

# Family Connections

THE NEMASKET GROUP

NEWSLETTER # 59

November-December 2011

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## HAPPY HOLIDAYS AND HAPPY NEW YEAR!

To you and your family from all of us at Family Connections!

We are grateful for our relationship with you and privileged to have the opportunity to serve you!



We look forward to continuing our work with you!

*Sandy Jorge Kathleen Jennifer Sherry*



### Family Connections Staff

**Sandra Kinney,**  
*Program Director*

**Kathleen Amaral,**  
*Family Advisor*

**Amy Cornell,**  
*Administrative Support*

**Jorge Pagan,**  
*Family Advisor*

**Jennifer Newcomer,**  
*Family Advisor*

**Sherry Amaral-Lopez,**  
*Family Advisor*

**Emily M. Nisenbaum,**  
*Associate Executive Director*



Dear Family Member,

I wanted to take this opportunity to reintroduce myself. I came aboard as an employee of the Nemasket Group for Family Connections several months ago and have enjoyed working with everyone here offering family support on a very individual basis. The families I have come to know have had a great impact on my life. Having a young boy with special needs has given me the perspective I need to effectively seek answers to questions that come up and to offer the support we all seek.

Back some months ago, I began co-facilitating a Sibshop program here in Fairhaven at Family Connections. I also have two healthy "typical" children and I am passionate about offering them a fun group where they can obtain peer support and meet kids that have similar life situations. So far, we have a small group of children who, I believe, find the Sibshop to be very rewarding. They are networking with other kids their age who all have special needs siblings. Our sibshop program meets monthly and is at no cost to the family. The group is for children 8-12, but if you have a child outside of that age range, please don't hesitate to contact us. We are keeping your information in hopes of creating other sibshop programs for different aged children.

We have events for families on the horizon. One such event is a dental clinic for all our families on February 29<sup>th</sup> from 4pm until 6pm. It is a traveling clinic of hygienists that do routine cleanings/ screenings and recommend follow-up if needed. We think it will be a great way to offer a much needed service for those of us who find oral hygiene difficult to do well. I know that it is often a battle to clean my son's teeth and I am sure this will be a welcomed event.

Happy Holiday to everyone!!

Kathleen Amaral  
508-999-4436 x133

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Hello! I would like to take this opportunity to reintroduce myself. My name is Jennifer Newcomer. I began working at the Nemasket Group for Family Connections back in March. I have three children, one of whom has special needs. I first learned about the Nemasket Group while attending the Family Leadership Series in 2008. My own personal experiences in working with the school department, the insurance companies, doctors, therapists, various other professionals, and even our local politicians, along with my participation in the Leadership Series was instrumental in helping me to develop the confidence in myself and in my own abilities to become a more effective advocate for my family. I quickly realized that if I didn't speak up for my daughter that someone else (who didn't know her) was going to do it for me or worse yet, we would just get lost in the shuffle. Eventually, I began to think about how great it would be if I could use my own knowledge to help other families.

I am excited for the opportunity to work for the Nemasket Group and to help other families who face similar challenges. Not only can I draw upon my own personal experiences and perspectives of a parent of a child with special needs, but I find that every day, I learn something new and am inspired by the families and individuals that I have been lucky enough to get to know.

Recently, I have had the opportunity to assist my co-worker, Kathleen Amaral, in developing a Sibling Support Group that has been lots of fun for everyone involved. We are also in the process of starting a Parent Support Group that I hope will be just as rewarding.

If there is any way that I can be of assistance to you or your family, please do not hesitate to contact me.

Sincerely,

Jennifer Newcomer  
(508) 999 4436 x 118

# Food for *Thought*



## **Hundreds Send letters to Governor, Secretary Bigby and Secretary Gonzalez asking for next Budget to Keep the Promise of Community. Will It Make a Difference?**

For the last several weeks, hundreds of disabilities advocates, including self-advocates, family members and human service workers have written to Governor Deval Patrick, Health & Human Services Secretary JudyAnn Bigby and Administration & Finance Secretary Jay Gonzalez to plead with the Administration to keep it's promise to restore and stabilize developmental disabilities programs once state revenues began to recover after the disastrous Great Recession of 2008.

