

# Family Connections

THE NEMASKET GROUP

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JANUARY - FEBRUARY 2011

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## FY'12 GOVERNOR'S HOUSE ONE BUDGET RELEASED IN JANUARY

FROM ARCMASS.ORG

Now the budget debate heads to the legislature. We face a tough session with many cuts affecting public safety, local aid and human services. With 47 new legislators there is much educational work ahead. As the budget now stands, hundreds to thousands of people are at risk of losing family support services, day and community living services this year.

The Governor did announce positive news for special education in his budget announcement: funding for the Special Education Circuit Breaker is \$213 million, an increase of \$80 million over fiscal year 2011. The account had been reduced and offset with federal emergency funds at the start of the recession.

Much of the DDS' line items have been level funded and Community Residential Services have received modest increases to serve individuals who transitioned last year from Community First and Turning 22.

DDS reductions include:

- Family support by 32% or \$14 Million (M)
- Day/employment services funded except for those who turned 22 last year - \$2.7 M cut or a little over 2% of that line item

....continued on page 2

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DDS reductions include:

- 2012 Residential funding for individuals leaving nursing homes is missing (\$7.75 M)
- Turning 22 has \$5 Million for 2012—we appreciate the appropriation but with 708 students identified for 2012, at least \$10 M. is needed for year 1 and \$19.9 M needed for this year's students for a full year (annualization)

The DDS budget (despite the cuts) is higher than last year to accommodate union bargaining agreements, Community First and Turning 22 programs:

- Community First includes individuals leaving state institutions and nursing homes – these services means costs are reduced in other line items (either state school account or MassHealth skilled nursing facilities)
- Turning 22 students graduate from special education programs across the state but are NOT guaranteed assistance as adults. There is no transfer of dollars from local cities or towns or Dept. of Education so the state needs to allocate new monies

To address these additional costs, decision makers have cut into other essential services. As was reported earlier this month, we face a similar dilemma in relation to MassHealth cuts. Utilization of our state's health insurance program continues to grow along with health care costs in general; this has resulted in the need for cost savings in many areas including long term care services. Even though the MassHealth cuts are not as deep as proposed two years ago, we are concerned about the two cuts below and their impact too on services.

- Day habilitation by near 4%
- Adult foster care by over 6%

Early Intervention which provides services to infants and toddlers received a cut of over 25%. Cut by \$8 million the account totals \$21.5 Million and it's the lowest funding in that account in the past 10 years.

One ray of hope---continued rebound of the state's economy; the legislature could have more dollars at its disposal than the governor had. If that's so, the education of legislators is essential so decision makers will understand the impact of the cuts. **It is critically important that you begin speaking with your legislators NOW about the importance of DDS services for your family.**

These service cuts affect different people in a variety of ways; keep these points in mind:

- More than ten thousand individuals have already lost some or all essential services (\$25 million was cut 18 months ago)
- These services – community living, day programs, family supports – are central to people's lives and past cuts have already pushed families to the brink.

The projected cuts will further dismantle the Safety Net for tens of thousands people with disabilities statewide.



## Massachusetts Families Organizing for Change

A statewide, grassroots coalition dedicated to individual and family support

### SE MASSACHUSETTS FAMILY LEADERSHIP SERIES

The **Family Leadership Series** focuses on supporting families and individuals to live in their communities as naturally and typically as desired. Applications from families with children or adult family members **of any age with any disability** are encouraged

The **Family Leadership Series** has a two fold purpose. The first is to offer information about “best practices” for people with disabilities. The second is to assist families in creating a vision for their family member and a process to achieve the vision by incorporating that information. The annual **SE Family Leadership Series** begins each fall and ends in April; it is comprised of four, two day sessions spread over the six month period. Participants are required to attend all four sessions.

#### The Series focuses on:

**Initiative and Leadership** – family members are given information on the background of the family support movement, leadership, advocacy and the significance of self-advocacy, how to effectively advocate for change and ways to influence funding and delivery systems.

**Creating A Vision** – a number of presenters offer their perspectives on a broad range of topics: Inclusion in schools; supported employment; positive practices; community living and family support. Families are supported to “imagine better” and to create a vision, with and for their family members, that guides their leadership and advocacy.

