

The

# ALLIANCE



National Alliance on Mental Illness of Pennsylvania

Summer 2006



*New Jersey Governor Richard J. Codey delivered the keynote address at the 2005 Annual Conference*

### A Message from our President



Having completed almost six years on the NAMI PA Board of Directors, the past five as President, it is encouraging to reflect on all that our organization has accomplished during this time.

We have expanded our outreach to diverse communities (including the African American, Latino and Amish communities, communities of faith, families with children and adolescents with mental health concerns, the classroom and the college campus) and continue to expand our efforts in each area of our mission. Through our ever increasing educational programs, our support services and our advocacy efforts, we continue to reach out to those whose lives are impacted by mental illness. Our annual state conferences have been on par with those of any national organization, and our annual regional conferences provide local affiliates with outstanding opportunities to learn and to network. Our efforts to include consumer participation at all levels within our organization has made us stronger and, by joining in with families, has made our voice that much more reflective of what recovery is all about.

(con't. on next page)

### Mark your Calendars! **Annual Conference 2006:** *Health, Home & Community:*

*Access to Quality Life*  
October 26th-29th, 2006  
Harrisburg, Pennsylvania



*Radisson Penn Harris*

### Medical Assistance/Medicaid Changes in Pennsylvania

*Healthchoices to be implemented statewide.*

The implementation of Medicare Part D Prescription Drug Assistance in Pennsylvania has direct impact on persons currently on, or enrolling in, Medical Assistance in Pennsylvania. As of January 1, 2006, prescription coverage for those on Medical Assistance in Pennsylvania will no longer be provided through Medicaid. Everyone enrolled will receive prescription coverage by Medicare Part D drug coverage.

(con't. on page 4)

### Inside...

- 2006 Regional Conferences
- Medicaid/Medical Assistance
- Educational Trainings
- A Message from our Executive Director
- A Letter from our President
- Veteran's MI Budget Increase
- Grading the States- Report from NAMI National
- Save the Date: NAMI Walks 2006 on September 16th

### NAMI National 'Grading the States' Report- Pennsylvania Summary

Pennsylvania is a study in contradictions. It has a complex mental healthcare system, serving a diverse and in many places aging population. Philadelphia, Pittsburgh, and Harrisburg are key centers, but to a significant degree, the state is county-driven, mountainous, and rural. The Pennsylvania Office of Mental Health and Substance Abuse Services (OMHSAS) itself describes the state as having a "highly decentralized mental health system" in which governance is an often confusing mix of town, city, country, and state jurisdictions."

(con't. on page 10)

### NAMI Walks

NAMI Walks is NAMI's signature annual public awareness and fundraising event. In 2006 there will be 60 walks held in communities across America. In Pennsylvania NAMI Walks 2005 drew over 600 participants.



Note: NAMI PA will be holding a special Veterans Plenary at the Annual Conference in October. Please make plans now to attend.

### **House Passes Veterans & Active Duty Spending Bill– Budget Increased**

In a demonstration of the growing concern of mental illness treatment services for veterans and current service members, the House this past week passed a \$136 billion bill that includes record increases for both veterans with mental illness and soldiers returning from active duty that have experienced a growing range of mental health disorders. The Military Quality of Life and Veterans Appropriations bill (HR 5385), includes FY 2007 funding for the Department of Veterans' Affairs (VA) and Department of Defense (DoD) health care programs. The bill cleared the House unanimously.

The Senate is expected to take up the measure later this summer. There is strong support in the Senate for additional investments to increase the capacity of both the VA and DoD to meet the mental illness treatment needs of veterans and active duty personnel.

HR 5385 includes a total allocation of \$25.412 billion for FY 2007 for VA medical services. This is nearly \$2.64 billion above current FY 2006 levels.

