

Family Connections

THE NEMASKET GROUP

NEWSLETTER # 55

MARCH - APRIL 2011

INSIDE THIS ISSUE

FRONT COVER

- Family Connections Welcomes Two New Staff Members.....1

FOOD FOR THOUGHT

- Life is Not a Dress Rehearsal.....2-3

INFORMATION TO SHARE

- Your Health.....4
- What is a SibShop?.....4
- PSWA of New England Walk/Silent Auction.....5
- Need a PCA?.....5
- A Diversity of Gifts, but the Same Spirit.....6-7
- DD Community Looks to Ways and Means Committee for Key Restorations.....7-8

AVAILABLE RESOURCES

- Literature:
My Baby Rides the Short Bus,
Stories of Vigilant Courage.....9
- The Hearts and Hands Walk for Autism and Family Fun Day.....10

FAMILY CONNECTIONS WELCOMES TWO NEW STAFF MEMBERS!

Introducing Kathleen Amaral...



My name is Kathleen Amaral and I recently started working for Family Connections on Tuesday, Wednesday and Friday. I was born and raised in West Warwick, Rhode Island, but marriage brought me to Massachusetts in 2001. My family lives in South Dartmouth and we have three children. My middle child was diagnosed with a rare genetic condition, Congenital Disorder of Glycosylation (C.D.G), in 2005 and lives with a myriad of health issues and developmental delays. As a parent of a child with special needs, I understand the importance of family support and I am looking forward to working with families.

Introducing Jennifer Newcomer...

Family Connections Staff



My name is Jennifer Newcomer. I live in Westport with my husband Anders and our three children, Dustin, Sage, and Emma. At 18 months old our youngest child, Emma, was diagnosed with a mixed seizure disorder, global developmental delay, and numerous other medical and behavioral conditions. The seizures remain uncontrolled and she continues to have numerous episodes on a daily basis. The challenges, obstacles, and joys that I have faced over the past 5 1/2 years have had an incredible impact on my life. I am extremely excited for the opportunity to use the knowledge that I have gained to help Family Connections in their goal to assist and support other families who face similar challenges.

Kathleen Amaral
Family Advisor

Louis Nisenbaum,
Executive Director

Jennifer Newcomer
Family Advisor

Amy Cornell,
Administrative Support

Emily M. Nisenbaum,
Associate Executive Director

Food for *Thought*

"Get ready!"

Actors are given a script. They learn their lines and practice the play over and over and over again, under the watchful eyes of the director. The set is constructed; costumes are donned; dress rehearsals begin. And at the appointed hour--ready or not--the curtain rises on opening night.

Life--for many people with disabilities--is not unlike the lives of actors preparing for a play, but with one significant difference. For actors, opening night signals the end of the readiness phase. But for people with disabilities, the dress rehearsals--getting ready for the real thing (LIFE)--continue indefinitely.

Parents and professionals depend on early intervention services (birth to three) to get babies and toddlers "ready" for preschool and/or public school. But by age three, most are not deemed "ready" for typical preschools. They're said to still need specialized services, and into a special ed preschool they go.

Special ed preschools attempt to get three- to five-year-olds "ready" for regular ed kindergarten. Yet far too many preschoolers with disabilities are never deemed "ready" for a regular ed kindergarten or first grade classroom. Some are even held back in preschool--and how, pray tell, does one fail preschool? Too often, the promise of special ed preschool is never realized as kindergartners are "placed" in a special ed resource room in the elementary school.

They, along with other students in many special ed classrooms (K-12), must then

LIFE IS NOT A DRESS REHEARSAL

Revolutionary Common Sense
by Kathie Snow, www.disabilityisnatural.com

somehow try to earn their way out of segregation. Only when they're considered "ready," are they "promoted" into a regular ed classroom. Even if they finally achieve this success, however, a tether remains. One infraction in the regular ed environment can land them back in a segregated

special ed room.

Sheltered workshops and other vocational services are supposed to get people "ready" for real jobs. Group homes and habilitation services are supposed to get people "ready" for independent living. But most "clients" never reach the level of readiness deemed necessary for working at a real job for living in a real home.

Get ready, get ready, get ready! The dress rehearsal for children and adults with disabilities never end. People with disabilities are on an assembly line, moving from one special program to the next. Does this mean people with disabilities are failures? Or could it mean today's programs and services are failing people with disabilities?

Barring a stock market crash and a severe economic depression, if the unemployment rate of the general population rose to 70-75 percent, we would probably attribute this to a failure of the educational system and other public services. We most likely would not blame the vast number of unemployed people.

