

# FAMILY CONNECTIONS

The Nemasket Group



Issue # 39

July-August 2007

NEWSLETTER

## Upcoming Events at Nemasket

### *Nemasket's 2007 Summer Sizzler!*

**Come celebrate summer with all of the staff and families of The Nemasket Group & Family Connections. We invite you to join us for a cook-out and an afternoon of fun, which includes:**

**Children's Activities, Arts & Crafts, Music, Good Food and More!**

**DATE:** August 16, 2007 {Rain or Shine} **TIME:** 4:00pm-7:00pm

**LOCATION:** The Nemasket Group 56 Bridge St. Fairhaven, MA 02719

**We hope you can join us!**

### *Nemasket's 6th Annual Golf Tournament @ ALLENDALE COUNTRY CLUB*

**DATE:** Monday, August 27th, 2007 **CHECK IN:** 11:30am-12:45pm **SHOT GUN START:** 1:00pm

**\$125 per Golfer** Register a foursome for only \$450 (Includes Golf, Cart, Prizes & Dinner)

**Hole Sponsor -\$100** Maximum 144 Golfers/36 Teams Proper Golf Attire/Spike-less Course

**Raffle, Auction, Award Ceremony & Dinner Immediately Following**

**Final Registration:** August 24th, 2007

**ALL PROCEEDS TO BENEFIT THE NEMASKET GROUP**

**For more information contact Kathy Souza at 508-999-4436 x122**

**For volunteer information, contact Kathy Souza no later than August 10th, 2007**

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### **Family Connections Staff:**

Sandra Kinney, *Program Director*

Ross Hooley, *Family Advisor*

Jorge Pagan, *Family Advisor*

Gloria Villalobo, *Family Advisor*

Sherry Amaral, *Family Advisor*

Emily Murgo Nisenbaum, *Associate Executive Director*

Louis Nisenbaum, *Executive Director*

***GOOD NEWS ON THE 2008 BUDGET:*** Governor Releases Budget Vetoes

On July 12, 2007, Governor Patrick released a list of vetoes, striking language and \$41 million from the \$26.8 billion FY2008 state budget. Patrick's vetoes were a fraction of those issued by his predecessor, former Gov. Mitt Romney, whose vetoes totaled \$573 million for the FY2007 budget.

**The Governor let stand priority accounts identified by The Arc, Mass. Families Organizing for Change, Association of Developmental Disabilities Providers, and Mass. Advocates Standing Strong – including Turning 22, Family Support, and the EOHHS salary reserve.**

As advocates, we always encourage everyone to remember to say thanks to follow up on our requests for support. In this case, you can write the Governor to let him know you appreciate his willingness to spare disability accounts from the Governor's list of vetoes. Mail to: Governor Deval Patrick  
State House, Rm. 360 Boston, MA 02133

***NEW APPOINTMENTS BY GOVERNOR DEVAL PATRICK:***

Dr. Jean Flatley McGuire-Assistant EOHHS Secretary - Disability Policies and Programs

Dr. Jean Flatley McGuire comes to the Executive Office of Health and Human Services (EOHHS) from Northeastern University, where she served as Senior Clinical Professor at the Bouvé College of Health Sciences. Prior to Northeastern, she served as Assistant Commissioner for the Massachusetts Department of Public Health from 1997-2003.

In her new role, she will oversee: the Department of Mental Retardation, the Massachusetts Rehabilitation Commission, the Massachusetts Commission for the Blind, the Massachusetts Commission for the Deaf and Hard of Hearing, the Chelsea Soldiers' Home and the Holyoke Soldiers' Home. Additionally, she will have cross-Secretariat responsibility for disability related policies and programs.

***Elin Howe Named New DMR Commissioner***

Elin Howe, former NY State Commissioner, has been appointed as the new Commissioner of the Massachusetts Department of Mental Retardation.

Elin Howe has almost 30 years of experience in the field of Developmental Disabilities, including almost four years as Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities. As Commissioner, she was responsible for policy development, planning, financing, regulating, managing, and providing services to approximately 75,000 New York State citizens with mental retardation and developmental disabilities.