For the last four budget years, community human service programs have seen deep program cuts, frozen rates, frozen salaries, and continued erosion of community organizations struggling to cope with increasing health insurance, fuel, rent, insurance and other costs of operation. People with disabilities and their families have suffered as 10,000 people lost family support services or were unable to obtain needed services.

Developmental disabilities advocates were advised by the Governor and members of the Legislature to keep the faith during the recession as State leaders worked to minimize cuts to human services which could have been worse than the ones that occurred.

The Governor and Legislature promised that when state revenues recovered, human services would once again see long standing problems addressed. Over the last two budget cycles, state revenues have shown a steady growth, and now developmental disabilities advocates are writing to the Governor and his Administration to remind them that the community system is still deeply in need of support.

Through the Association of Developmental Disabilities Providers Action Center, hundreds of hearts wrenching letters have been sent to the Governor and his team.

It is our hope that this outreach to the Governor will result in the Governor's House One Budget, to be released in January 2012, making developmental disability issues a key element of the Governor's Agenda.

# “GIRLS DON’T PLAY DRUMS”

From the [www.disabilityisnatural.com](http://www.disabilityisnatural.com) E-Newsletter by Kathie Snow

In 1960, I was a too-tall and too-gangly 10-year-old girl – and tomboy – in the fifth grade. Because I was the tallest of *all* the fifth-graders, I was chosen to play Tom Sawyer in the school play. There was nothing to be done about my being taller than all my classmates in real life, but the teacher apparently felt it was *not* okay for a girl to be taller than the boys in the play – heaven forbid! Since I was a ham (*and* a tomboy) portraying a male was okay with me.

But something even greater was awaiting fifth-graders: being in the school band! At the first band meeting, most of us fairly salivated at the sight of the bright and shiny instruments; we couldn’t wait to get our grimy hands on them and make our mark in the musical world. And there was no doubt what I drooled over: the drum set!

Mr. Smith, the larger-than-life band director, kept our rowdy bunch in line as he spoke briefly to each student, deciding who would play what. What my turn came, I blurted out my desire as I pictured myself holding the sticks, banging away on the snare drum and the high hat. But my reverie was shattered by Mr. Smith’s directive; “Girls don’t play drums.” His words, tone of voice, and body language left no doubt: this was not negotiable. Nevertheless, I asked “Why not?” Did he think I wasn’t strong enough? I wasn’t asking to hoist the heavy tuba – how much could a set of drumsticks weigh? Was it not “lady-like” to play the drums? (But I was Tom Sawyer!) “*They just don’t*,” he said. “You’ll play the saxophone.”

So the saxophone (sex-a-phone some us snickered) it was. I learned to wet the reed and finger the keys and played with determination, while my heart pined for the sticks, drums, and high hat.

I never did understand Mr. Smith’s decision. Was it based on a logical reason, on 1960’s customs, or on his belief that it was inappropriate for a girl to play drums? Would he have said that boys couldn’t play the flute (“too girlish”)? Yet another teacher thought it was okay for a girl to portray a boy in the school play. I-Didn’t-Get-It-Then-and-Still-Don’t. In another time, at other schools, band directors *did* allow girls to play drums, and some of those young ladies went on to earn a living from their talent!

Our attitudes and beliefs drive our actions and can have a profound impact – positive or negative – on another’s life. How many times a day do we behave like Mr. Smith: Knee-Jerk Reaction – Because I Said So – Those Are the Rules – That’s Just the Way It Is – etc., etc., etc.? (Add your own to this list.)

When we behave this way, how many dreams are lost, what harm have we caused? Equally important, these reactions – or inactions, like maintaining the status quo – can also negatively impact one’s “organization” (e.g., family, school, workplace, etc.) by stifling new ideas, inhibiting positive change, and more.

If we want better outcomes for people with disabilities, families, schools, and organizations, let’s be more skeptical about our “rules.” Let’s challenge conventional wisdom and question treasured traditions. Let’s explore possibilities and ask, “Why not?” When we do, what dreams will be realized? What talents and abilities will be revealed? What hopes will be fulfilled? What powers will be unleashed?

Girls *can* play drums. And the better outcomes we want *can* be achieved with a change in attitudes and actions. It’s time to march to the beat of a different drum.