But now consider the current 70-75 percent unemployment rate for people with disabilities--a figure that has held steady for the past 20+ years, despite more than a quarter of

"Practice!"

a century of federal special education law and more than a decade of the Americans with Disabilities Act. If we apply the logic in the previous paragraph, can we not see that something is very wrong with special education and other disability service systems--that the failure rests there, and not on the shoulders of people with disabilities?

Thinking about the brouhaha over "standards" in today's public schools can open our minds to the dilemma in Disability World. States have established standardized tests for students, to measure effectiveness of teachers and schools. Low test scores are (supposedly) seen as a reflection of poor reaching and/or school management, rather than a reflection of individual student ability. In other words, the problem--theoretically--rests squarely on the shoulders of those providing the services, not those receiving the services. Wouldn't this same logic also apply to disability services?

If so, does the fact that the majority of people with disabilities are unemployed/underemployed mean sheltered workshops and vocational and habilitation services have failed to adequately prepare people for real jobs and independent and/or supported living?

Or does the fact that we still have sheltered workshops and habilitation centers prove that public school special ed services have failed to adequately prepare students with disabilities for life as successful adults? Or does the fact that so many students remain in segregated K-12 classrooms mean that special ed preschools have failed in their efforts to get students "ready" for inclusion in regular classrooms? Or does the high number of young children in special ed preschools indicate a failure of early intervention services?

But wait! Perhaps the failure of disability service systems actually rests in the philosophy that keeps these systems running: The "readiness" paradigm. Disability services have devised artificial levels of readiness and competence based on an able-bodied standard

that many people with disabilities are unable to achieve (in some cases, the bar is constantly being raised and remains out of reach). And the resulting "not ready" status assigned to individuals with disabilities keeps the service system in business! If we choose to continue down the current path, the majority of today's children with disabilities will become adults who maintain the 70-75 percent unemployment rate, living below the poverty line, and never achieving their dreams.

Do we not realize that placing people in special "get ready" environments *retards* their growth and development? As Tom Powell, a learned man and father of an adult son with autism, once taught me, "If you want to learn to play basketball, you can talk to others about it, read about it, or watch others play, But the only way to really learn to play basketball is to get on the court and play!"

Are we truly willing to let even one precious day of a person's life be wasted in the demeaning, and often futile, attempt to meet another's standard of "readiness"? Would you be willing to exchange one day of the life you've chosen--a life of successes and struggles, laughter and tears--for one day of trying to reach a level of competence or success *as measure by someone else*? Would you be willing to spend your life in one dress rehearsal after another?

People with disabilities can achieve success in the same ways as people without disabilities: by having the right tools, accommodations, and supports in place (the things people without disabilities could not do without). In the great drama we call life, we each have an important role to play, and our individual performances can contribute to the overall good, or cause the play to close after one performance.

When we change our way of thinking, we'll know people with disabilities have been ready for opening night all along; it is actually we who have been stuck in the rehearsal mode.

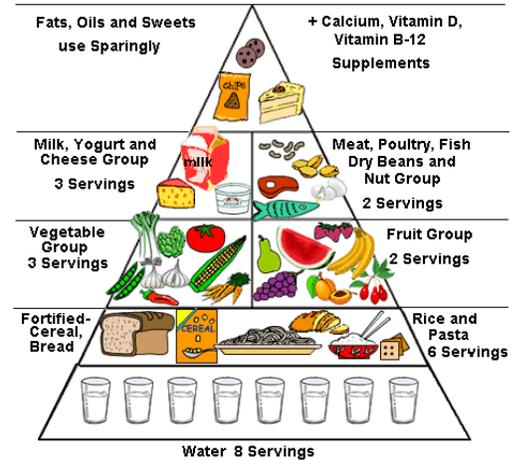
People with disabilities have always been ready for opening night!

Information to Share

YOUR HEALTH

HELPGUIDE.ORG offers a fantastic and in depth guide to: Healthy Fast Food and Tips for Making Healthier Fast Food Choices. This guide also includes comparisons of "Less Healthy" and "Healthier Choices" for Burger Chains, Fried Chicken Chains, Mexican Restaurants and Sub Shops, as well as PDF files of nutritional information from popular fast food restaurants.

For more information, please visit:
http://www.helpguide.org/life/fast_food_nutrition.htm



What is a Sibshop?

Sibshops are scheduled workshops that provide an opportunity for brothers and sisters of children with special needs to obtain peer support and education within a highly recreational context. Organizers and families appreciate that the workshops take a wellness approach, and the siblings who attend the workshops appreciate that they're fun and engaging. Siblings are often the family member most likely to have the longest relationship with the brother/sister with special needs and although they are not therapy, Sibshops prove to be therapeutic for some children.