**Policy Making at the Local, State and Federal Level** – family members receive information on how to develop networks with professionals and families, how to access and control resources that affect family stress and satisfaction and how to use legislative change to procure resources.

Food and overnight lodging for each family is paid for by the Department of Developmental Services and other state agencies, organizations and businesses. Respite/child care/nursing for family members is also funded.

Families who have completed the Series have had a tremendous impact on systems change for families and individuals with disabilities in Massachusetts. Family members have been active in policy and decision making locally, regionally and statewide and some have decided to do legislative advocacy work. Some families have been involved in community organizing and advocacy on a local level. Others have used their talents and skills to create change for their child with a disability and/or their families.

#### For more information, contact:

Dianne Huggon  
800-406-3632  
[mfofc@comcast.net](mailto:mfofc@comcast.net)



**“The Leadership Series not only educated me, it made me think differently. It was great to leave with our visions – I am convinced that there will be better future!” FLS Graduate**



# Food for *Thought*

## ALTERED PARENTING

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

During a presentation, I shared the experiences common to many parents (myself included) after a child is diagnosed with a disability: a prognosis is delivered, therapies and interventions are prescribed, and the lives of the child and the family are radically transformed. But, I emphasized, the day after the diagnosis, the child is no different that he/she was the day before: *the child didn't change*. Who changed? The parents. We change our dreams, the way we see our child, the way we treat our child, primarily because of the negative information provided to us by physicians and/or other professionals.

A woman in the audience--who happened to be a pediatric nurse--piped up with, "Yep, that's Altered Parenting!" I hadn't heard this terminology before, and she explained that she saw Altered Parenting in most parents whose children were diagnosed with life-threatening illnesses. Often, the changes in the parents were immediate and visible to her--a stranger. She encouraged parents to *not* go down this path, but her advice had little impact.

I could see how this might happen to parents whose children had *life-threatening* illnesses. But why a similar experience for parents of children with developmental disabilities, whose conditions are usually *not* life-threatening? Perhaps because many parents experience what *feels* like death--the death of the *dream* of a "normal" child. And what does Altered Parenting lead to? An Altered Life for the child with a disability, as well as for other members of the family.

There are probably as many examples of Altered Parenting as there are parents. In general, it can include odd-and potentially harmful-behavior and a loss of common sense. One example is the usual practice of enrolling a child who is not yet talking in a segregated special ed preschool where other children are also not talking. If we want the child to learn to talk, he should be with other children who talk! Yet

children need, and we follow that advice, even though it makes no sense.

We may become so focused on trying to "fix" our children through therapies and interventions that we forget the really important things in life, like ensuring our children are always included so they'll have friends and enjoy ordinary childhood experiences; learn to be responsible; receive a good education so they can become successful as adults; have whatever assistive technology devises, accommodations, and supports they need to do all of the above; and more.

Many parents haven't heeded the lessons of adults with disabilities (and common sense), about the unintended negative consequences of years of pediatric therapies (that send "you're not okay" messages) and the harmful outcomes of segregation in schools, recreation, and other places (that send "you're not okay" and "you don't belong" messages). We may have low expectations for our children with disabilities, and we do things to them that we would never do to our children who do not have disabilities.

In addition, our actions on behalf of the child with the disability have a powerful impact on our other children and the family, as whole. The sanctity of the home, *for everyone*, can be compromised by home-based interventions/therapies. Brothers and sisters may have to play second fiddle to the child with a disability, and this can foster a host of negative outcomes. One parent may relinquish the spousal role, as he /she assumes the "caregiver" role of the child with a disability. When the marriage takes a backseat, the family is in jeopardy.

We may also become financially dependent on "the system" (embracing the Entitlement Mentality), and emotionally dependent on professionals, believing we're not competent to raise our children without "experts" assuming some of our parental

**A child can never be better than what his parents think of him.**

-Marcelene Cox

responsibility. Albert Einstein's definition of insanity comes to mind: "Doing the same things over and over again, and expecting a different result." Today, we're doing many of the same things (interventions, therapies, special services, etc.) that parents of children with disabilities who came before us did, with the same dismal outcomes! Children with disabilities continue to be segregated, live unnatural lives, receive a substandard education and more. These experiences contribute to the estimated 75-90 percent unemployment rate of adults with disabilities. This is probably *not* the dream of most parents *or their children*.