**The indispensable new skill that organizations need to build is a way to institutionalize skeptical thinking, challenges to orthodoxy, and the questioning of fundamental premises.**

*Matt Miller*

# Information to *Share*



## iPad Learning Series

You are invited to attend the **iPad Learning Series**, a seven-part series presented by the UNH Institute on Disability and sponsored by [Assistive Technology in New Hampshire \(ATinNH\)](#). All sessions will be held at the IOD Professional Development Center in Concord, NH.

Since its release, the iPad has been an important tool in achieving educational success for all students, especially students with disabilities. Its accessibility, reasonable cost, and plethora of available applications make it an incredible resource for both students and teachers. This series will address the basics of operating an iPad as well as how to:

- Teach with an iPad.
- Manage iPads in a school.
- Use applications (apps) for specific disabilities and activities.

Workshops are limited to 25 registrants. Registration will begin 1/2 hour prior to the start of the session. Participants will be eligible for staff development credits.

### Series Dates and Topics:

- January 18, 2012 - [iPad 101](#)  
Time: 4pm–6pm | Registration Fee: \$59
- February 6, 2012 - [Using iPad Applications as Classroom Support](#)  
Time: 4pm–6pm | Registration Fee: \$59
- March 5, 2012 - [Apps for Autism: Social Stories and Visual Schedules](#)  
Time: 4pm–6pm | Registration Fee: \$59
- March 19, 2012 - [Apps for Autism: Behavior Tracking and Video Modeling](#)  
Time: 4pm–6pm | Registration Fee: \$59
- April 6, 2012 - [Managing iPads in Your School](#)  
Time: 9am–12pm | Registration Fee: \$79
- May 18, 2012 - [It's All Free!](#)  
Time: 9am–3pm | Registration Fee: \$115
- May 21, 2012 - [iPad Training for Rehabilitation Professionals](#)  
Time: 9am–1pm | Registration Fee: \$79

### Location:

Institute on Disability  
Professional Development Ctr.  
56 Old Suncook Road  
Concord, NH 03301  
<http://iod.unh.edu>





# 5 Steps to Getting an iPad Covered by Insurance: A mom's story of success

by Guest Contributor - Dawn Sconfienza Gaita

As a parent of a child with special needs, I understand firsthand the financial struggles that come with the job. When I discovered the iPad and the benefits it could have for my son, it became my mission to find a way to provide one for him. This is a simplified version of the steps I took in getting my iPad covered by insurance, and it is my hope that others can benefit from this information.

1. Check your medical benefits for your "Durable Medical Coverage." (Mine covered 50%, but since we had already met our out-of-pocket max, they covered at 100%)
2. Phone your insurance company and ask, "Please assign me to a case manager that is experienced with special needs children."
3. After you are provided a case manager, explain that you need the iPad as an augmentative communication device INCLUDING the Proloquo2go App (or TouchChat, OneVoice, TapToTalk, etc.) Provide comparison costs to a more expensive system such as the Dynavox, and remind them that you are opting for a more cost-effective device. Focus on Proloquo2go (or your chosen Aug Comm app) and that is being introduced by Speech Therapists and OT's in public schools for special needs kids as well as in private therapy, say nothing negative at all. If they have never heard of the Proloquo2go program, ask for their email address to send them a link and/or encourage them to visit the proloquo2go website. You could also provide links to the Youtube demonstrations provided by proloquo2go (or app demos provided on a4cwsn.com). Be sure to ask the case manager for all the necessary approval codes and coverage information so you are aware and comfortable with any out-of-pocket expenses you may incur. They may tell you "NO" at this point. If they do, ask them to email or fax you a letter of denial immediately. Local Developmental Disability Divisions/Boards and many private funding organizations will require a medical insurance denial to apply for funds, so getting this letter can be very helpful. Don't get discouraged, there are still more ways to get funding!
4. Find supporting documentation and case studies to include with your claim. Google articles on "iPads for children with special needs" or "benefits for children with [your child's specific condition] and iPads," etc.
5. Copy your most recent speech evaluation and IEP if it indicates anything helpful. And, have every doctor, therapist, school personnel or anyone else write a letter supporting your child's need for an "Augmentative Communication device such as the iPad with Proloquo2go."

