



# Monday Morning

May 2006

[www.njcdd.org/mondaymorning.htm](http://www.njcdd.org/mondaymorning.htm)

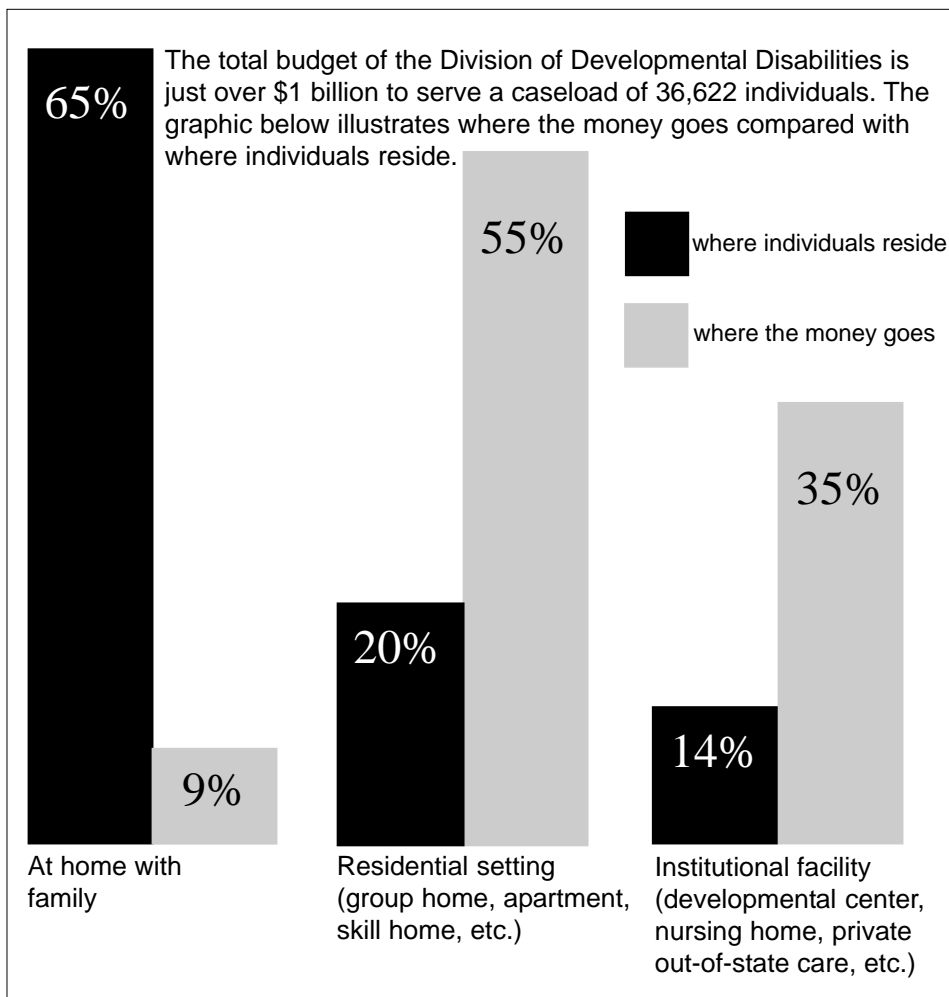
Volume 12, No.4

## FAMILIES TO STATE: "KEEP US TOGETHER"

This year's proposed state budget does not increase funding for support services to families with a member with developmental disabilities living at home.

Without these supports, families could be at a greater risk to experience family violence—individuals with developmental disabilities who reside at home with no support for them or their family may be vulnerable to being abused at any stage of their life. Parents may become burned out and seek far more costly out-of-home placement for their family member with disabilities.

At regional public forums, organized by a coalition of agencies concerned about support for families, family members and individuals with disabilities told panels of state legislators and leaders in the disability community how crucial these supports are to keep their families together. In fact, the public forums have been dubbed the "Keep Us Together" hearings. Families are asking for increased dollars in the state budget for support services for them, for students leaving school and for people on the State's waiting list who do not want to leave their families.



The Division of Developmental Disabilities, which provides respite services, transitional services for people graduating from high school and self-directed service options

known as Real Life Choices, has a caseload of 36,622 individuals. Sixty-five percent of the division's caseload live at home with their families.

*(continued on page 2)*

## Families seek support to stay together

(continued from page 1)

lies. However, only nine percent of the division's \$1 billion budget is dedicated to these families.