Howe has provided consultation services on developmental disabilities issues in five states including: New Mexico, Indiana, California, Iowa and Georgia. During her tenure as NY Commissioner, Ms. Howe increased access to home and community based services by greatly expanding two waiver programs, one for children and adults and another specifically targeted to children with developmental disabilities and complex medical needs. Additionally she closed several institutions during her tenure and expanded the role of individuals with disabilities by supporting self-advocacy efforts.

*We wish both Dr. Jean Flatley McGuire and Commissioner Elin Howe well  
as they begin their new tenure.*

**Editor's Note:** *Following are two interesting and thought provoking articles. Both illustrate that while we have made great strides in supports for individuals with disabilities and families, there are disturbing societal trends worthy of reflection, concern and action.*

## A mother's view of a word that wounds: 'Retard'

By Theresa Howard

You are such a retard.

You've heard the expression. Sometimes it's preceded by an expletive, as in "you're such a f—ing retard." Either way, with or without the curse word, it's a harsh statement. But one, it seems, that's become increasingly acceptable. So much so that in one recent week I kept track of how many times I heard it and who said it. I heard it daily — whether it was a colleague, a neighbor talking to his dog, an actor from a hit TV show during an interview with me, a top level advertising executive, young men playfully swapping insults or Tony Soprano to his son after a botched suicide attempt.

Last year, the r-word was in the title of a *Two and a Half Men* episode. It's a word that, unlike "pimp" or the n-word, is always derogatory. For reasons that I can't understand, pimp has become synonymous with style. The n-word, for a handful of African-Americans, is a term of endearment — until someone outside the circle uses it. Then it becomes derogatory.

But no matter how or by whom the r-word is used, it's always in a negative context. You don't hear, "What a great idea, that's so retarded." You don't hear, "Awesome catch — what a retard move."

While some are advocating that the n-word be banished from America's lexicon, who is the voice for the 7.5 million Americans with intellectual disabilities who truly are mentally retarded? Who is defending their dignity while everyday folks — educated adults at that — take a term that clinically applies to the disabled and use it as an insult?

What's my fascination with the r-word? I take it very personally. And I'm not a person who is easily offended. I am, however, the mother of a 6-month-old daughter who was born with Down syndrome. Lydia Catherine is sweet. She's got a warm smile and very knowing blue eyes. She's got a subtle little dimple and a tiny tuft of strawberry blonde hair that swirls into one single swoop into the air.

When she looks at me, I feel like she can see all the fears, concerns, doubts and questions that swim around in my heart and my mind every day. Will she be smart enough to know when she hears people say the word "retard" that they are talking about her?

This is not new territory for me. I grew up the sibling of a Down syndrome sister. Catherine Anne was 41 when she passed away four years ago. She was born at a time when "mongolian idiot" was the operative term, and doctors suggested to my parents to leave her behind and she'd be taken care of. It really meant she would have been institutionalized. They didn't listen. Catherine lived with my parents until the day she died.

## **A mother's view of a word that wounds:** *Continued*

For as long as I can remember, I corrected people when they said the r-word. I flashed dirty looks to people who stared. I told parents to tell their child that it's not polite. Ever gregarious, Catherine would smile at strangers, many of whom would be so uncomfortable that they didn't know what to do. Even after Catherine passed away, I continued to correct people for a few years. Then I got tired. I no longer felt it was my battle.

Until Dec. 10, when Lydia was born. My journey has begun all over again, this time with me as the mother and my older daughter, Sofia, as the sibling. If I was protective of my sister, I am almost scared of how protective I will be for Lydia and her own sister. But as she grows up in a time when "retard" is a socially acceptable slur, professional organizations are trying to change the clinical term. Last November, the American Association on Mental Retardation changed its name to the American Association on Intellectual and Developmental Disabilities. The Special Olympics is advocating that "retarded" be dropped from the vernacular.

Fixing the terminology is only a start. The bigger issue is acceptance of people with disabilities. Do your part. Don't stare. Say hello. Be inclusive. And when you want to insult someone's intelligence, remember to use a different word.

