

## Family Connections Staff

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THE NEMASKET GROUP

# Family Connections

## More Budget Cuts for People with Disabilities and Families!

Hundreds of individuals with disabilities, their families and caretakers have held a vigil in the lobby of the Governor's Office to protest the Governor's plans to eliminate services for thousands of people with developmental disabilities. The vigil began Thursday, October 8 and ended on Monday, October 19. Continuing activities are planned and will continue until the Governor meets with developmental disabilities stakeholders to indicate he will protect disabilities services.

The Arc of Massachusetts and Massachusetts Families Organizing for Change (MFOFC) organized the event because of what they believe is the Governor's current plan to terminate over 10,000 people from community services provided by the Department of Developmental Services. Executive directors Leo Sarkissian of The Arc and Susan Nadworny of MFOFC said the proposed cuts would destroy the Commonwealth's safety net for the most vulnerable people in the state, causing them to lose residential, employment, transportation and family supports.

*Sarkissian stated: "If the governor goes ahead with tens of millions of dollars in mid-October 9C cuts and \$750 million in FY 11 cuts to human services, it will mean the dismantling of the disability community services system."*

*Nadworny stated: "Thousands of consumers, family members and human service workers are in shock over the Governor's proposed abandonment of people with developmental disabilities."*

Organizers have been alarmed by the Governor's potential plans, noting that the human services and disabilities community cannot bear any further cuts in essential services. Currently a People First! Campaign is being organized. We anticipate this campaign continuing through the FY '11 budget process.

**Please – call the Governor (617-725-4005)**

***Tell whoever you talk to (most likely an aide) that you are concerned about the harm already inflicted on services for individuals with intellectual and developmental disabilities and that further erosion of the Safety Net cannot be withstood. Make your story as personal as possible.***

***What services do you get? What help do you need throughout the day? What services do get help with that you couldn't manage without?***

***We hope to maintain the services you receive through Family Connections and other programs. Further budget cuts will put your services in serious jeopardy. Please act NOW to tell the Governor that he must protect Massachusetts' most vulnerable citizens.***

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## NEED A PCA?

PCA available Monday through Friday 4-8 PM. If interested, please call Sandy for additional information at (508) 999-4436 x 128

# Upcoming Events



## INCLUDING SAMUEL



A DOCUMENTARY BY DAN HABIB

***Watch Including Samuel on  
RI PBS on 10/29/09 @ 10:00 PM***

Before his son Samuel was diagnosed with cerebral palsy, photojournalist Dan Habib rarely thought about the inclusion of people with disabilities. Now he thinks about inclusion every day. Shot and produced over four years,

Habib's award-winning documentary film, *Including Samuel*, honestly chronicles the Habib family's efforts to include Samuel in every facet of their lives. The film also features four other families with varied inclusion experiences, plus interviews with dozens of teachers, young people, parents and disability rights experts.

*Including Samuel* is a highly personal, passionately photographed film that captures the cultural and systemic barriers to inclusion. *Including Samuel* has been featured on NPR's *All Things Considered*, *Good Morning American NOW* and in the *Washington Post* and the *Boston Globe*. *Exceptional Parent* magazine said "Including Samuel is a must see film."

The film won the Positive Images in Media award from TASH, an international group committed to the full inclusion of people with disabilities. The film was also screened at the Sprout Film Festival at the Metropolitan Museum of Art (NYC) and named "Best Documentary" at the Somewhat North of Boston Film Festival. The global aid group Mercy Corps is using the film to support the Iraqi disability rights movement.

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For more information, visit: [www.includingsamuel.com](http://www.includingsamuel.com)

## Joining Voices

An annual conference to support families in advocating for children & youth with special health care needs.

Hosted by the Massachusetts Family-to-Family Health Information Center, a project of Mass Family Voices @ Federation for Children with Special Needs.

**Wednesday, November 4, 2009  
Hoagland-Pincus Conference Center  
222 Maple Avenue  
Shrewsbury, MA 01545**

A free day of learning and networking for families with children & youth with special healthcare needs (including mental, behavioral, emotional needs).