In contrast, the division spends 55 percent of its budget on residential settings like group homes, supervised apartments and skill homes, serving only 20 percent of its caseload. According to the division, 60 percent of the 3,300 people on the state's priority waiting list for residential services want less costly in-home supports to stay together, because they are not ready for out-of-home placements.

"Helping families now, before they burn out, will help New Jersey's taxpayers for years to come," said Monique Wilson, Statewide Family Support Coordinator. "In-home supports cost a lot less than out-of-home residential services. The vast majority of new people applying for state services are under age 22, and they are not requesting out-of-home placement, but support for their families while they live there."

Traditional community-based residential programs cost \$90,000 to \$146,000 per year. Through Real

Life Choices, family members are given a budget between \$14,000-\$63,000 for home renovation, transportation or aides to help with daily living activities, so they can stay at home

The testimony at the public hearings will be transcribed and presented to the Assembly and Senate appropriations committees at a press conference this summer.

For more on this issue, log onto [www.njcdd.org](http://www.njcdd.org).

## Action Alert on health insurance marketplace bill

Families USA, based in Washington, D.C., is asking advocates to urge their U.S. Senators to oppose a bill that the agency calls, "one of the most damaging private market proposals in recent memory."

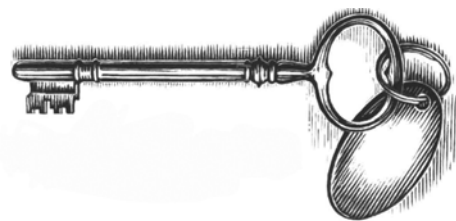
The Health Insurance Marketplace Modernization Act (HIMMA, S.1955) was introduced by Senator Mike Enzi of Wyoming and passed through the relevant committee on a party line vote on March 15th.

According to Families USA, the bill would strip away mandated benefits that state legislatures have worked hard to pass over past de-

acades. HIMMA would impede access to health care providers that state legislatures have deemed necessary in their respective states.

In addition, the bill would undermine valuable rating rules that prevent insurers from discriminating based on health status, age, gender, and other criteria that prevent health care costs from skyrocketing for many Americans.

## Summer Inclusion Conference aims to unlock doors



The New Jersey Coalition for Inclusive Education will present its Summer Inclusion Conference June 28-29 at the Montgomery High School in Skillman, NJ. The conference is titled "The Keys to Inclusion: Unlocking the Doors for Children with Mild to Significant Disabilities."

Presentors include Jonathan Mooney, author of "Learning Outside

# NJCDD

*Monday Morning* is published by the New Jersey Council on Developmental Disabilities

**Chair:** Maureen Babula **Vice Chair:** Lorraine D'Sylva-Lee **Editor/Writer:** Greg Mizanin

**ADDRESS:** PO Box 700, 20 West State Street, Trenton, NJ 08625-0700. **INFORMATION:** 1.800.216.1199

**OFFICE:** 609.292.3745 **TDD:** 609.777.3238 **FAX:** 609.292.7114 **INTERNET:** [www.njcdd.org](http://www.njcdd.org) **EMAIL:** [njddc@njddc.org](mailto:njddc@njddc.org)

*Monday Morning* is a compilation of news stories from various sources, organized to provide information about proposed federal and state policies, programs and laws to New Jersey's grass-roots disability community. The opinions expressed are not necessarily representative of the opinions of all or a majority of the members of the N.J. Council on Developmental Disabilities.

*Monday Morning* is an initiative of the "Monday Morning Project," an effort by disability community advocates to mobilize people with disabilities to preserve the rights they are entitled to under current federal law; to preserve vital support services; and to give people with disabilities and their advocates a major role in determining how federal funds and matching state dollars

the Lines,” a memoir/alternative study skills guide with insights from growing up with learning disabilities.

Also scheduled to present are David and Cyndi Pitonyak, nationally recognized experts on positive approaches to difficult behaviors and fully inclusive education for children with significant disabilities.

Workshops include: “Individualizing Transition,” “Parents’ Toolbox for Inclusion,” “The Home-School Assistive Technology Connection,” “Parent Resources and Inclusive Childcare” and “Working Toward Effective Inclusion.”

Conference partners are NJ Education Association; NJ Dept. of Education, Office of Special Education Programs; NJ Council on Developmental Disabilities, National Down Syndrome Society; Statewide Parent Advocacy Network and NJ Association of School Psychologists.

The Montgomery High School is located at 1014 Route 601, Skillman, NJ 08558.

Parent scholarships are available. For a full brochure and registration form, log onto [www.njcie.org](http://www.njcie.org) or contact the Coalition at 732.613.0400 or by e-mail at [njcie@comcast.org](mailto:njcie@comcast.org).