*Theresa Howard is an advertising reporter for USA TODAY. She lives in Hoboken, N.J., with her husband, Peter Baracskai, and their two girls. (Photo -- Lydia Catherine: Author's daughter was born with Down syndrome.)*




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## **Justice for All: Haunting Echoes of Eugenics**

By Andrew J. Imparato and Anne C. Sommers

In its preamble, the recently unveiled U.N. Convention on the Rights of Persons With Disabilities recognizes "the inherent dignity and worth and equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world."

We wonder what Oliver Wendell Holmes would have said about that.

This month marked the 80th anniversary of the disgraceful Supreme Court decision in *Buck v. Bell*, which upheld Virginia's involuntary sterilization laws. In his majority opinion, Holmes declared: "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind . . . Three generations of imbeciles is enough."

Although eugenics was eventually dismissed as "junk science," it didn't happen before states authorized more than 60,000 forcible sterilizations and segregated, institutionalized, and denied marriage and parental rights to those deemed "genetically unfit."

Though society may be inclined to regard Holmes's detestable opinion in *Buck v. Bell* as a relic of a time past, eerie similarities exist in contemporary remarks of the well-respected. *Continued on pg. 5*

### **Haunting Echoes of Eugenics: Continued**

Justifying the sterilization of "genetically unfit" individuals, Holmes wrote that Carrie Buck was "the probable potential parent of socially inadequate offspring."

Some 72 years later, renowned embryologist Bob Edwards said, "Soon it will be a sin for parents to have a child that carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children."

Not long ago, an embryo entrepreneur boasted on her business's Web site, "In the process of screening donors, we select only those that have clean medical backgrounds. . . . The embryos that are available have all been medically 'graded,' so that the recipient family knows the quality of the embryos that they will be implanting."

In the past, eugenicists emphasized the "burden" of disability. Holmes wrote that individuals with disabilities "sap the strength of the State."

In recent years, Peter Singer, a professor of bioethics at Princeton University, has said, "It does not seem quite wise to increase any further draining of limited resources by increasing the number of children with impairments."

In January, the American College of Obstetricians and Gynecologists urged all women regardless of age to undergo prenatal screening for Down syndrome, aware of statistics that greater than 85 percent of pregnancies diagnosed with Down syndrome end in abortion. Several states recognize life with a disability as an injury in "wrongful life" lawsuits, and certain judges who hear these cases agree that in some instances, selective abortions help answer a greater policy concern in curbing health-care expenditures.

Last fall, Britain's Royal College of Obstetricians and Gynecologists argued for "active euthanasia" of significantly disabled newborns to spare parents emotional and financial burden. Two years earlier, the Groningen Protocol emerged in the Netherlands; it proposed selection criteria for euthanizing babies and children with disabilities.

And across the United States, "futile care" policies have required that the most vulnerable give up their hospital beds -- and lives -- for those with more "potential." In stark contrast to words such as "defective," "burdensome" and "futile" are the words of civil rights laws that liberate and defend.

The Americans with Disabilities Act recognizes disability as a natural part of the human experience that in no way should limit an individual's ability to participate fully in all aspects of society. The U.N. convention reaffirms that people with disabilities have both a right to life and a right to the effective enjoyment of that life on an equal basis with others.

On this 80th anniversary of Buck, let's not foolishly believe that victims of eugenics are an artifact of history. So long as we speak in terms of good genes and bad genes, recognize a life with a disability as an injury, and allow health policies to value some lives over others, we continue to create human rights violations every day.

*Source: Andrew J. Imparto is president and chief executive, and Anne C. Sommers is the policy counsel of the American Association of People with Disabilities, based in Washington, D.C.*

## **The 9th Annual Autism Summer Institute**

**Raising Expectations: Presuming Competence! The Importance of High Expectations for Learning, Communication and Friendship**

### **Event Details:**

**Dates:** August 13-16, 2007

**Time:** August 13-15: 8am - 3:30pm  
August 16: 8am to 12pm

**Registration Fee:** \$399

Self-Advocate / Student / Parent rate: \$299

Keynote only rate: \$60 each

**Location:** University of NH, Holloway Commons, Durham, NH

**To Register:** online @ [IOD.UNH.EDU](http://IOD.UNH.EDU)

**OR** call Family Connections for a copy of the registration form

### **Description:**

The goal of the Autism Summer Institute is to provide strength-based perspectives about students with Autism Spectrum Disorders (ASD) to improve the quality of education in inclusive settings.