In short, our lives can become warped, and many think it's because of the child with a disability, and all the "stuff" that accompanies a disability diagnosis. But, again, it wasn't the child who changed; it was the parents. And no one is holding a gun to our heads to make us do all the things we do! Granted we don't have the power to make everything perfect. Educators, for example, may stand in the way of an inclusive education for our children.

The bottom line: *our children are our responsibility*. Professionals may carve up our children into "pieces:" physical, occupational, and speech therapists, etc. concentrate on different body parts; early intervention targets birth-to-3, special ed preschool focuses on ages 3-to-5; and so on. As parents, we must be the ones who see the *whole child, across the lifespan*. Others focus on our children's "problems," we must focus on our precious and unique children, who have strengths and abilities, and who deserve a most wonderful childhood, just like their brothers and sisters. Let's end Altered Parenting and take back our lives!

Let's value and follow the natural wisdom of our parental instincts; *we know when something doesn't feel right!* We can stop listening to "helpful" professionals who don't believe in our children's potential. (With friends like that, who needs enemies?)

We can focus on what's really important: the child living a Real Life, included in all aspects of society, *just the way he or she is*. We need to stop trying to change our children through interventions, therapies, etc. We can use therapists as

consultants, as necessary; they can help us learn how to incorporate beneficial activities into our children's lives in the most natural ways possible, in ordinary, inclusive environments. When my son, Benjamin, was younger, karate lessons promoted better range of motion in his arms than occupational therapy!

We can recognize the value of assistive technology and accommodations, and provide those for our children. A child does not need to walk, talk, etc. to live a wonderful life, but she may need a power wheelchair, a communication device, etc. Let's provide our children with whatever they need to be successful, such as a computer for writing and/or learning, instead of holding them back because they "can't write" or "can't read at grade level," and so forth.

Let's treat our children like they don't have disabilities, such as expecting them to be responsible and giving them opportunities to do so, and ensuring they participate in age-appropriate activities (doing chores, getting an allowance, making friends, and doing the same kinds of things as their brothers/sisters). Let's not allow our children's diagnoses to run their lives.

Let's restore the hopes and dreams we had for our children before the diagnosis, and do whatever it takes to turn dreams into reality. If we don't dream out-loud for our children, how will they learn to dream for themselves?

We can ask: "Am I parenting my child with a disability in a significantly different way than my other children? Am I making decisions that are having a negative impact on my child and my family?"

We have the best of intentions, but our parental common sense and belief in our own competence can be eroded by professional interference. Many "experts" may come in and out of our children's lives (if we let them), but we must be *the constant*, and do whatever it takes to ensure our children live the wonderful lives they deserve. Altered Parenting leads to Altered Childhoods. If we want our children to live Real Lives, they need Real Parenting. And no, it's not always easy, but our children are worth it, and they're counting on us.

**Love means that the adult be genuinely concerned with the evolution of the true nature of the child. Children are not able to respond to a love which tries to fashion them according to the concept of an adult, no matter how good the latter's intention may be.**  
-Dr. Gotthard Booth



# Available *Resources*

## 16th Annual ASD Symposium

When: Thursday, March 10 & Friday, March 11, 2011

Where: Rhodes on the Pawtuxet, Cranston, RI

A fundraiser for our annual parent retreat

Co-hosted by Barry Prizant, Ph.D., CCC-SLP, Childhood Communication Services & Barbara Domingue, M.Ed, Community Autism Resources, Inc.

### THURSDAY, MARCH 10

Spend the day with Jed Baker, Ph.D.

*No More Meltdowns: Handling Challenging Behaviors & Teaching Social Skills*

Jed Baker, Ph.D. is the director of the Social Skills Training Project, a private organization serving individuals with autism and social communication problems. He is the author of Social Skills Training for Children and Adolescents with Aspergers Syndrome and Social Communication Problems; Preparing for Life: The Complete Handbook for the Transition to Adulthood for Those with Autism and Aspergers Syndrome; The Social Skills Picture Book; The Social Skills Picture Book for High School and Beyond; and No More Meltdowns: Positive Strategies for Managing and Preventing Out-of-Control Behavior. His work has also been featured on ABC World News, Nightline, the CBS Early Show, and the Discovery Health Channel.