Download the Joining Voices Conference Brochure at [massfamilyvoices.org](http://massfamilyvoices.org)

Registration Deadline Friday, October 23, 2009. Space is limited and registration priority is given to family members of children and youth with special health care needs. If you have questions or want more information, call the Massachusetts Family-to-Family Health Information Center at 1-800-331-0688, ext. 210 or e-mail [massfv@fcsn.org](mailto:massfv@fcsn.org).

# DDS Guidance for Caregivers of Children and Adults with Intellectual Disability Living at Home

(This information was compiled from information provided by CDC and the Massachusetts DPH)

As you are all aware, the Centers for Disease Control and Prevention (CDC) is preparing for a H1N1 flu (Swine flu) outbreak this Fall. While there is no need to be overly alarmed, the situation should be taken seriously. If you care for someone with intellectual disability at home be particularly vigilant as often they are unable to express symptoms of illness to you. The most important step is to have the individual vaccinated as soon as it is available. **Individuals with intellectual disability are among those who are considered high priority for receiving the H1N1 vaccine. Check with your child's Health Care Provider (HCP) or your local health department to determine where and when the vaccine can be received.**

There are a number of steps that you can take to help prevent the spread of H1N1 flu.

## 1) Precautions to take to prevent the spread of H1N1 flu

- a. Wash hands frequently with soap and water or use alcohol based gels.
- b. Avoid holding, hugging, kissing, or shaking hands with anyone who has a cold or the flu.
- c. Avoid touching your nose, mouth or eyes.
- d. Cough or sneeze into a tissue, or into your elbow instead of into your hands.
- e. Clean things that are touched often like door handles and telephones.
- f. Try to avoid close contact with sick people.

**Be aware of the symptoms of H1N1 flu.** They are very similar to seasonal flu. The most common symptoms include fever, cough, sore throat, body aches, headache, chills and fatigue. Some people also have diarrhea and vomiting.

## 3) What to do if symptoms develop.

- If symptoms develop your child's Health Care Provider (HCP) should be contacted. He/she will decide what type of testing and/or treatment is indicated.
- Keep home until fever free for 24 hours without the use of fever reducing medications.
- Make sure they get plenty of rest.
- Keep in bedroom as much as possible away from other household members.
- Makee sure they drink plenty of fluids.
- Be watchful for emergency warning signs that might indicate the need to seek medical attention.

Contact the HCP immediately if an individual has difficulty breathing, has discoloration in the lips, is vomiting and unable to keep liquids down, has signs of dehydration such as dizziness, absence of urination, or seizures.

For more information regarding H1N1 flu, please refer to the Massachusetts Department of Public Health web site listed below or contact the Department of Public Health at (617) 983-6800. **Massachusetts Department of Public Health Website on influenza: <http://www.mass.gov/dph/flu>**

THE ALZHEIMER'S  
ASSOCIATION  
OF MASSACHUSETTS AND  
NEW HAMPSHIRE  
AND  
THE MASSACHUSETTS  
DEPARTMENT  
OF DEVELOPMENTAL  
SERVICES

*Presents  
The 2<sup>nd</sup> Annual*

**Finding Our Way Together:  
Care Coordination for Individuals with  
Down Syndrome and Alzheimer's  
Disease**

**Friday, November 6, 2009  
10:00 am to 4:00 pm**

**Devens Common Center  
31 Andrews Parkway  
Devens, Massachusetts  
978-772-0188**

**Program Information**

The second annual state -wide Alzheimer's Disease conference is intended to educate staff, clinicians and families about the current trends and information available in this field. The Conference will follow a format of "tracks" - clinician, staff and family - in order to allow attendees to hear about and discuss the aspects of this disease that are relative to the role they play in the person's life. This year, we are opening the conference later in the day and starting with breakout tracks in order to better accommodate DSP and family members. The keynote Presentation will occur during lunch.