## National disability organization to consult with NY Mets

United Spinal Association, a national disability rights organization based in Queens, has been selected by the New York Mets to ensure that its new ballpark, scheduled for completion by Opening Day 2009, will be fully accessible to all fans

*(continued on page 4)*

## 17<sup>th</sup> Annual Conference on Medical Care for Persons with Developmental Disabilities

The 17<sup>th</sup> Annual Conference on Medical Care will be held on Friday, June 2, 2006 at the Westin Princeton in Forrestal Village. The conference is sponsored by The Arc of New Jersey’s Mainstreaming Medical Care Program.

The keynote address will be given by **Roger Louis Chaufournier**, Chairman of the Board and Chief Executive Officer of Patient Infosystems, a health services and population health management company. The keynote speech will be followed by an interactive panel discussion entitled, “Chronic Disease Management for Individuals with Diabetes,” moderated by **John Nevins, D.O.**, Co-Medical Director, The Arc of Monmouth. **Ann Clemency Kohler**, the Director of Medicaid, will provide up-to-date information on New Jersey’s Medicaid system. Conference attendees will choose from among these 10 timely workshops:

- Health Policy: Medicaid Under Fire: Is the Pressure Going to Let Up?; and Medicare Prescription Drug Coverage: Where are we Headed?
- Co-Occurring Disorders: Providing Quality Supports and Services for Individuals with a Dual Diagnosis: An Overview of Successful Programs in Other States; and Benchmarking Excellence in Behavioral Health Programming for Dually Diagnosed Adults
- Genetic Disorders: Family History And Genetic Risk For Illness; and The Genetic Causes of Developmental Disabilities
- Lead Poisoning: Lead Exposure: What It Does to Our Children; and Lead Forum: Programs for the Lead Burdened Child
- Sexuality Issues: Sex, The Law, and Persons with Developmental Disabilities; and Assessing Sexual Abuse In Individuals With Developmental Disabilities: Breaking The Cycle. This conference is for everyone who is concerned about providing quality health and mental health care to persons with developmental disabilities, including: health and mental health professionals; administrative and direct care staff at provider agencies; social workers; family members; HMO representatives; and employees of the Departments of Human Services and Health and Senior Services.

The registration deadline is May 19th, and early registration is advised. A registration fee of \$50 includes continental breakfast and all materials; a fee of \$75 also includes lunch at the conference. The conference brochure is available on The Arc of New Jersey’s website: [www.arcnj.org](http://www.arcnj.org); click on “Conferences.” For further information or to request a brochure, please call 732-246-2525, ext. 28, or e-mail: [dflynn@arcnj.org](mailto:dflynn@arcnj.org)

National disability organization to consult with NY Mets

*(continued from page 3)*

with disabilities.

“Ensuring that our new ballpark is accessible for our fans with disabilities is very important to us. We have worked with the United Spinal Association on making accessibility improvements to Shea Stadium” said Andrew L. Cairns, Vice President of the Mets Development Company.

United Spinal’s Accessibility Services team will be working with the architectural firm HOK Sport to develop what Director Dominic Marinelli predicts will be one of “the most accessible ballparks in the country.”

In an effort to gather feedback on preliminary elements of the design, United Spinal will host informational meetings for fans with disabilities at Shea Stadium.

“Celebrating Women...where we’ve been, where we are, where we’re going.”

A seminar targeted to women with disabilities and others interested in gaining a better understanding of health and lifestyle issues affecting women with disabilities.

Saturday, June 3, 2006

Time: 9:30 AM to 3:00 PM

Location: Hyatt Regency Jersey City, 2 Exchange Place, Jersey City

**Keynote by Kate Blisard  
Panel Discussions about Social Issues, Relationships and Sexual Health regarding Women with Disabilities**

Seating is limited.

Registration is by phone only. Call and reserve your place early. Deadline for registration is May 25, 2006, if places are available.

Contact Pat Krupka, NJCDD, 609 - 984 - 4513

TTY/TDD 609 - 777 - 3238

This FREE forum is jointly sponsored by:

- ❖ Women with Disabilities Health Care Task Force, NJ Council on Developmental Disabilities
- ❖ Speicher-Rubin Women’s Center, New Jersey City University

Return Service Requested

PRESORTED  
 FIRST-CLASS MAIL  
 U.S. POSTAGE  
**PAID**  
 TRENTON, N.J.  
 PERMIT NO. 21

**monday morning**  
 New Jersey Council on Developmental Disabilities  
 PO Box 700  
 Trenton, New Jersey 08625