placed in a residential program during the next fiscal year, the cost would be astronomical.

Preserving funding for DDS Family Support & Respite makes financial sense for Massachusetts.

Contact the Budget Conference Committee via email; go to addp.org and click Take Action

<u>Take Action ASAP</u> to ask the Conference Committee to support key budget priorities at DDS and MassHealth:

- **DDS Family Support and Respite** (line item 5920-3000) Accept House's position at \$51,004,298. Since 2009 over 11,000 people with disabilities and their families have lost in home supports and therapies. House number supports over 4,000 families. Senate budget cuts line by \$5 Million.
- Mass Health Day Habilitation (line item 4000-0700) Accept House's position preserving the six hour service day, not cutting \$15 million (\$7.5 million of which are federal funds). This cut will hurt families and group living situations which must figure out how to cover one hour per day.
- Salary Reserve (line item 1599-6901) Accept Senate's position at \$20 Million, which will
 provide the first annualized raise in years for direct support professionals earning under
 \$40,000.
- **DDS Transportation** (line item 5911-2000) Accept House's position, restoring \$3 million allowing people with disabilities to go to work and not have to quit their jobs or stay at home increasing residential costs of group homes.

The members of the Budget Conference Committee are:

- Sen. Stephen Brewer, Chairman, Ways
 & Means Committee
- Rep. Vinny deMacedo, Ranking Republican Member
- Rep. Brian Dempsey, Chairman, Ways
 & Means Committee
- Sen. Jennifer Flanagan, Vice Chair, Ways & Means Committee
- Sen. Michael Knapik, Ranking Republican Member
- Rep. Stephen Kulik, Vice Chair





Everyone Needs To Be Needed

Revolutionary Common Sense

By Kathie Snow

We are all born helpers. Think of young children who try their hardest to help Daddy in the yard, or want to push the vacuum cleaner with their tiny hands. As we grow, we help with chores around the house. And at different points during our adolescence, we may decide we're not too keen on helping, but we usually do it anyway. As adults, we come full circle: we help because it feels good, because we believe in a cause or an organization, or because someone tells us they need our help. We *need* to care about others; to feel responsible for something or someone outside of ourselves. It feels good to be needed; *we need to be needed* – all of us.

Volunteering at church, being a youth leader, cleaning up a park, and a variety of other helping activities create that wonderful feeling of being needed. Helping also shifts our focus to others – we put our own dilemmas aside for awhile. In giving to others, we give ourselves a gift.

Sadly, we have exempted many children and adults with disabilities from both the responsibilities and joys of helping. We may feel they're unable to help. But this simply is not true!

When my son was in kindergarten, he used a manual wheelchair that he could push only for short distances. However, this didn't cause any real problems since his classmates were more than willing to help. In fact, they fought over who would have the *privilege of pushing!*

One day, Benj came home and said, "Mommy, I wish someone else in my class used a

be the only one who was "different." But to be sure, I asked him what he meant. He replied, "Cause I would like to help someone, too!" He knew his friends helped him because he used a wheelchair. He saw how important his friends felt when they helped – and how much fun they had, too. Benj wanted to feel needed and important, and have fun helping, too. He thought if there was another student who used a wheelchair that he could help that child! From then on, we made sure to find ways Benj could help others. Because he had used a computer from a very young age, he

wheelchair." I thought he meant he didn't want to

was able to help his peers who didn't know much about computers. When people with disabilities are *expected* to help others, they will – like the rest of us – rise to the occasion. They'll feel needed, valuable, and important, just as other helpers do. But the benefits don't stop there.

When we see what people with disabilities can do to help others, we'll see abilities and strengths we didn't see before. We'll learn how competent people with disabilities really are. And when a person with a disabilitity volunteers in the community, connections are formed and friendships are made, both of which can lead to employment, independent living, inclusion, and real lives.

We can no longer afford to deny people the pleasures and responsibilities of helping. Everyone has something to contribute. *Someone* needs the assistance of the child or adult with a disability in *your* life; create the opportunity and then share in the joy!

Nothing makes one feel so strong as a call for help.

George McDonald

Fatherhood Withhout Far

What child doesn't adore being with dad? Fathers, grandfathers, uncles, or other male role models are so important in a child's life. They provide what moms and other females can't – an intangible, sometimes mystical, influence that profoundly impacts a child's daily experiences and shapes her life.