### FRIDAY, MARCH 11

**Spend the morning with Carol Gray**

*Gray's Guide to Bullying for Children with ASD: The Real World*

Carol Gray, The Gray Center for Social Learning and Understanding and Consultant to Children and Adults with Autism Spectrum Disorders and other Social Communication Challenges. She is a consultant, speaker, and author serving people with autism spectrum disorders (ASD) and those who work on their behalf. She is best known for developing Social Stories™ and her groundbreaking work on bullying, loss and learning, and the habits of effective educators. Carol is the recipient of the Barbara Lipinski award for her international contributions to the education and welfare of children with ASD.

**Spend the afternoon with Ros Blackburn**

*Logically Illogical : Information and Insight into Autism*

Back by popular demand, Ros Blackburn is an adult with autism who lives in England. She is an engaging and insightful speaker who gives talks to parents and professionals throughout the UK.

Visit [www.community-autism-resources.com](http://www.community-autism-resources.com) to register or call Kelly @ 508-965-5705

The symposium includes lunch and complimentary parking!!!



# TRANSITION

EMPOWERING EDUCATORS, PARENTS,  
STUDENTS AND THE COMMUNITY

**WHERE: Taunton Holiday Inn**  
700 Myles Standish Blvd  
Taunton, MA 02780

**WHEN: Thursday, March 10, 2011**  
6:30--8:30 PM  
(Light refreshment provided)

## **This workshop will address:**

- Individual Education Plan (IEP) and Mass. Transition Planning Form (TPF) for students 14 to 22 years of age.
- Individualized planning of education and supports
- Self-determination and self-advocacy
- Education beyond the classroom
- Vocational assessments
- Post-secondary education

**Please Note: Students between the ages of 13 and 22 are invited to attend.**

For more information and registration contact Marilyn Weber at 617-640-1007 or E-mail: [maroweber@gmail.com](mailto:maroweber@gmail.com)

## **Issues to be discussed with students:**

- Self-determination and self-advocacy
- Knowing my IEP
- What does transition mean



Family



**WorkWithoutLimits**  
Putting abilities to work in Massachusetts.

**MDSC 27th Annual Conference *My Great Story***  
**Saturday, March 19, 2011**  
**DCU Center in Worcester, MA**  
**8:00am to 4:00pm**

You're invited to join us to hear national and local experts present on a variety of topics relating to Down syndrome. We are expecting over 550 parents, self-advocates, brothers and sisters, educators and other professionals from the New England area to gather for this dynamic day of networking in the Down syndrome community.

The conference will feature:

- Over 19 Workshops
- Awards Luncheon
- Keynote address by Ben Majewski, Self Advocate
- Tracks for Parents, Educators, Young Adults, and Brothers and Sisters

**Expert speakers and topics include:**

Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know. - *Brian Skotko, MD, MPP*

When it's not just Down syndrome: Addressing the needs of children with Down syndrome and significant medical, developmental, or behavioral issues - *Emily Jean Davidson, MD, MPH and Charlotte Gray*

The Facts of Life... and More: Sexuality Across the Lifespan - *Leslie Walker-Hirsch, IMEd, FAAIDD*

Mental Health Issues in Down syndrome - *Kerim M. Munir, MD, MPH, DSc*

Total Communication & Down syndrome: Building upon strengths to enhance communication - *Rebecca Therriault, MS, CCC-SLP*

The Essentials of Behavioral Management for Individuals with Down Syndrome - *Nancy R. Sullivan, PhD*

Piecing it All Together: Understanding Down syndrome and Alzheimer's disease - *Julie Moran, DO*

The Ins and Outs of Toilet Training: Developing an Effective Plan for your Child - *Kimberly Dunn, MSN, PNP*

Principles and Practices of Literacy Learning - *Karen A. Erickson, PhD, and David A. Koppenhaver, PhD*

Inclusion for Individuals with Down Syndrome - *Richard Villa, PhD*

*And more...*

**For information, please call Family Connections @ 508-999-0077 or go to: [conference@mdsc.org](mailto:conference@mdsc.org) .**

**The MDSC is integrating the National Down Syndrome Society's "My Great Story" public awareness campaign into this year's conference theme.**





# Beyond Duct Tape and Velcro

## **101 AT Solutions YOU Can Make Using Everyday Materials**

What if you only had five minutes to make a solution for someone and had the basic tools and materials in the trunk of your car? Just think of the possibilities!