Participants will gain skills and knowledge that will help support the full participation of students with ASD in their schools and communities. This Institute offers a unique combination of keynote presentations and workgroups. The registration fee includes participation in all four days activities. A separate fee has been established for those interested in attending one or more keynote presentations only.

The Autism Summer Institute is presented by the NH Resource Center on Autism Spectrum Disorders in collaboration with [The Autism National Committee](#) and [The Autism Society of New Hampshire](#)

### **Keynote Presenters:**

#### **Ros Blackburn - Monday, August 13, 2007 • 9:00am - 10:30am**

As a highly sought after international speaker, Ros draws on her experience living with severe autism and being a recipient and observer of care services and educational approaches. Ros tells it “as it is” and does not disguise the fear and limitations, which are part of her daily experience. She explores her journey with humor and passion, offering valuable insight as well as helpful advice on practical strategies. Philosophically, her position on ASD is best summarized as an insistence on the need for high expectations for people with ASD linked to equally high levels of support. In a quote from her mother, Ros pleads that one should “Never, never make autism the excuse, but help the person overcome the problems caused by it.”

#### **Jamie Burke - Tuesday, August 14, 2007 • 9:00am - 10:30am**

Best known for the Facilitated Communication (FC) video “Inside the Edge,” Jamie, a 19-year-old with autism, is a freshman at Syracuse University. Although he didn’t speak his first words until he was 12, Jamie is able to communicate with a poetic elegance and has addressed audiences all over the

### **The 9th Annual Autism Summer Institute: *Continued***

world. He recently joined TASH in presenting to Congress a public policy statement, "The Right to Communicate." He has been featured on CNN, in People and Time magazines, and at numerous IOD conferences. He continues to be a strong advocate for FC as a gateway to speech and literacy. Jamie attributes much of his life's successes to years of innovative therapy and access to inclusive classrooms.

#### **CarolAnn Edscorn - Wednesday, August 15, 2007 • 9:00am - 10:30am**

Born and raised in New England, CarolAnn has learned never to let Asperger's Syndrome define her boundaries or limit her aspirations. A lover of the liberal arts, CarolAnn attended the University of Rhode Island, graduating in 1976 with a BFA in Acting and Directing. She later attended Southern Illinois University, where she earned a master's in Urban Affairs Management and Public Policy Analysis, specializing in Education and Health programs. A master of many trades, she has dabbled in professional music, ordained ministry, art, published writing, acting, directing, and teaching at the post-secondary level. She and her husband Christopher have five children, ages eight through 20, all of whom CarolAnn has educated at home.

#### **Donna Williams - Thursday, August 16, 2007 • 9:00am - 10:30am**

Author, artist, musician, celebrated international public speaker, and autism consultant, Donna was born in Australia and showed signs of autism from infancy. She began to write as a preteen, and was encouraged to publish an early autobiographical manuscript which became the international best-seller "Nobody, Nowhere," one of the first autobiographies published by an individual with autism. In addition to her large volume of published work, she has written and recorded a music album, co-founded Autism Network International, has become an accomplished painter and sculptor, and written several screenplays. As a consultant in the field of autism, she has worked with hundreds of people on the autistic spectrum through schools, health and human services, and directly with families and adults with autism.

#### **Who Should Attend?**

The Autism Summer Institute is designed for, and will benefit, university students, individuals with ASD and their families, teachers, paraprofessionals, speech and language pathologists, occupational therapists, physical therapists, school administrators, guidance counselors, psychologists, school-family teams, and others.



## **Summer Fun!** By Gloria Villalobo

In June of this year, the Southeast Regional office of the Department of Mental Retardation (DMR) gave family support provider agencies the opportunity to receive one time funding that was available for children who are DMR eligible. The intention was to create a one-week recreation program during school vacation that would be inclusive of children with disabilities, their siblings and families.

As veteran employees of Family Connections/The Nemasket Group, my co-worker (Jorge Pagan) and I decided that we would write a simple proposal and create a one week program for the children, siblings and families who are part of our Support Group, who would otherwise not have the opportunity to participate in this type of program.