For some men, however, raising a child with a disability is not only an unknown experience, but it can also be confusing and/or frightening. It can be especially unsettling for first-time fathers. Because mothers typically handle doctor's

visits, therapy sessions, and working with professionals, dads may feel powerless and/or "clueless" about a child's condition. In turn, this unawareness may cause a man to be uncomfortable with his child. But it doesn't have to be

this way. Fatherhood without fear can and should rule the day!

First, dads (or other father figures) can take the big leap and become more involved in dealing with professionals (educators, therapists, medical personnel, and others). Accompany your wife and child to as many appointments and meetings as possible. No matter how competent your wife may appear to be, she needs you! We moms may seem to have everything under control most of the time, but underneath the surface, we want and need your strength, companionship, wisdom, and common sense.

Second interact with your child as if he or she does not have a disability. When a child has a physical disability and/or

significant medical needs, dads are sometimes afraid to play with a child (or feel they don't know how) in the same way they play with children who do not have disabilities. As a result, a child with a disability may not receive the magical gift that's part and parcel of a father's attention.

What does it mean to interact with a child as if he/she doesn't have a disability? In your family, my husband, Mark, and our son, Benjamin (who has cerebral palsy and uses a power wheelchair), regularly "wresled" on the bed when Benj was

younger. They both took their glasses off and prepared for battle! Mark "pinned" Benj and then rolled off the bed when Benj "pushed" him off. Then Mark put Benj on top of him so Benj could "pin" his dad. These were priceless moments for both

of them, and allowed the two guys to engage in some all-important "male bonding" experiences.

Some children appear to be fragile or they may be unable to move their bodies the same ways other kids do. Even so, this doesn't erase their wants or needs to rough-house, be ticked, roll around in the grass, ride on Dad's shoulders, go fishing, help Dad with his chores, and do the same things all kids enjoy doing. Children with disabilities need these interactions just as much (and sometimes more) as children without disabilities. So figure out how to provide accommodations or assistance so your child can benefit from all the wonderful things only you – Dad – can bestow on your child.

Play with your child as if she does not have a disability!



2012 Gunnar Dybwad Leadership Award Recipient Louis Nisenbaum

Louis Nisenbaum, the Nemasket Group's Executive Director for 27 years, received this year's Gunnar Dybwad Leadership Award posthumously; the award is presented annually to an individual who has made a significant impact on enhancing the lives of individuals with disabilities in the Commonwealth.



Lou lived his life committed to enhancing the lives of individuals with intellectual disabilities. For over forty years he was a leader in a cultural movement that changed the lives of thousands of people. From his early experiences as a young man, Lou saw the need to empower people with disabilities rather than simply provide care. His personal values drove him to bring new ideas and a commitment to change to the status quo. He studied disability services in Denmark in a tour arranged by Gunnar and Rosemary Dybwad with whom he had connected at Brandeis University. There he witnessed what could be done for people in a society that valued people with disabilities and also very much valued those who provided support to them.

He went on to establish a new community residence in Attleboro, one of the very first that was run by a private non-profit corporation. He later became an innovator in the independent living movement by guiding people to establish their own accessible apartments and to exercise self determination in the organization of their supports. Lou also was a co-founder of The Coalition for Community Living, a self advocacy organization that began in Southeastern Mass. In this activity, he worked closely with Gunnar Dybwad to network with other such groups across the state with the goal of establishing a statewide organization. These early efforts helped lead to the eventual creation of MASS-Massachusetts Advocates Standing Strong.

All of those experiences propelled Lou to create a service design for a new agency; one that would have community integration as its core and one which would seek constant improvement through the use of self examination and external evaluation. Lou's idea for the Nemasket Group was about creating a community of caring. This inclusive community would empower people to act in new ways. Lou's personal knowledge of the members of that community assisted them in their path of individual development. His courage and personal example inspired support staff to exert every measure to assist individuals to enjoy full participation in their community. As the success of his efforts grew over the course of twenty-seven years, there was change in the culture of the community as well. Employers and neighbors saw not labels but individuals who sought the opportunities and challenges common to all. Individuals and families saw not limitations but possibilities.

Lou was born in Maine and always cherished his roots there. Lou knew that in the Maine woods you needed someone to mark a trail so that others who would follow would know where to go and not get lost. And if the trail was well marked, those that followed it over the years would have confidence in it. They would know that even if their travels may be difficult at times, if they followed the marked trail, they would get to where they wanted to go. In his life and in his work, Lou left a well marked trail for those left behind to continue his legacy.