The more information you can provide, the less likely they will argue against the need. My personal insurance required that I pay for the device and then submit a claim form for reimbursement.

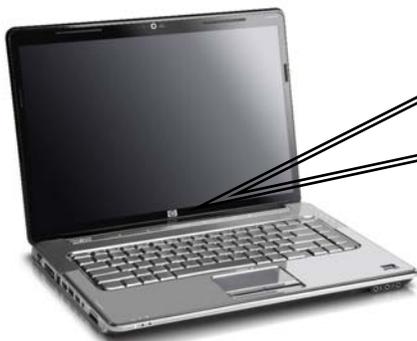
For more information about the 5 steps and the iPad a Day Grant, please visit:

<http://www.itaalk.org/fundingsources/medicalinsurancecoverage.html>

# Available *Resources*

## The MassAccess Housing Registry

The MassAccess Housing Registry is a Massachusetts database for affordable housing with a feature that highlights homes for people with disabilities that need accessible or barrier-free housing. Search for apartments, homes, a specific accessibility or adaptability need, income-based or subsidized, or by state, region. Visit [massaccesshousingregistry.org](http://massaccesshousingregistry.org) for more information.



### **Planning for Life after Special Education in Massachusetts: A Transition Services Online Manual**

From the Disability Law Center; the Protection & Advocacy Agency for Massachusetts is now available at <http://www.dlc-ma.org/manual/>

- Basic Legal Rights
- Forms
- Resources
- Video

This Manual is written for parents and students who are advocating for better transition services, including social, vocational and independent living skills. It is written in an easy-to-understand format but also contains “Endnotes” and an Appendix at the end of the Manual with legal information for attorneys and experienced advocates.

The Manual was edited by the Disability Law Center (DLC), in partnership with the Federation for Children with Special Needs, the Institute for Community Inclusion, and Mass. Advocates for Children. It was written by the Northeastern University School of Law Legal Skills in Social Context program.

DLC will be updating and improving the Manual on a regular basis. We plan to include more videos of students, parents and advocates, in English, ASL and Spanish, as well as updates on legal developments, new forms, and other practical advice.



## **New Medicaid Resource Available from The Arc**

The Arc is excited to announce a valuable new resource available at [www.thearc.org](http://www.thearc.org) to help guide people with intellectual and developmental disabilities and their families through the complexities of Medicaid benefits, services and supports. The Medicaid Reference Desk offers detailed, state- by-state information about Medicaid benefits, a glossary of terms, answers to frequently asked questions, person-centered planning resources and a blog from The Arc's training specialist about issues related to Medicaid, self-advocacy and person-centered planning.

Medicaid is the largest source of financing for disabilities services in the United States. For people with disabilities and for those who provide their care, Medicaid serves as a valuable safety net. Often the only source of financial assistance for health care, Medicaid plays a critical role for people with disabilities in providing coverage and access to care. Medicaid is, however, extremely complicated. At least half of the funds for Medicaid programs come from the Federal government with the remainder coming from state funds. Federal law contains detailed requirements and limitations on eligibility, services, and financing. But, state law varies widely.

This project was made possible by a grant from the U.S. Department of Health and Human Services, Administration on Developmental Disabilities (Grant No. 90 DN0215). We encourage you to explore the Medicaid Reference Desk via the Resources section of [www.thearc.org](http://www.thearc.org) or [www.thedesk.info](http://www.thedesk.info).

Massachusetts Department of Public Health

## **Children and Youth with Special Health Care Needs Program**

### **Call us if:**

- You have concerns about your child's health or development
- Your child visits the doctor more than other children
- You have questions about what services and supports are available to help your family
- You feel as if no one knows how hard it is to care for your child
- You need help paying for your child's medical and related expenses.

### **Our programs include:**

- Community Support Line
- Care Coordination
- Catastrophic Illness in Children Relief Fund
- Family Initiatives
- Family TIES of Massachusetts\*
- Hearing Aid Program
- MassCARE
- MASSTART
- Medical Review Team
- Pediatric Palliative Care
- Public Benefits Training
- Universal Newborn Hearing Screening

\*A DPH-funded project of the Federation for Children with Special Needs



**800-882-1435**



## Free Cell Phone and Service for low income families

Have you been looking for a worry-free way to stay in touch? Assurance Wireless is a Lifeline Assistance program brought to you by Virgin Mobile. If you qualify for Lifetime Assistance, you can receive a FREE Cell phone and 250 FREE monthly minutes.

