

FAMILY SUPPORT NEWS

January, 2009



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A private, non-profit corporation dedicated to enhancing the quality of life of individuals with developmental disabilities in Belmont, Waltham, Watertown, Brighton, Brookline & surrounding communities.



Join our Newsletter and Advocacy Bulletin Mailing List. Call or email us with your name and address!

HAPPY NEW YEAR From Beaverbrook STEP!

Dear Beaverbrook STEP family members,

The new year brings many new opportunities and challenges to Beaverbrook STEP. Although services funded by DMR were not cut during Governor Patrick's initial budget cuts in October of 2008, the worsening economic crisis promises that significant budget cuts loom over the horizon. Cuts to human services during this fiscal year are probably unavoidable because tax revenues are not close to meeting the projected revenues required to fund the FY 2009 Massachusetts budget. Additionally, it appears that the new budget being developed by the state for Fiscal Year 2010 (July 1, 2009-June 30, 2010) will also reflect significant reductions in spending. Our senior team is currently developing budget alternatives in order to deal proactively with these likely reductions. We will keep you apprised of the budget situation as it unfolds over the next few months.

On a happier note, Beaverbrook STEP welcomed over 24 parents, siblings and other family members at the Third Annual Family Social which was held on Tuesday, September 9, 2008. The buffet dinner and social were followed by a lively group discussion that focused on the topic "What Adult Siblings Want Their Parents to Know". Siblings and parents shared their concerns and everyone agreed upon the importance of sibling involvement in planning for the long term care of their family members with special needs. Many families would like their adult children to be more informed about their family member's life, goals and activities.

In 2009 Beaverbrook STEP will conduct a Family Support Survey to determine workshop topics and other services that family members want developed. Also, we can add additional family members, particularly adult siblings, to our newsletter and family support mailing list. Just call or email the names and addresses to us. (See contact form at: www.beaverbrookstep.org)

Over the next 2 months Beaverbrook STEP will be mailing out Family Satisfaction Surveys. We hope that many of you will return these to the main office. This is an opportunity for family members to assess current services and to offer ideas for improvements.

We want to thank so many of you for attending our fun Holiday Dinner in December. Lastly, I want wish everyone a Happy New Year. May 2009 bring you peace, fulfillment and good health.

Sincerely, Ginny Connolly

Governor Patrick Announces 4 MA Institutions will Close by 2012

On December 12, 2008, The Arc of Mass. issued a press release about Governor Patrick's historic announcement that four of the State's six institutions (Fernald, Glavin, Monson and Templeton) would be closed by 2012, stating that it "is a clear victory for those with intellectual and developmental disabilities in the Commonwealth, and those who care and advocate for them".

The press release also indicated that the "administration's plan features the transition of hundreds of individuals from institutional settings to integrated community living options. Despite sharp national trends toward community-based options, 900 individuals statewide remain in institutions".

A two-part Boston Globe series on caring for children with disabilities

BALANCING ACTS A parental juggling job:

Workplace stigmas add to struggles of people with disabled children

BOSSES RESPONDING TO SPECIAL NEEDS

By Maggie Jackson

The articles are available on line at:

1. www.boston.com/jobs/news/articles/2008/12/14/a_parental_juggling_job/
2. www.boston.com/business/articles/2008/12/28/bosses_responding_to_special_needs/

Join the list serv for adult siblings:

www.siblingsupport.org/connect/the-sibnet-listserv



How to Contact your State and Federal Elected Officials:

www.arcmass.org Click on State House Dome picture "Take Action Now" on Home Page. Enter your home zip code and you will get the names of your Congressional and MA State Legislature elected officials.

www.mass.gov/legis/memmenu.htm Alphabetized list of State Senators and House Representatives with mail and email addresses, as well as phone numbers.

INTERESTED IN MORE INFORMATION ABOUT QUALITY OF LIFE ISSUES FOR FAMILIES? CHECK OUT THE WEB SITE FOR THE BEACH CENTER ON DISABILITY AT THE UNIVERSITY OF KANAS. YOU CAN ACCESS GREAT ARTICLES INCLUDING "FAMILY QUALITY OF LIFE CONVERSATION GUIDE" BASED UPON THE BEACH CENTER FAMILY QUALITY OF LIFE SURVEY. FAMILIES CAN USE THIS GUIDE AS A WAY TO IDENTIFY PRIORITIES FOR SUPPORTS AND SERVICES.

WWW.BEACHCENTER.ORG/FAMILIES/FAMILY_RESEARCH_TOOLKIT.ASPX

WHAT SIBLINGS WOULD LIKE PARENTS AND SERVICE PROVIDERS TO KNOW

(Source: The Sibling Support Project: www.siblingsupport.org)

IN THE UNITED STATES, THERE ARE OVER SIX MILLION PEOPLE WHO HAVE SPECIAL HEALTH, DEVELOPMENTAL, AND MENTAL HEALTH CONCERNS. MOST OF THESE PEOPLE HAVE TYPICALLY-DEVELOPING BROTHERS AND SISTERS.

- ✓ Brothers and sisters will be in the lives of family members with special needs longer than anyone....after parents are gone and special education is a memory.
- ✓ Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.
- ✓ Even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better.
- ✓ True "family-centered" care and services will arrive when siblings are actively included in agencies' functional definition of "family".

The Sibling Support Project facilitated a discussion on SibNet, its listserv for adult siblings of people with disabilities, regarding the considerations they want from parents, other family members, and service providers. Here are some of the typical themes presented by SibNet members; for the full summary with recommendations go to: www.siblingsupport.org.

- ◆ Siblings have the right to their own lives.
- ◆ Acknowledge siblings' concerns too.
- ◆ Expect Typical Behavior from Typically-Developing Siblings.

How Parents & Providers Can Help Siblings:

- ◆ Set Expectations for the family member with special needs.
- ◆ Siblings have the right to a safe environment.
- ◆ Siblings need opportunities for peer support too.
- ◆ Help siblings with their concerns about the future.
- ◆ Parents perspective is more influential for siblings than the actual disability.
- ◆ Include siblings in the definition of "Family".
- ◆ Communication among parents, providers and siblings is very important.
- ◆ Actively reach out to brothers and sisters.
- ◆ Learn more about life as a sibling.
- ◆ Include brothers and sisters in policy and decision making.
- ◆ Fund services for brothers and sisters.