Massachusetts Alliance for 21st Century Disability Policy (MA21)

This is the first in a Series providing information on a statewide coalition working on disability policy.

The mission of the Massachusetts Alliance for 21st Century Disability Policy (MA21) is to advance full community participation for individuals with intellectual and developmental disabilities.

INTRODUCTION to the work of the MA 21 Coalition:

"Disability is Natural" is more than just a saying. It is a guide to how we -people with disabilities and our families - would like to interact with the world and how we would like the world to interact with us. Though what we are asking is simple – to have the same opportunities as anyone else - we realize the sea-change this represents from our long and often troubled history in this country. We are individuals, first and foremost, with our own individual cultures, tastes, emotions, wants, needs, and opinions. We deserve the same access to education, medical care, social activities, employment opportunities, and transportation options as anyone. While we may rely on our families and/or communities to help us, it is everyone's primary responsibility when making decisions on our behalf to ascertain our personal wishes and abide by them. This is how anyone would expect to be treated. We recognize the huge task before us. From the moment a disability is diagnosed, society treats us and our families differently. This is true not only of laypeople, but even of many of the best-trained professionals and those with experience treating and interacting with people with disabilities. People with disabilities have rarely been treated as equals, as highlighted by our exclusion from America's historic civil rights struggle. Despite this history, we acknowledge the great advances that have been made and are optimistic that the future can and will be brighter still. We repeat: Disability is Natural. We have no doubt society will one day appreciate this, but we intend to make it happen sooner rather than later.

Next in the Series: Guiding Principles and System Barriers

Collaborating Partners include:

The Arc of Massachusetts 217 South Street Waltham, MA 02453 781-891-6270 www.arcmass.org

Massachusetts Families Organizing for Change (MFOFC) P.O. Box 61 Raynham, MA 02768 508-814-6946 www.mfofc.org

Massachusetts Advocates Standing Strong (MASS) P.O. Box 6025 North Plymouth, MA 02362 1-866-426-2253 (Ma. toll free) www.massadvocatesstandingstrong.org Massachusetts Developmental Disabilities Council (MDDC) 1150 Hancock Street Third Floor, Suite 300 Quincy, MA 02169 617-770-7676 www.mass.gov/mddc

Massachusetts Down Syndrome Congress (MDSC) P.O. Box 866 Melrose, MA 02176 800-664-MDSC (6372) www.mdsc.org

FREE!



Check out the FREE attractions every Friday throughout Massachusetts June 29 through August 31.

Great opportunity to visit the following places in Massachusetts this summer:

Tanglewood

Isabella Stewart Gardner Museum

Peabody Essex Museum

Heritage Museums & Gardens

Museum of African American History

Boston Children's Museum

Stone Zoo

Cape Cod Museum of Art

Wenham Museum

Sterling and Francine Clark Art Institute

Franklin Park Zoo

Children's Museum at Holyoke

Danforth Museum of Art

deCordova Sculpture Park and Museum

Reagle Music Theatre

Buttonwood Park Zoo

Mass Audubon Visual Arts Center

Hancock Shaker Village

Pilgrim Monument and Provincetown

Museum

Higgins Armory Museum

Commonwealth Shakespeare Company

Children's Museum in Easton

Springfield Museums

N.E. Historic Genealogical Society

New Repertory Theatre

Museum of Fine Arts Boston

Norman Rockwell Museum

Amelia Park Children's Museum

Fuller Craft Museum

Arnold Arboretum

Battleship Cove

Berkshire Museum

Cape Cod Children's Museum

Fruitlands Museum

The Sports Museum

Institute of Contemporary Art

Edward Gorev House

New Bedford Whaling Museum

Garden in the Woods

Concord Museum

Boston Harbor Island Alliance

USS Constitution Museum

American Textile History Museum

Old Sturbridge Village

Basketball Hall of Fame

JFK Library & Museum

Plimoth Plantation

The Discovery Museums

MASS MoCA

EcoTarium

Get your 2012 Free Fun Fridays Calendar at:

http://www.highlandstreet.org/special-programs/free-fun-fridays.html



TSA Helpline for Travelers with Disabilities

1-855-787-

2227

The Transportation Security Administration (TSA) announced the launch of TSA Cares today, a new helpline number designed to assist travelers with disabilities and medical conditions, prior to getting to the airport. Travelers may call TSA Cares toll free at 1-855-787 2227 prior to traveling with questions about screening policies, procedures and what to expect at the security checkpoint.