In allocating resources for the VA medical care system the House bill uses the Independent Budget (IB) as a baseline. This IB - which was endorsed by the NAMI Veterans Council - draws on outside experts and Veterans Service Organizations (VSOs) to assess what the agency will need to meet both medical and mental illness treatment needs of all eligible veterans. To enhance this baseline assessment, the House bill adds an additional \$400 million to be used exclusively for mental health services. Within the total allocation, the House bill directs that no less than \$2.8 billion is to be directed to mental illness treatment.  
(con't. on pg. 8)

### **(con't. from pg. 1) President's Message**

As we welcome opportunities to maintain and to set goals that will have a positive impact on peoples' lives, we also face many challenges along the way. Where we see the great strides in medications and how they have given people their lives back, we also see potential cuts in funding for research on third generation psychotropics. Where we see people getting into or returning to the workforce, we also see an ever increasing need for safe and affordable housing. Where we see more recovery-oriented services being developed and implemented, we also see funding being reduced. As advocates our work is cut out for us, and we need a strong and consistent voice so that our message is heard.

(concluded on pg. 4)

**THE ALLIANCE** is the NAMI PA State Newsletter, brought to you by members of our Board, Staff, Volunteers and Members... You can contact us at:

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**Contact the state  
office or your local  
affiliate for  
volunteer  
activities!**

## Depression in Children and Adolescents

By: Jyoti R. Shah, MD, DFAPA

Depression and suicide are national public health problems for children and adolescents. Major depression affects an estimated 2.5% of children and 8.3% of adolescents in the United States alone. That's approximately 2.6 million young people ages 6 to 17.



Clinical depression can affect every facet of a young person's life: family and peer relationships, academic performance. Without appropriate treatment, the consequences of depression are extremely serious. Children are likely to have ongoing problems in school, at home, and with their peers. 4 of 10 will have a second occurrence of depression within 2 years. Depressed children are also at increased risk for substance abuse, eating disorders and teen-age pregnancy. Depression tends to be an episodic, recurrent illness, associated with crippling anxiety, thoughts of suicide, and/or difficulty with concentration.

In children, these classic symptoms often may be obscured by other behavioral and physical complaints – often attributed to “being a teenager.”

Behaviors such as:

- irritable or cranky mood
- loss of interest in sports or activities with friends
- weight loss or gain
- frequent complaints of physical illness (i.e., headache, stomach ache)
- refusal to wake for school in the morning
- talk of running away from home or efforts to do so
- persistent boredom
- oppositional or negative behavior
- poor performance in school, and/or frequent absences

Once a young person has a single period of depression, they are more likely to experience depression again later in life.

SHOP OUR ONLINE STORE at  
[HTTP://NAMIPA.NAMI.ORG](http://NAMIPA.NAMI.ORG)

## A Message from Executive Director Jim Jordan 2005 Proved to be a Year of Opportunities and Challenges



This issue will summarize a productive 2005. Please take a few minutes to review pictures from our Annual Conference. Our Annual Conference 2005 provided an opportunity for participants to meet New Jersey Governor Richard J. Codey, State Supreme Court Justice Sandra Schultz Newman, Department of Corrections Secretary Jeffery A. Beard, Ph.D. and NIMH Deputy Director Richard Nakamura, Ph.D. These presenters were joined by an outstanding collection of speakers who covered a wide range of topics relating to the conference theme Depression: “Its Impact on the Workplace, Home and Community.”

Training and education opportunities were expanded in 2005 and have continued to increase during the first half of 2006. NAMI PA now provides the following education programs free to qualified participants (see website for details and registration information) during the year: Family-to-Family, Peer-to-Peer, In Our Own Voice, Support Group Facilitator Training and Provider Training. We also hold special trainings to certify instructors for these programs. In addition, we provide IRB Training at our Annual Conference. We also have two programs which are being tested this spring. Families in Crisis is a pilot program for families with young children up to age 20 who have mental illness. In addition, we are also offering Parents and Teachers as Allies. This program is a team presentation for schoolteachers, guidance counselors and other staff.