***If interested, call Family  
Connections @ 508-999-0077 for a  
brochure.***

**FOR EDUCATORS:  
MDSC 6<sup>th</sup> Annual Educators  
Forum**

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*4 ` ] ] V X V ` W e Y M o g a n C a m p u s C e n t e r d t  
Thursday, November 12, 2009  
8:00 am – 3:00 pm*

*Keynote Speaker: > R c R D R a ` \_ t D Y V g Z \_ k  
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Department, School of 6 U f T R e S z r a c u s e  
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The 6 U f T R e ` c d i s d e s i g n e d f o r E d u c a t o r s  
across Massachusetts to spend a "school day" together  
at a local university (College of the Holy Cross  
in Worcester, MA), to share best practices and to learn  
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students with Down syndrome. The 6th Annual  
Educators Forum, V / [ @ ~ \ á Ú | á à ~ ^ à [ E  
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2009.

**Sessions for:**

- Educators at the elementary, middle and high school level
- Teachers new to teaching children with Down syndrome
- General and special education teachers

Attendees at the Educator's Forum are eligible to receive six (6) Professional Development Points (PDP's) toward renewal of their teaching certificate.

Early bird registration fee through October 30<sup>th</sup>:  
\$85/educator (includes continental breakfast and luncheon) \$95 from November 1<sup>st</sup> on.

To register and view the complete program agenda go to: <http://mdsc.kintera.org/edforum2009>.  
For more information please contact us at [mdsc@mdsc.org](mailto:mdsc@mdsc.org)



# Available Resources

## **The Massachusetts Assistive Technology Loan Program**

The Massachusetts Assistive Technology Loan Program, operated by Easter Seals Massachusetts, is an alternative financing project that gives people with disabilities and elders access to low interest cash loans to purchase assistive devices and services. The program has many options that can help - even for people who don't think they would qualify for a loan.

Assistive Technology (AT) is any device that helps a person achieve greater independence and lead a more productive life. Many different items are considered assistive technology, including:

- **Hearing aids**
- **Computers with special programs**
  - **Flashing doorbells**
  - **Electric wheelchairs or scooters**
  - **Adapted vehicles**
- **Home modifications such as ramps and widened doorways**

An assistive technology service helps people determine which device may be right for them. It also helps people locate and purchase devices, trains them on their use, and provides maintenance and repair. The MA AT Loan Program can refer loan recipients to assistive technology services that meet their specific needs.

This program is supported by grants to the Massachusetts Rehabilitation Commission from the National Institute on Disability and Rehabilitation Research, US Department of Education and the Commonwealth of Massachusetts. The MA AT Loan Program is operated and maintained by Easter Seals Massachusetts in partnership with Sovereign Bank.

### ***What to know more?***

***For more information, call Jason Luciano, Ph.D., program director***

***Toll-Free at***

***Easter Seals Massachusetts:***

***1-800-244-2756 x 428 or 431 (voice)***

***1-800-564-9700 (TTY)***

***[www.massatloan.org](http://www.massatloan.org)***

***E-mail us at [info@massatloan.org](mailto:info@massatloan.org)***



getATstuff

Assistive Technology  
Exchange in New England

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 exchange is a free “classified ad” designed to help people buy, sell or give away equipment.

The Assistive Technology Exchange in New England is primarily for New Englanders, although we do accept entries from neighboring states.

Visit the site and browse the listings - <http://www.getatstuff.com>. To view contact information or to post your own items on the site, you must be a registered user and be logged into the site.

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 & Vehicle Modifications
- Computers & Computer-Related
  - Recreation, Sports & Leisure
  - Other

*The Assistive Technology Exchange in New England can be contacted via e-mail at [ATinMA@getatstuff.com](mailto:ATinMA@getatstuff.com) or by phone at Toll-Free 1-866-682-9955 (in state), (617) 204-3851 (voice), (617) 204-3815 (TTY), or (617) 204-3877 (fax).*

## MassEDP

The Massachusetts Equipment Distribution Program (MassEDP) provides residents with a permanent sensory, physical or cognitive disability access to specialized telephones at reduced cost or for free, depending on income. They may be hands free, cordless or equipped with memory, amplification, text or signalers.