### How do you qualify?

As a Massachusetts resident, you may qualify for Assurance Wireless if you participate in certain public assistance programs, such as the following:

- Mass Health or Medicaid
- Food stamps/SNAP
- Supplemental Security income (SSI)
- Low income Home Energy Assistance program (LIHEAP)
- Emergency Aid to the Elderly, Disabled and Children (EAEDC)
- Transitional Aid to Families with Dependent Children (TAFDC)

It's easy to apply! Question, call 1-888-898-4888 or visit [assurancewireless.com](http://assurancewireless.com)

### Here's what you can get:

- A FREE Assurance Wireless phone
- 250 FREE Voice Minutes
- The ability to keep your current phone number
- Voicemail Account, Call Waiting, and Caller ID included
- 911 Access
- No annual contract

Or, choose from the \$5/mo. Offer to get 500 Total Voice Minutes or our \$20/mo. Offer to get 1000 Total Voice Minutes + 1000 Texts

Lifeline Assistance is available to one qualifying customer per household and is not transferable.



*Sibshops is a program for brothers and sisters of kids with special needs!*



## Family Connections

### Sibshops

Our Sibshops are scheduled for the  
 1<sup>st</sup> Thursday of each month from 5pm until 8pm  
**\*\*December Sibshop moved to Wednesday 12/21 from 5-8\*\***  
*Regular schedule will resume in February on 2/2*

They are held at the  
 Nemasket Group  
 56 Bridge Street  
 Fairhaven, MA 02719



Our Sibshop program is for children ages 8-12  
 Who have siblings with special needs. Sibshops are a great place to meet other children  
 with similar life situations and play fun games!

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

*\*space is limited and registration required\**

# Save the Date:



## An IEP for My Child

January 12, 2012 from 10:00 am -12:00 pm

Put on by the Federation for Children with Special Needs. Every child with a disability who receives special education services must have an Individualized Education Program (IEP). This workshop takes parents step-by-step through IEP development, including how to articulate a vision, using evaluations to write measurable goals, and measuring their child's progress. This workshop will be held at the Kennedy Donovan Center, 32 Commercial Street, South Yarmouth, MA 02664. For more information or registration please call Kerri Pearlman at 508-385-6019 x 105 or via e-mail at [kpearlman@kdc.org](mailto:kpearlman@kdc.org)

# Save the Date:

## "Focus" on Vision Impairment & Blindness Conference

Meeting the Needs of Individuals with  
Intellectual Disability & Vision Loss

March 14, 2012

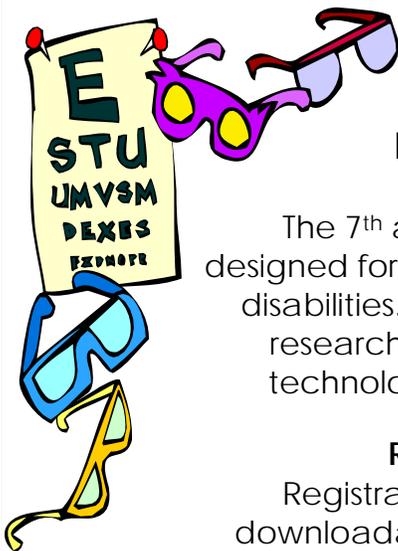
8:00 am - 3:30 pm

Four Points by Sheraton, Norwood, MA

The 7<sup>th</sup> annual "FOCUS" on Vision Impairment & Blindness Conference is designed for people working with individuals with vision loss and intellectual disabilities. This year's conference will include presentations on current research and practice in areas of medical, clinical, recreation and technology that can positively impact the lives of these individuals.