NAMI National has issued its “Grading the States” Report which provides an assessment of the state mental health systems. Although Pennsylvania received a D+, it is important to understand the purpose of this report. The report reflects the experiences and perceptions of family members and consumers, state mental health authorities and public sources of information. It is the first comprehensive assessment of state mental health systems in 15 years. The report is not political. It does not target any one administration nor does it favor any political party. The report follows three major reports – the U.S. Surgeon General’s Report on Mental Health (1999), the President’s New Freedom Commission on Mental Health (2003), and the Institute of Medicine of the National Academy of Sciences Report (2005). This report identifies positive accomplishments and areas that need improvements. While funding is identified as an issue for all states, it is not the primary focus of the report. The report suggests that Pennsylvania’s most urgent needs are a comprehensive system blueprint, better information access and hospital land used as a trust for people with mental illness. It also addresses the need to utilize available funding efficiently. (con’t. on page 11)

## Resources

### Medicare:

- HHS Medicare Part D:  
<http://www.cms.hhs.gov/medicarerereform/pdbma/> or call 800-633-4227
- NAMI General information:  
<http://www.nami.org/medicare/mma> or 800-950-NAMI

### Medicaid/Managed Care:

- MH/MR County Offices  
<http://pacounties2.org/mhmrpaap/membership.html>
- OMHSAS  
<http://www.dpw.state.pa.us/general/aboutdpw/dpworganization/omhsas/default.htm> or call 800-525-0674
- OMAP  
<http://www.dpw.state.pa.us/general/aboutdpw/dpworganization/omap/aboutomap/default.htm> or call 866-542-3015

### House Bill 2654 Dedicates Proceeds of Selling State Mental Health Facilities

**HARRISBURG, May 1** – State Rep. Dan Frankel, D-Allegheny, has introduced a bill to dedicate any proceeds from the sale of state-owned mental health facilities to help to ensure that adequate funding is available for the care of those released into the community.

Each year, the state Department of Public Welfare conducts annual reviews of each state-owned mental health facility to determine whether there are any opportunities for consolidation or closure. Once the decision is made to close or consolidate a facility, patients are either transferred to other state-  
*(con't. on page 10)*

## Support

### SURROGATE FAMILY MEMBER PROGRAM

The Surrogate Family Member Program is a unique, grassroots initiative that addresses the need for a person to perform the role of family advocate without being related to the MH consumer. The position may be paid. The pilot program was developed and put in place in Clearfield/Jefferson Counties in 2005-2006.

**Position Description:** Partners with another Surrogate Family Member in representing the family approach on behalf of consumers in the Mental Health System.

**Duties:** Organize team meetings; Substitute as the consumer's family in team meetings; Encourage consumer to set goals and take leadership role in team meetings; Facilitate communication; Assist in developing plan for consumer's recovery; Coordinate direction of treatment.

**Background:** The Surrogate position requires knowledge of mental illnesses, the mental health system, skilled communication, and general knowledge of laws and regulations. Formal mental health training is not required. A strong desire to advocate for individuals is necessary.

For Further information contact Paul Hamilton at 814-752-1633 or [bapa@csonline.net](mailto:bapa@csonline.net).

Information on implementation contact Tom Brandon, MH Program Director, Clearfield/Jefferson Counties at 814.265.1060

**"To travel hopefully is a better thing than to arrive" Robert Louis Stevenson**

### *(con't. from pg. 1)* Medical Assistance/Medicaid Changes

Medicaid will still cover other services (inpatient, outpatient, etc.). At the time of this printing, the 2006 enrollment period to choose the plan that best fits their needs and budget ended on May 15th, 2006.

**Important Facts on Service Delivery** - OMAP (Office of Medical Assistance Programs) administers Physical Health services for those on Medicaid. OMHSAS administers Behavioral Health services for those on Medicaid. Point of entry for Medicaid eligible persons for both Physical and Behavioral Health are provided through the county MH/MR (Mental Health, Mental Retardation) Offices. *(con't. on page 8)*

*(con't. from page 1)*

### President's Message

We continually strive to have our voice reflect that of the consumer and the family member, and therefore need your involvement and input. We will continue to work with other advocacy groups so that our legislators know we present a strong and united effort. We will also continue to grow and strengthen our affiliates, the true grassroots and the source of guidance and direction for NAMI.