"TSA Cares provides passengers with disabilities and medical needs another resource to use before they fly, so they know what to expect when going through the screening process," said TSA Administrator John Pistole. "This additional level of personal communication helps ensure that even those who do not travel often are aware of our screening policies before they arrive at the airport."

Since its inception, TSA has provided information to all travelers through its TSA Contact Center and Customer Service Managers in airports nationwide. TSA Cares will serve as an additional, dedicated resource for passengers with disabilities, medical conditions or other circumstances or their loved ones who want to prepare for the screening process prior to flying.

When a passenger with a disability or medical condition calls TSA Cares, a representative will provide assistance, either with information about screening that is relevant to the passenger's specific disability or medical condition, or the passenger may be referred to disability experts at TSA. TSA recommends that passengers call approximately 72 hours ahead of travel so that TSA Cares has the opportunity to coordinate checkpoint support with a TSA Customer Service Manager located at the airport when necessary.

Every person and item must be screened before entering the secure area of an airport and the manner in which the screening is conducted will depend on the passenger's abilities and any specific equipment brought to the security checkpoint.

All travelers may ask to speak to a TSA supervisor if questions about screening procedures arise while at the security checkpoint. The hours of operation for the TSA Cares helpline are Monday through Friday 9 a.m. – 9 p.m. EST, excluding federal holidays. After hours, travelers can find information about traveling with disabilities and medical needs on TSA's website.

All travelers can contact TSA using Talk To TSA, a web-based tool that allows passengers to reach out to an airport Customer Service Manager directly, and the TSA Contact Center, <u>1 866-289-9673</u> and <u>TSA-ContactCenter@dhs.gov</u>, where travelers can ask questions, provide suggestions and file complaints. Travelers who are deaf or hard of hearing can use a relay service to contact TSA Cares or can e-mail <u>TSA-ContactCenter@dhs.gov</u>

U.S. Department of Education Issues Resource Document that Discourages Restraint and Seclusion

The U.S. Department of Education issued a publication that outlines principles for educators, parents and other stakeholders to consider when developing or refining policies and procedures to support positive behavioral interventions and avoid the use of restraint and seclusion.

The goal of this resource document is to help ensure that schools are safe and healthy environments where all students can learn, develop and participate in instructional programs that promote high levels of academic achievement. The document also provides a synopsis of ongoing efforts by federal agencies to address national concerns about using restraint and seclusion in schools, and includes links to state restraint and seclusion policies and procedures.

Available Resources

Autism Spectrum Support Group

The next meeting will be on:



Date: June 18th, 2012

Time: 9:30 - 11:30 a.m.

Location:

The Nemasket Group 56 Bridge Street Fairhaven, MA 02719



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Light refreshments will be served.



If you will be attending, RSVP with Sherry Lopez by Friday, June 15th, 2012 at 508-999-4436 Ext. 207

♠ 71%

ad 후 9:03 PM

Lights, Camera, Action!

101 Creative Uses for the iPad Camera to Support Individuals with Disabilities

July 23, 2012

9:00 am - 3:00 pm

Institute on Disability @ University of New Hampshire
Grappone Conference Center
70 Constitution Avenue
Concord, New Hampshire

Description:

The iPad camera provides incredible opportunities for individuals with disabilities to fully participate in all life activities. This workshop will demonstrate over 100 apps that use photos, videos, and scanned images captured with the iPad camera to support individuals who experience vision, hearing, communication, intellectual, and neurobehavioral impairments. Participants will learn how to use the camera to:

- Capture, scan, edit, organize, and share photos and videos
- Magnify images
- Create instructional materials
- Promote skill acquisition
- · Encourage creative play
- Make a video presenter
- And much more!

Participants will also learn how the iPad camera can be adapted to enable full access.

For more information and to register: http://iod.unh.edu/Home.aspx

The Nemasket Group's

2012 Summer Sizzler



DATE: August 16, 2012

(rain or shine)

TIME: 4:00 - 7:00 pm

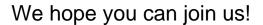
LOCATION: The Nemasket Group

56 Bridge Street, Fairhaven, MA 02719

Come celebrate summer with the staff and families of The Nemasket Group and the Family Connections Center. Join us for a cook-out and lots of fun!



Food and drinks will be provided by The Nemasket Group. Families are asked to bring dessert and lawn chairs.