You are invited to attend **BeyondDuct Tape and Velcro: 101 AT Solutions YOU Can Make Using Everyday Materials** on Wednesday, March 9, 2011 at the IOD Professional Development Center in Concord, NH. This hands-on workshop uses 42 different tools and materials for fabricating hundreds of AT solutions in minutes without the use of electricity. Each participant will use a "MacGyver AT Kit" of assorted tools and materials and will fabricate five assistive technology solutions. In addition, each participant will receive a switch-making kit, a "Mini MacGyver AT Tape Kit" containing 10 specialty tapes, an AT transformer kit that includes 14 PVC pieces for fabricating 15 different AT solutions, and a copy of the book *Assistive Technology Solutions in Minutes* containing over 600 examples.

General and special educators, paraprofessionals, AT and technology providers, physical and occupational therapists, speech language pathologists, vocational rehabilitation counselors, disability support services staff, family members, students, and others are encouraged to attend.

**Date:** Wednesday, March 9, 2011

**Time:** 9am to 3pm, *registration begins at 8:30am*

**Location:** IOD Professional Development Center, 56 Old Suncook Rd, Concord, NH

**Registration Fee:** \$175, includes continental breakfast, lunch, and materials

**Workshop Instructor:** Therese Willkomm, Ph.D.

### **About the Presenter:**

Therese Willkomm, Ph.D. is currently the Director of the New Hampshire Statewide Assistive Technology Program (ATinNH) with the Institute on Disability at the University of New Hampshire, and is Clinical Assistant Professor in the UNH Department of Occupational Therapy. In addition, Dr. Willkomm coordinates the Graduate Certificate in Assistive Technology program and the Disability Studies minor. She has been providing and managing assistive technology services for over 28 years in the areas of home, school, and worksite modifications for persons with disabilities. She is known nationally and internationally as "The MacGyver of Assistive Technology" and for her work in rural rehabilitation. Dr. Willkomm has presented in 38 states, five foreign countries, and three U.S. territories and has authored 22 publications including "Make a Difference Today! Assistive Technology Solutions in Minutes

Go to <http://www.iod.unh.edu/> for more information.



# **FEDERATION FOR CHILDREN WITH SPECIAL NEEDS ANNUAL CONFERENCE**

*Visions of Community 2011*

**Saturday, March 12, 2011 • World Trade Center - Boston**

**Keynote Speaker:** actor, screenwriter, and essayist - **Marianne Leone** author of *Knowing Jesse - A Mother's Story of Grief, Grace, and Everyday Bliss*

The Federation for Children with Special Needs, along with co-sponsors the Early Intervention Parent Leadership Project, Massachusetts Families Organizing for Change, Family TIES of Massachusetts, Massachusetts Family Voices and the Family-to-Family Health Information Center, Massachusetts Parent Information and Resource Center, the Parent Training and Information Project, and the Parent/Professional Advocacy League, is excited to announce this year's ***Visions of Community Conference - Informing, Educating, & Empowering Families and the Professionals Who Serve Them*** will be held Saturday March 12, 2011 at the Seaport/World Trade Center-Boston.

The conference features dozens of break-out sessions (many presented and/or translated into Spanish, Portuguese, and Cantonese) with topical strands and information covering Early Childhood, Special Education, No Child Left Behind (NCLB), the Individuals with Disabilities Education Act (IDEA), Health Care for Children with Special Needs, Transition, Social/Recreation Opportunities and more. Network with other parents and families and pick up free resources in our exhibit hall packed with more than 60 vendors.