### Registration Forms available December 2011:

Registration Brochure and Form, including CEU information, will be downloadable from "Training and Events" section of DDS website: [www.mass.gov/dds/visionloss](http://www.mass.gov/dds/visionloss) and from the "Perkins Training Center Schedule" on the Perkins website: [www.perkins.org/professional/ptc](http://www.perkins.org/professional/ptc)





# Family Connections

Is proud to host  
**MASS CHILDREN HEALTHY SMILES**



## **DENTAL CLINIC**

Here at the Nemasket group  
56 Bridge Street  
Fairhaven, Ma

**WEDNESDAY FEBRUARY 29<sup>th</sup> from 4pm until 6pm**

- Dental Screening
- Cleaning
- Sealants
- Fluoride Varnish
- Home care instruction

**Appointments are set into 30 minute sessions. Space is limited. Please call to schedule an appointment and to obtain the permission release forms:**

**Kathleen Amaral 508-999-4436 ext 133**

**Deadline is Friday February 10<sup>th</sup>**

# THE 17TH ANNUAL ASD SYMPOSIUM

**When: Thursday and Friday March 15 - 16, 2012**

**Where: [Rhodes on the Pawtuxet](#), Cranston RI**

Every year, in conjunction with [Dr. Barry Prizant, Ph.D., CCC-SLP](#), CAR puts on our Annual ASD Symposium. The ASD Symposium is held every year in the Providence RI area, and has been going on for over 15 years.

This symposium was the first national forum to address the importance of understanding interests, strengths, and talents of people with Autism Spectrum Disorder (ASD) relative to social, academic, vocational, and leisure skills and settings. Presentations and discussions focus on the importance of identifying and enhancing these abilities for people with ASD of all ages and all ability levels in educational, community, home, and vocational settings. The symposia is intended for educators, SLPs, OTs, psychologists, paraprofessionals, social workers, therapists, family members, and other care givers who live with and/or support the development of people with ASD.

## **THURSDAY, MARCH 15**

Spend the morning with [Deborah Lipsky, M.Ed.](#)

*From Anxiety to Meltdown: How Individuals on the Autism Spectrum Deal with Anxiety, Experience Meltdowns, Manifest Tantrums, and How You Can Intervene Effectively*

Diagnosed only six years ago with high functioning autism, she has found her own unique solutions and strategies for coping with autism as an adult. Deborah has a way of letting attendees “feel” what it is like to be autistic and her interactive style of presenting keeps audiences always riveted.

Spend the afternoon with Barry Prizant & Barbara Domingue

*Practical Strategies for Developing Trust with Persons with Autism and their Families*

The success and quality of life achieved by persons with ASD depends on the development of trusting and supportive relationships. Trust must be developed in school settings with all staff, as persons with ASD are more available for learning and for engaging successfully with others. Barry and Barbara will consider qualities of interpersonal support and characteristics of interactions that underlie the development of trusting relationships with persons with ASD, and their families. Practical strategies will be discussed for enhancing trust with people with ASD of all ages and ability levels, and their families.

## **FRIDAY, MARCH 16**

Spend the day with [Brenda Fossett, Ph.D., BCBA-D](#)

*Technology for Your Toolbox: Using the iPad to Support Communication and Learning*

This presentation is essentially a “show and tell” of apps across a variety of categories, such as learning to use the touch screen, cause/effect, early learning, visual supports, AAC, language development, literacy, math, etc. It’s been extremely well-received for its practicality and strategies.

Brenda is a faculty member in the Dept of Educational and Counseling Psychology and Special Education at the University of British Columbia in Vancouver, BC. Her clinical work has centered around developing and implementing intervention programs for individuals with ASD.

The symposium includes lunch and complimentary parking!!

For more information and registration materials visit: [www.community-autism-resources.com](http://www.community-autism-resources.com) or call Family Connections for assistance.



## Save the Date:



### Parent Support Group

January 17<sup>th</sup>, 2012  
10:00 a.m. - 12:00 p.m.

Please join us for the first of our new monthly Parent/Caregiver Support Group.  
Meetings to be held at:

The Nemasket Group  
56 Bridge Street  
Fairhaven, MA 02719

Our goal is to create a safe & welcoming place for parents/caregivers of individuals with special needs to exchange information, provide emotional support, offer encouragement, reduce stress and develop friendships.

Bring your ideas, suggestions, visions and desires as we work together to create a strong network of support.

*"You alone can do it-but you can't do it alone"*

---

the  
**nemasket**  
group

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

### 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