Please Save This Date

Monday, August 27, 2012



The Nemasket Group

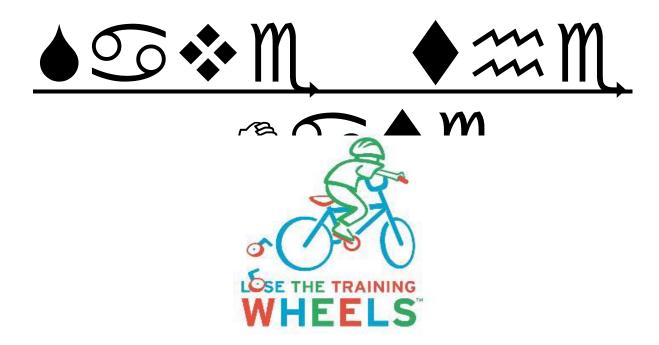
11th Annual Charity Golf Tournament

Allendale Country Club

North Dartmouth, MA

Players of All Levels Welcome

Interested in becoming a Sponsor or donating a Raffle or Auction Item?
Please call 508-999-4436 x 122 or E-mail Golf@nemasketgroup.org



The Scituate CORSE Foundation (Community of Resources for Special Education) is pleased to be hosting Lose the Training Wheels ™ the week of August 20th – 24th. The mission of the Lose the Training Wheels Camp is to instruct up to 40 children with disabilities, ages 8 –22 to ride conventional bicycles without training wheels who would otherwise be relegated to staying on training wheels, standing by, or riding cumbersome special purpose bikes & tricycles. The program is a one week bicycle training experience designed to provide an environment conducive to learning to ride a bike. The camp will provide specialized equipment as well as coaching & encouragement. The camp will be run by the highly qualified staff of Lose the Training Wheels.

Monday August 20th- Friday August 24th 2012 WHEN:

WHERE: Gates Intermediate School, Scituate MA

TIMES: 8:30AM to 9:45AM

> 12:30 PM to 1:45 PM 2:00 PM to 3:15 PM 3:30 PM to 4:45 PM

10:00AM-11:15AM FILLED

REGISTRATION: www.corsefoundation.org

FEE: \$150

EMAIL: scituatelttw@gmail.com



Building a Home Conference

Saturday ~ September 29, 2012

8 AM - 5 PM

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

A full day of motivation, showing families how to BUILD A HOME and LIFE for their loved ones with disabilities giving them interdependent *full lives* in their community. This conference will give you an opportunity to network and meet individuals who are making it work.

Welcome ♦ Susan Nadworny, MFOFC Chairperson

Remarks

Commissioner Flin Howe

Keynote ♦ Gail Fanjoy "Housing as part of an overall Good Life"

Ms. Fanjoy is the Executive Director of KFI, A community-based provider agency in Millinocket, Maine



Partial list of Workshops:

- *Person-Centered Planning, You have to know what you want *Family Panels: How they made it happen *Housing Authority, Section 8's *Creating a budget and a financial life plan *Partnering with the Department of Developmental Services (DDS) *Top 10 tips for parents to help their sons and daughters to live inspiring lives *Staffing and roommates *Autism housing survey results *Accessing services; knowing where the doors are *Housing 101- learn about a variety of creative living arrangements *Maximizing the entitlement of school * Benefits, Friendships and More
- ♦ RESOURCE FAIR and A LEGISLATIVE CALL TO ACTION! ♦

Sponsored by Massachusetts Families Organizing for Change (MFOFC) in appreciation to the Niel M Wreidt 2003 Revocable Trust, Donald N. Freedman, Trustee.

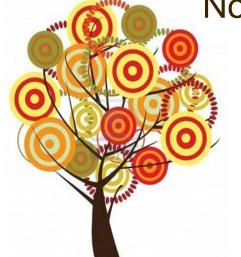
Co-sponsored by the Massachusetts Developmental Disabilities Council (MDDC) in collaboration with Arcmass, Arc of Greater Haverhill and Newburyport, EMARC, and the DDS Statewide Advisory Council (SAC).

save the date

The Nemasket Group's 21st Annual

HOLIday Bazaar

November 17th, 2012



Our Holiday Bazaar, located at 56 Bridge Street in Fairhaven, features some of the finest artisans in Southeastern MA, delicious food available for breakfast & lunch, 100+ Item Chinese Auction, Silent Auctions, 50/50 Raffle & large ticket Raffle Baskets at the Nemasket Table.

Email HolidayBazaar@NemasketGroup.org for more info Visit us at www.NemasketGroup.org

nemasket group

NON PROFIT ORGANIZATION US POSTAGE PAID FAIRHAVEN, MA PERMIT NO. 51

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		
	15	