For a list with specific features or program requirements, visit [www.massedp.com](http://www.massedp.com) or call (800) 300-5658 (Voice/TTY)



## **Community Support Line 1-800-882-1435**

The Division for Perinatal, Early Childhood, and Special Health Need's toll-free statewide\* Community Support Line offers information, technical assistance and referral for families with children with special health needs. Experienced Community Resource Specialists are available to assist families Monday through Friday (except holidays) from 9:00 a.m. until 5:00 p.m. Resource Specialists answer questions and provide information and assistance about, and referral to, a broad range of programs including:

- Public benefits information and eligibility (SSI, CommonHealth, MassHealth, etc.)
- Catastrophic Illness in Children Relief Fund and the Flexible Medical Fund
  - Care Coordination services
  - Family-to-family supports (Family TIES, etc)
- Other programs within the Department of Public Health, other agencies (MassHealth, DMR, DMH, etc) and community-based programs that may be able to provide assistance

Families and providers are welcome to call the community support line for assistance. **The Resource Specialists' goal is to help answer specific questions and requests, as well as to ensure that families are informed about all the public programs they may be eligible for, and community resources that might provide additional assistance.** Resource Specialists are available for follow-up assistance with families, and often have multiple contacts with a family. If a family requires longer-term assistance, Resource Specialists will provide a referral for the family to the DPH Care Coordination program.

For more information about the Community Support Line, contact Sandra Broughton, Director of Community Support at (617) 994.9819

### **The Catastrophic Illness in Children Relief Fund**

*When other resources end, we begin.*

The Catastrophic Illness in Children Relief Fund (CICRF) helps families bear the excessive financial burdens associated with the care of children with special health care needs and disabilities. CICRF is a payor of last resort. It provides financial assistance for Massachusetts families with children experiencing a medical condition requiring services that are not covered by a private insurer, federal or state assistance, or any other financial source.

The Fund is designed to act as a safety net for families who have excessive expenses related to a child's medical needs. The family may be responsible for these expenses due to:

- A lack of insurance or dependent coverage
- Expenses that are greater than the maximum benefit allowed by their insurance company
- Pre-existing conditions, co-payments, and other expenses that are not covered by insurance

CICRF is a reimbursement program. The expense must have already been incurred in order to be eligible for the Fund and to receive reimbursement. In cases of extreme medical emergency, the CICRF Commission may grant approval before the expense is incurred.

#### **FOR MORE INFORMATION:**

**Catastrophic Illness in Children Relief Fund  
Massachusetts Department of Public Health  
250 Washington St., 5th Floor  
Boston, MA 02108-4619  
Phone: 1-800-882-1435  
TTY 617-624-5992**

**[www.mass.gov/cicrf](http://www.mass.gov/cicrf)**

## 2 f e Z d ^ 4 R c V d

AutismCares helps families affected by autism to cover costs associated with critical living expenses such as; housing, utilities, car repair, daycare, funeral expenses, and other essential items on a ca] à E ´ se Basiâ.

Families must complete an online application and identify vendor(s) to be covered by the award.

**New! The mR i Z ^ f ^ D f warU s\$1,000 pec WRŽ^ Z ] j**

Eligible families have a child (children) diagnosed with Autism Spectrum Disorder, an income of \$50,000 or less, and experienced one or more qualifying events in the previous 90 days. Qualifying events are:

- Natural disaster: fire, flood, hurricane, tornado, severe storm or earthquake
- Death or critical illness in the nuclear family
- Victim of a violent crime
- Loss of home through foreclosure, eviction or natural disaster
- Termination of employment for the primary incomeE arner within previous 90 days.

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## CATHOLIC SOCIAL SERVICE HOUSING AND HOUSING RETENTION

Housing and Housing Retention Programs are funded through Catholic Charities USA, and Fannie Mae. The "No Place Like Home" is a HUD-Certified housing counseling agency and is a Chapa Seal of Approval agency. The program offers housing counseling for both homeowners and renters alike, addressing foreclosures, pre-purchase counseling, credit counseling, and budget counseling.