Whatever NAMI hat you wear - whether you are a Family to Family teacher, a Peer to Peer facilitator, an In Our Own Voice presenter, a member of a Provider Education Program team, a support group or NAMICARE or NAMI-CAN facilitator, or someone who lives with or cares for someone who lives with mental illness, you are the hero in this effort. We want to do all that we can to make NAMI PA reflect your needs and your hopes.

**Carol Caruso, President,  
NAMI PA Board of Directors**

### Lifekeeper Promise

A poem by Sandy Martin

Someone we love  
Did not keep their life  
In pain and anguish  
They ended their strife  
In this lifetime on Earth  
We'll see them no more  
Yet we carry them always  
In our soul, in our core  
Now we're left here  
And we must stay  
We have Life to live  
To the fullest each day  
For we are the Lifekeepers  
A promise we make  
To celebrate their Lives  
Our own not to take  
We are the Lifekeepers  
Truth Bearers, Peace Seekers  
We are the Wounded  
We are the Healed  
We are the Lifekeepers  
Our commitment now sealed

## Employment

### **Mental Illness Exacts a High Financial, Human Toll**

Leah Carlson Shepherd Employee Benefit News February 2006

Having adequate supports for workers with mental illness benefits organizations financially and socially, experts say. Helen Darling, president of the National Business Group on Health, notes, "Mental health and substance abuse disorders currently cost U.S. employers billions of dollars annually in lost worker productivity. All will benefit if we reduce the terrible burden of depression and other serious mental health problems that sap strength, productivity and a decent quality of life out of employees and their families."

She urges companies to do more to promote good mental health and get help for troubled workers early, in order to prevent or alleviate the symptoms of mental illness before the situation worsens. Employees with poor mental health may need help to get through the workday and get along with coworkers, and this is where an employee assistance program can be useful and effective, Darling adds.

### **Cost of illness**

For businesses looking to reduce benefit payouts, it's important to not overlook the impact of mental illness. The employer's cost of mental illness is reflected in paid sick days, lost productivity, health insurance claims and disability insurance claims.

Treatment costs for mental illness and substance abuse totaled \$104 billion, or 7.6% of total health care spending in the United States, in 2001, according to a guide recently released by the National Business Group on Health.

Furthermore, mental illness causes more work loss and work impairment than common physical ailments like asthma, diabetes and arthritis. In fact, 217 million days of work are lost each year due to productivity declines related to mental illness, costing companies \$17 billion per year.

Mental illness and substance abuse disorders are among the top sources of short-term and long-term disability claims. Approximately 8% of U.S. adults reported having experienced at least one major depressive episode in the last year, according to the federal Substance Abuse and Mental Health Services Administration. Often, depression coexists with other problems, such as alcohol abuse, anxiety disorder or poor physical health.

*(con't. on page 8)*

## Forensics

### **Forensics and Criminal Justice Activities 2005**

In 2005, NAMI PA hosted two Criminal Justice Symposiums throughout the Commonwealth. On May 18, 2005, our NAMI Scranton affiliate hosted the first regional CJS Symposium at the Lackawanna County Heritage Center. A second Symposium was held on October 27, 2005 in conjunction with our annual conference. Both of the symposiums were co-sponsored by the PA Department of Corrections and the PA Board of Probation and Parole, and were well attended by professionals from the Criminal Justice system, the Mental Health system as well as consumers and family members.

The purpose of the symposiums is to attract criminal justice system professionals from all disciplines to come together to address one of the country's most human failures – the incarceration of persons with

mental illness who may also suffer from a co-occurring drug abuse disorder.

In addition to the CJS Symposiums, NAMI PA continues to provide Forensic Training on co-occurring disorders to those in the Criminal Justice system. The mission of NAMI Pennsylvania's Criminal Justice Training and Education Program is to educate criminal justice system professionals about the true nature of mental illness and co-occurring drug and alcohol disorders. We work in collaboration with mental health, substance abuse and other professionals, to ensure our curriculum is continually updated and represents the most current information about mental health, co-occurring drug and alcohol disorders and their biological causes, symptoms, and treatment. By the end of this year, NAMI PA will have trained four Municipal Police agencies, and one Campus Police force.