Most of the time, our children are headed in different directions, to do different things, because of differences in abilities. We thought this would be a good opportunity for all children in the same family to share the same experience. These children and their parents are part of our Hispanic parent support group for the Spanish speaking families in our community.

On June 25th through the 29th, we enjoyed a complete week of fun filled activities which included:

### ***A Day At The Buttonwood Park Zoo***



### ***A Day Of Creativity at ARTWORKS-New Bedford***



**Summer Fun!** *Continued*

*Fun In The Sun-Fort Taber, New Bedford*



*Dartmouth Mall-Movie and Lunch*



*Splashing Fun- Water Wizz of Cape Cod*



We would like to take this opportunity to say thank you to the Department of Mental Retardation, as well as, Family Connections/The Nemasket Group for allowing us the freedom and flexibility to create such beautiful memories and experiences for families in our communities.



## **Health U: A Weight Loss Study for Teens with Down Syndrome**

### **What is Health U.?**

Health U. is a study that is designed to compare different weight loss programs for teenagers with Down syndrome who are overweight. The study emphasizes a sensible, balanced diet and achievable levels of physical activity geared toward weight loss and health promotion. Participation is completely voluntary and requires both parent and teen involvement throughout the program. The study compares different weight loss approaches in a “randomized controlled trial,” which means that participants are randomly assigned to separate groups that use different weight loss approaches. The number of visits to the Shriver Center will depend on the group to which you are assigned.

### **What are more details about each specific group?**

There is a Nutrition & Activity Education Group where participants will learn healthy eating and physical activity habits. There is a Behavioral Intervention Group where participants will learn behavioral approaches to setting and reaching healthy lifestyle goals. Participants enrolled in both the Nutrition & Activity Education Group and Behavioral Intervention Group will attend 16 evening classes over the course of 6 months. Participants from these two groups will be compared to determine which type of classes are the most effective. There is also a Wait List Group where participants will not attend any classes until the end of the study (total study length is about 1 year). After 1 year, participants in the Wait List Group will be invited to take the classes that are determined to be the most effective.

### **What are the Health U. classes like?**

The classes are taught by a nutritionist and/or a behavioral psychologist and a research assistant. They are interactive, hands-on, and designed to be fun and engaging. Teens receive weekly “prizes” such as t-shirts, water bottles, and gift certificates to maintain their motivation.

### **What will we do in the study?**

All participants will be weighed and measured before the study starts, as well as at various intervals over a 1 year period once the study begins. All participants will attend several screening visits prior to the start of the program. Participants will also wear a lightweight activity monitor for a week at the beginning, middle, and end of the program. We will also ask parents and teens to keep a 3-day record of what the teen ate at different times throughout the study.

### **Who can participate?**

Healthy adolescents ages 13-21 with Down syndrome are invited to volunteer. Medical approval is required from the teen’s doctor. Adolescents must be living at home & clinically overweight. They should also have an IQ between 45-69 and the ability to participate in a group classroom setting. Because this is a research study, participation may be limited by certain medical problems.

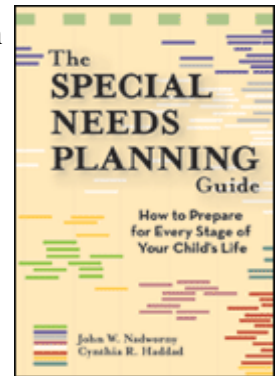
### **Would you like to be a part of Health U.?**

Health U is a new study researching weight loss strategies for overweight teenagers with Down syndrome. If this sounds like a program your family would like to join, you are invited to volunteer for the study. Classes and visits will be conducted at the Shriver Center in Waltham, MA. Participation is free.

*For more information, please contact Melissa Maslin at:  
781.642.0292 or via email at: [shriverhealth@umassmed.edu](mailto:shriverhealth@umassmed.edu)*

## **The Special Needs Planning Guide** By John W. Nadworny & Cynthia R. Haddad How to Prepare for Every Stage of Your Child's Life:

Developed by two financial planning experts who also have family members with special needs, this one-of-a-kind book is an absolute must-have as parents and other caregivers plan for the lasting financial security of their families.