Family Connections is planning on offering our families the Sibshop program. We want to set it up to specifically meet the needs of the children who want to participate. Family Connections would like to hear from families as soon as possible so we can better prepare to meet your needs.

Please fill out a short questionnaire online at:
<http://www.surveymonkey.com/s/5JTXXZT>

Your input is of most importance to us.
We will try to best accommodate our families based on your answers.

*If you do not have access to the internet,
please contact Kathleen Amaral at 508-999-4436 ext. 133*



On **June 4th 2011**, PWSA of New England plans to hold a Walk/Silent Auction for the New England PWS Community.

The event will be held at:
Borderland State Park
259 Massapoag Avenue
North Easton, MA 02356

For more information, to donate or to check out Silent Auction items, please visit:
<http://www.firstgiving.com/pwsaNewEngland>

Prader-Willi syndrome is a complex non-hereditary birth defect resulting from an abnormality on the 15th chromosome. PWS typically causes low muscle tone, short stature if not treated with growth hormone, incomplete sexual development, and a chronic feeling of hunger that, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive eating and life-threatening obesity, among many other medical and developmental issues. PWS is the most common known genetic cause of life-threatening obesity. Prader-Willi syndrome is a life-long condition and currently there is no cure.

*Prader-Willi Syndrome Association New England is a non-profit organization with a 501(c)(3) status as designated by the IRS and is dedicated to improving and enhancing the lives of everyone affected by Prader-Willi syndrome. This event will benefit both the PWSA New England and PWSA USA National organizations.



NEED A PCA?

PCA available Nights and Weekends. If interested, please call Sandy for additional information at:

(508) 999-4436 x 128



Bridges to Faith & Spiritual Connections



Present

A diversity of gifts, but the same Spirit

Spirituality and membership in faith communities is an often neglected but crucially important part of the lives of people with intellectual and developmental disabilities, as it is for all of us. Our congregations, our communities and our human service support workers all need to work together to support such membership and belonging.

In this workshop we will explore specific strategies to develop and sustain people's membership in their faith communities, led by **Jeff McNair** who is Professor of Special Education at California Baptist University, and by **Tom Doody** who is the coordinator of North Quabbin Citizen Advocacy (see biographies on next page). Jeff and Tom will be joined by a panel of local clergy and congregation members who will tell their stories of supporting people with disabilities as members of their faith communities.

Friday, April 15, 2011

8:30 A.M. to 2:00 P.M.

Registration from 8:00 A.M. to 8:30 A.M.

Location: Trinity Lutheran Church

16 Temple Place, Fairhaven, MA 02719-4005

Lunch will be provided

Registration Fee \$ 10.00

For more info please contact Trina Bigham 508-542-5589 or

email: bridges_to_faith@bettercommunity or

Jack Yates 508-468-8923 or email: YatesSNS@aol.com

To register: Make checks payable to Better Community Living and mail along with name, affiliation and address to

**Trina Bigham - Bridges to Faith,
One B Green Street, Fairhaven, MA 02719**

Directions:

From East or West - take Rt 195 to Rt 240/ exit 18, at 2nd set of lights turn right onto Rt 6/Huttleston Ave. Drive 0.4 miles. Turn left on Washington St. Drive 0.2 miles. Temple Place is first right. Trinity Lutheran Church is on the left.

Jeff McNair is Professor of Special Education at California Baptist University and directs the moderate/severe disabilities program. He also directs the entirely online, MA program in Disability Studies. Jeff is the Executive Director of the National Association of Christians in Special Education (NACSPED) and is currently the President of the AAIDD's Religion and Spirituality Division. Recently he took a part time position as Director of the Policy Center for the Joni and Friends Organization's Christian Institute on Disability. He and his wife Kathi have also been personally involved in church ministry to adults with intellectual disabilities for over 30 years.

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Tom Doody has been involved with disabled people for almost forty years. He has worked in a variety of services in direct care, management, and consultative roles. For the past thirty years he has been actively involved with Social Role Valorization training and is an associate of Dr. Wolf Wolfensberger (the originator of Social Role Valorization). For the past twenty-five years, his main work has been as a coordinator of North Quabbin Citizen Advocacy, an organization exclusively focused on recruiting and supporting freely-given relationships between disabled people and their non-disabled neighbors. The main focus of his consultation work has been to encourage families and agency staff to actively promote community inclusion and freely-given relationships. For the past eight years, Tom has coordinated the Christian Education program at the church he attends. In this role, he has worked to develop a fully inclusive church experience for all of the involved youngsters and adults.

DD COMMUNITY LOOKS TO WAYS & MEANS COMMITTEE FOR KEY RESTORATIONS

As legislators move from hearing to hearing in the State House, members of the House Ways & Means Committee, led by Haverhill Democratic Representative Brian Dempsey, are entering the final three weeks of pulling together the House version of the FY 2012 Budget.