"Love is the only sane and satisfactory answer to the problem of human existence. "  
Erich Fromm German Psychoanalyst & Writer

Annual Conference 2005 Pictorial Review



You can find more pictures from the conference, join, donate (including your used vehicle!), and shop for NAMI merchandise on our website at <http://namipa.nami.org>.

# NAMI WALKS PA

★ ★ ★ ★ ★ FOR THE MIND OF AMERICA  
State Capitol, Harrisburg  
Saturday September 16, 2006

Check out pictures  
below from our  
2005 WALK!

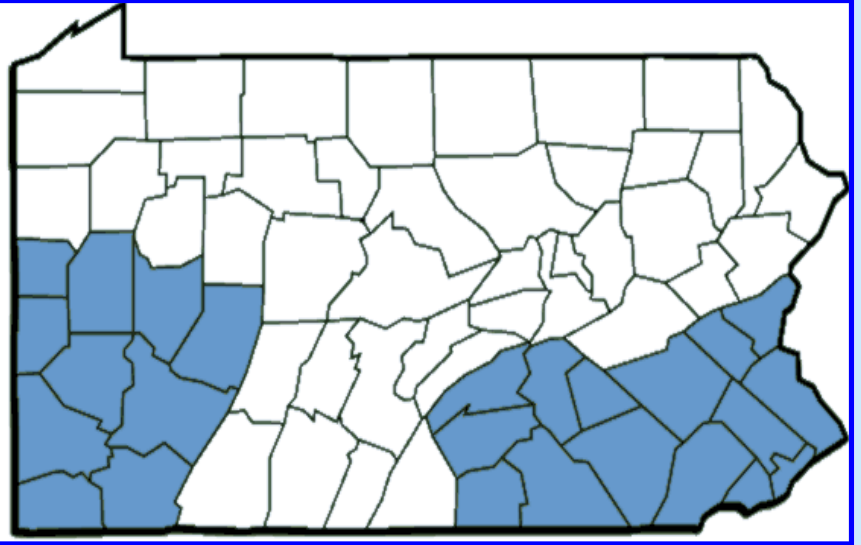


## Medical Assistance/Medicaid Changes

(con't. from page 4)

The state funds and administers Medicaid benefits for physical and behavioral healthcare to recipients in Pennsylvania either through mandatory coverage (HealthChoices), or ACCESS Plus and Voluntary (Fee For Service).

- **HealthChoices:** The HealthChoices Program is Pennsylvania's mandatory managed care programs for Medical Assistance recipients where the county/counties have chosen a **single** Behavioral Health Insurance Provider. HealthChoices is the MCO contractor being phased in over time statewide. HealthChoices is currently in SW, SE and Lehigh/Capitol area counties. Implementation in the remaining counties is scheduled by July 2007.



- **Access Plus and Voluntary:** Provides Physical and Behavioral Health Services for those on Medical Assistance in counties which do not yet have HealthChoices. Behavioral Health Services in non-HealthChoices counties are provided through the county MH/MR office, and administered by OMHSAS. Behavioral Health Services in Healthchoices counties are/will be provided by a single, contracted health insurance provider.

## (con't. from pg. 2) Veterans

This is the second year in a row that the House Appropriations Committee has gone the extra step of requiring a minimum allocation for mental illness treatment services in the VA. It is a further reflection of the strong bipartisan support in Congress for addressing the treatment needs of veterans living with mental illness, both from the aging Vietnam era veteran population, and anticipated demand among veterans of recent conflicts including Iraq and Afghanistan.

HR 5385 includes a total allocation of \$21.02 billion for health care programs in the Department of Defense. This is \$684.6 million above the total appropriated for the current fiscal year. More importantly, the House bill directs DoD to allocate no less than \$25 million for an initiative to more effectively integrate mental health screening and counseling into daily activities that DoD undertakes, both for active duty soldiers, and troops returning from overseas duty.