Transforming the financial planning presentations they've given to families across the country into a thorough, easy-to-read resource, the well-known authors give parents a chronological guide for each stage from birth to adulthood. Parents will get comprehensive advice and strategies on how to address:

**Financial Factors:** including mortgages and other expenses, insurance policies, investments, and savings legal factors—such as conducting estate planning, weighing guardianship with less restrictive alternatives, and creating a Special Needs Trust to ensure a child's future.

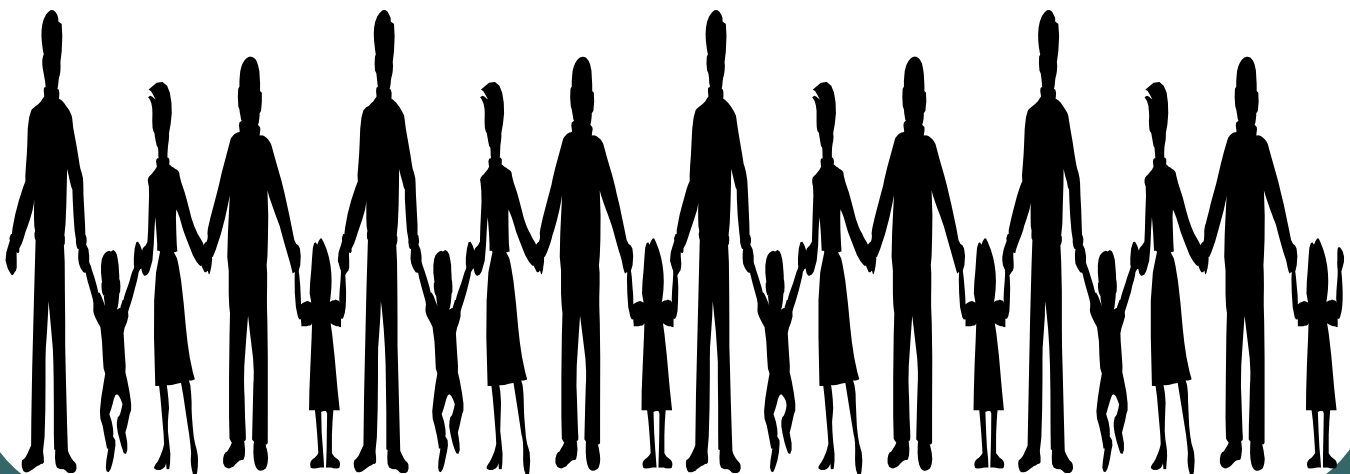
**Government Factors:** identifying and supplementing government benefits, such as residential services, supported employment, and respite care.

**Family and Support Factors:** such as the family's values, the parents' careers, sibling considerations, and contributions of extended family members emotional factors—such as dealing with both positive and negative feelings, staying connected with others, and using strong emotions to fuel advocacy.

Included are all the tools families need to create an effective action plan for their finances: planning checklists and forms, a helpful glossary of financial terms, “planning pointers” that help readers remember key points, and extended case studies dramatizing other families' evolving challenges and solutions. Plus, the CD-ROM in the back of the book contains a helpful Financial Planning Timeline and a printable Letter of Intent that lets parents communicate key information, concerns, and desires to future caretakers.

A book parents will use for the rest of their lives, this guide is also a necessary addition to the reference library of every service provider.

***Family Connections has multiple copies-Call to borrow one. 508-999-0077***



## Blue Mountain Center for Living Arts



Blue Mountain Center For Living Arts offers Massage, Reiki, Psychotherapy and expressive arts therapy. Serving Individuals and Groups, Adults, Adolescents and Children in each of the following areas: Ancient Healing Arts, Ancient Healing Art Supplies, Art Therapy, Expressive Art Classes, Mandala & Spirit Art Workshops, Maskmaking, Spirit Art Gallery. Accepting MassHealth payments.

**Contact:** Anna D'Epiro Trafton LICSW ATR

**Located at:** 15 Middle Street, Fairhaven, MA.

**Ph:** 508-997-5989 or 508-243-7931

**Email:** [bluemtfarm@aol.com](mailto:bluemtfarm@aol.com)

the  
**nemasket**  
group

### Family Connections

Joint Project of The Nemasket Group and

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Creating a network of family support

For individuals with developmental

Disabilities and their families