For more information and/or a brochure, please call Family Connections @ 508-999-0077 or visit [www.fscn.org/conferences/voc2011/keynote.php](http://www.fscn.org/conferences/voc2011/keynote.php)

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## **2011 Regional Health Dialogues**

**The Massachusetts Department of Public Health Invites You to Participate in Our Sixth Round of Regional Health Dialogues.**

**Please Join MDPH Commissioner John Auerbach** for a statewide series of Regional Health Dialogues to discuss **New Priorities in Public Health Policy and Programs**. Each session will provide the opportunity to meet the Commissioner and members of his senior staff and to discuss how to strengthen public health in this challenging economic environment. We look forward to your participation.

### **Southeast**

**Monday, March 21, 2011**

**1:30 PM - 3:30 PM**

Middleborough Town Hall Ballroom  
10 Nickerson Avenue, Middleborough



## Did you know?

*The following information is reprinted from the Department of Transitional Assistance website.*

### **What is the Fuel Assistance Program?**

It is an energy assistance program that can help you pay for heating your house or apartment during the heating season, between November 1st and April 30th of each year.

### **What benefits are available?**

The Fuel Assistance Program can help you pay for any fuel (including but not limited to: oil, propane, natural gas, or electric) that you use to heat your house or apartment. If your rent includes heat, the Fuel Assistance Program may help you pay a portion of your rent.

### **When can you apply?**

The application process for the 2010-2011 heating season will begin in October 2010. Applications will be taken by fuel assistance agencies until April 30, 2011. You should apply as soon as possible, as applicants are served on a first come first serve basis. If you received fuel assistance benefits last year, you will receive an application in the mail. If you do not receive a fuel assistance application in the mail, apply by calling and/or visiting the nearest fuel assistance agency in your area.

### **Where can you apply?**

You can apply for fuel assistance at an agency in or near your community. A complete list of fuel assistance agencies is included in this pamphlet. Your case manager can tell you which agency covers your area, or you can call the toll-free "Hotline" at: **1-800-632-8175**, or on the internet at <http://www.mass.gov/dhcd>. Information about other programs is also available at this number and website.

### **Will this reduce the amount of your cash assistance or Supplemental Nutrition Assistance Program (SNAP) benefits?**

No. The benefits that you receive from the Fuel Assistance Program will not reduce your cash assistance or SNAP benefits.

In fact, you may be entitled to more SNAP benefits if:

1. you receive SNAP benefits, and
2. you receive fuel assistance, and
3. your heat is included in your rent.

If you meet these three conditions, call your case manager to see if you qualify for additional SNAP benefits.

### **What verifications do you need?**

You must show proof of your monthly income. If you receive TAFDC or EAEDC, the enclosed notice contains the verification of your monthly cash assistance. Mail this notice with your application, or take it with you to the nearest fuel assistance agency. Be sure to save the notice until you apply for fuel assistance. You may be eligible for other discounts from your utility company. Ask your utility company for the income guidelines for these discounts.

### **Can you get help with heat and utility bills from Emergency Assistance?**

No. You are not eligible to receive help to cover heat and utility arrearage payments through the Emergency Assistance program.

The Massachusetts Developmental Disabilities Council  
and The Arc of Massachusetts cordially invite you to join  
people with disabilities, advocates, family members, and  
agency directors at the  
**33<sup>rd</sup> Annual Legislative Reception**



***Join us at our 33<sup>rd</sup> Annual Legislative Reception on  
Wednesday, March 2, 2011***

***10:30 am – 1 pm***

***“A Life of Opportunity”***

**To register for the Legislative Reception go to: [www.arcmass.org](http://www.arcmass.org)**

Join the **Massachusetts Developmental Disabilities Council** and the **Arc of Massachusetts** at our annual legislative reception. Invited guests include Governor Deval Patrick, Lt. Governor Timothy Murray, State Senators and Representatives, State Cabinet Secretaries, and Commissioners. This is an ideal opportunity for persons with disabilities, family members, advocates, state agency heads and their staff, and legislators to interact and catch up on legislative, budget, and policy priorities.

Representative John Scibak will be presented the MDDC award and Senator Fred Berry will be presented The Arc of Massachusetts award as Legislators of the Year in recognition of their advocacy for persons with disabilities.

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the  
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group

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### **Family Connections**

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



United Way  
of Greater New Bedford

Creating a network of family support  
For individuals with developmental  
Disabilities and their families