**With the current mortgage crisis going on in the United States, call ASAP to get a appointment.**

*There's no place like home...*

Make the dream come true - find and keep a home of your own.

- Education workshops toward home ownership
- Current homeowners in financial difficulty
- Individuals with credit card debt
- Need assistance on budgeting
- Assistance with Sub Prime and Adjustable Rate Mortgages

**New Bedford (508) 997-7337 OR Fall River (508) 674 - 4681**

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## **ANOTHER RESOURCE...**

**For children's things: clothes, toys, furniture, books,  
etc.**

***GIFT TO GIVE***

**21 Cove Street Mill  
New Bedford, MA 02744  
508-717-8715**

**Program Manager – Cheryl Ritchotte**

# MEDICAL CARE COORDINATION FOR CHILDREN AND ADULTS

The National Birth Defects Center is dedicated to the diagnosis and treatment of children and adults with genetic diseases, birth defects and developmental delays/mental retardation. The NBDC was established in 1982 with the aim to improve the coordination of care for this population of patients as well as to make care available in their local communities. Our main office is located in Waltham and we also have a satellite network of 10 locations covering much of Massachusetts.

The following are locations in SE Massachusetts:

Cape Cod Hospital – Hyannis

I.H. Schwartz Children’s Rehabilitation Center – Dartmouth

Nantucket Cottage Hospital – Nantucket

Rehabilitation Hospital of the Cape and Islands – Sandwich

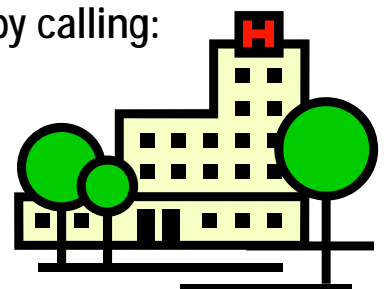
Each of our locations is handicap accessible. We see patients of any age and follow patients regularly along with their primary care physicians. We accept all types of insurance. Interpreter services are available at the hospital-based locations.

Our staff includes patient-care coordinators who will help families arrange specialty appointments local to their communities or in a coordinated fashion in order to diminish the travel required.

Our staff also includes a Board Certified Genetic Counselor who is available to discuss hereditary diseases, recurrence risks and environmental causes of birth defects.

Our Therapy and the Performing Arts program offers support for various therapeutic programs throughout Massachusetts.

Appointments for any location can be made by calling:  
781 – 466 – 9555 (9AM - 5 PM)



## Massachusetts PCA Directory Helps Elders and People with Disabilities Find Personal Care Assistants More Easily

The task of finding and hiring a personal care assistant (PCA) is now easier for MassHealth eligible elders and people with disabilities, thanks to a new contract between the Massachusetts PCA Workforce Council and Rewarding Work Resources, Inc, a nonprofit company located in Dedham, Mass.

The web-based Massachusetts PCA directory - available at [www.mass.gov/findpca](http://www.mass.gov/findpca) and free to individuals who qualify for the MassHealth PCA program - has a current searchable database of nearly 5,000 individuals ready to work as personal care assistants. Individuals seeking assistance can use the website to find qualified PCAs, and may search for workers by zip code and screen for criteria such as access to a car, hours of availability, experience, and a range of other relevant factors. The website, which is also available in Spanish, is accessible for people using any kind of assistive technology.

*Elders and people with disabilities who participate in the MassHealth PCA program and do not have access to a computer or who have questions about using the directory, should contact their Personal Care Management (PCM) agency for assistance. PCA users with general questions can call toll-free 1-866-212-9675. Individuals looking for work as PCAs can register free-of-charge 24 hours a day on the website at [www.mass.gov/findpca](http://www.mass.gov/findpca) or by calling toll-free 1-866-211-WORK (9675).*



### 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