Here's how the Massachusetts Budget and Policy Center describes the challenge of balancing the FY 12 budget:

In the coming fiscal year (FY 2012) the state is facing a budget gap of approximately \$1.9 billion dollars between the cost of providing current services and the revenue projected to be available. The Governor's budget (House 1) proposes closing this gap with a combination of deep cuts, significant reforms, limited use of reserve funds and other temporary revenues, and modest revenue initiatives... (including) reducing day health services for frail elders and disabled adults.

Advocacy groups have met with individual legislators to urge restoration of the following key items:

Line Item 5920-3000 DDS Respite & Family Support: The Governor's budget cuts services for 4000 individuals and families. Services that are at risk for loss include in home supports, individual therapies, reduced hours for autism resource centers,

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emergency assistance, respite hours for beleaguered families and individual family emergency counseling.

Line Item 4000-0300 Mass Health Day Habilitation, Adult Foster Care and Adult Day Health Services. The Governor's budget reduces long term care rate reimbursements by \$15 million, saving the State General Fund \$7.5 million, while losing \$7.5 million in matching federal dollars. Hundreds of families and consumers turned out at public hearings and have begged the Administration to pull back this cut; citing the tremendous risk to the health and safety of people with disabilities if these cuts were to occur and staff were terminated in these programs.

As of March 15, 2011, the Administration announced they were not immediately implementing these Mass Health rate cuts, but would conduct "further study". If these cuts are withdrawn, the FY 12 budget will need to be amended to restore these cuts.

Line Item 5920-2025 Day & Employment & Line Item 5920-2000 Residential Services are underfunded making it impossible to meet Court Rolland obligations and Turning 22 Case Loads.

Line Item 5948-0012 & Line item 7061-0012 DESE/DDS Family Preservation Support. The Governor recommends \$6.5 million to support this cost effective program that keeps kids in their homes, but fails to provide the needed language to direct DESE to send the dollars to DDS. Without this language inserted, DESE has not sent the fully appropriated amount, thus the Governor's intent is in doubt.

Chairman Dempsey is expected to release his Committee's budget recommendation on Wednesday, April 13, 2011; and amendments are likely to be filed by April 15, 2011 for debate the following week.

PLEASE: Call or email your Representatives and ask them to protect services for individuals with disabilities and families. As the House of Representatives prepares its budget, ask your legislator to consider the needs of individuals with disabilities and their families who rely on state funding to continue to live in their communities. We KNOW the economy is in crisis – creating crisis in the lives of our families is not a solution for that.

Representative William Straus
Room 134
William.Straus@mahouse.gov
617-722-2400

Representative William Cabral
Room 466
Antonio.Cabral@mahouse.gov
617-722-2017

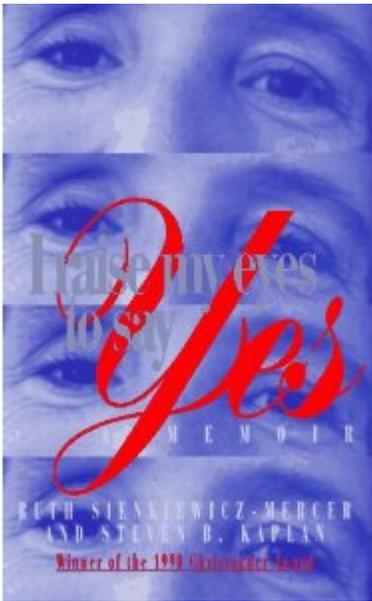
Representative Robert Kozcera
Room 448
Robert.Kozcera@mahouse.gov
617-722-2582

Susan Williams Gifford
Room 542
Susan.Gifford@mahouse.gov
617-722-2976

Representative Stephen Canessa
Room 489
Stephen.Canessa@mahouse.gov
617-722-2460

Available *Resources*

Literature



I Raise My Eyes to Say Yes

Ruth Sienkiewicz-Mercer

Ruth Sienkiewicz-Mercer was born in 1950. She has never spoken a word; never walked, never fed herself, never combed her own hair. Trapped in a body that is functionally useless, her mind works perfectly. This is her story. Absorbing and heartbreaking, it was written with the collaboration of Ruth's friend, Steven Kaplan. Without any self pity Ruth recounts her early childhood with a loving family and some happy years at a rehabilitation center, then virtual incarceration at the notorious Belchertown State School in Massachusetts. After 16 years she was released and now she enjoys a life of purpose and personal triumph. **I Raise My Eyes to Say Yes** will permanently alter your perception of the severely disabled and it will inspire you with the extraordinary power of love, thought, and the human spirit.

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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