A legislative report accompanying HR 5385 notes:

*Mental Health. --The Committee is very concerned about the mental health and wellness of troops returning from conflicts overseas. The full impact of the emotional toll that combat takes from our troops may not be fully realized for years into the future. The Committee believes that mental health and wellness need to be integrated into all aspects of military training, combat and support and that care*

(concluded on pg. 9)

NAMI Pennsylvania provides information and resources regarding the state Medicaid program to assist families in choosing the best care. Please use our resources on our website at [namipa.nami.org](http://namipa.nami.org), [nami-pa@nami.org](mailto:nami-pa@nami.org) or 800-223-0500.

## (con't. from page 5) MI - High Human Toll

Given the high prevalence of depression, benefit managers would be wise to scrutinize their company's mental health benefits. The NBGH guide recommends:

- Reimbursing primary care doctors and non-psychiatrist physicians for screening, assessing and diagnosing mental illness and substance abuse disorders
- Improving collaboration between disease management programs, general medical care and specialty behavioral health care
- Depression screenings for employees with chronic health conditions
- Requiring disease management vendors to screen workers for depression
- Referring employees on disability for a psychiatric condition to the EAP for return-to-work assistance
- Reducing redundancies between EAPs and health plans by restructuring EAPs
- Monitoring patient progress with evidence-based tools
- Documenting diagnosis upon initiation of treatment

Source: <http://www.benefitnews.com/pfv.cfm?id=8576>, New York Association of Psychiatric Rehabilitation Services.

**NAMI PA Dedicates the Annual Public Servant Award as the "SENATOR ROBERT J. THOMPSON Public Servant of the Year Award."** *In honor of the recent passing of this dedicated and respected state senator.*

Senator 'Bob' Thompson, age 68, died unexpectedly on Friday January 28<sup>th</sup>, 2006.

NAMI PA awarded Senator Thompson with their "Leader in Advocacy Award" at their annual statewide conference in October 2000.

Senator Thompson was a major advocate for persons with mental illness, particularly those inappropriately incarcerated, or those not receiving treatment for lack of adequate facilities. He was instrumental in obtaining funding for Chester County to study new methods for diversionary programs for those involved in the judicial system where prison would be inappropriate.



He was Chairman of the National Criminal Justice Board of Directors of the Council of State Governments. He was elected Senator in 1995 and served as the Chairman of the Senate Appropriations Committee. Prior to election to the legislature, he served as President of the local PTA, as Township Supervisor, County Commissioner, and was a founding Director and first President of the Chester County Chamber of Commerce. He and his wife, Nancy, were involved with and recently honored by the Chester County Historical Society.

Viewing and memorial services were held in West Chester on February 3<sup>rd</sup> and 4<sup>th</sup>, with close to a thousand persons attending, including Governor Ed Rendell and members of the PA Senate and House of Representatives. Senator Thompson was a great supporter of NAMI and he will be greatly missed.

*(con't. from pg. 8) Veterans*

*cannot stop when the soldier returns home from the battlefield... The primary reason for soldiers failing to seek treatment for mental health issues is the stigma associated with seeking help... the military needs to begin to integrate mandatory mental health services and counseling into daily activities.*

*Mandatory programs [sic] as part of a soldier's tour of duty eliminates stigma associated with seeking care. [sic] Increased funds are to be used to initiate programs that make mental health screening and counseling a mandatory part of the operating procedures of soldiers in battle. [sic] DoD is to continue to work with the VA to study mental health issues, particularly PTSD.*

Excerpted from H.Rpt. 109-464, p. 40

**Editors Note: Please make plans to join our special Veterans Plenary Session at the Annual Conference in October.**

*"We learn as much from sorrow as from joy, as much from illness as from health, from handicap as from advantage and indeed perhaps more."*

*Pearl S. Buck American writer & winner of Nobel in literature*

**Special Needs Legal Planning for Parents Who Have a Son or Daughter with a Disability**  
**By Attorneys L. Mark Russell and Arnold E. Grant**

**The Good News**

Although you may hear over the next several months about the "Draconian/Severe/Punitive" (take your pick of an adjective) new Medicaid transfer rules that were signed into law by the President on February 8th, these new rules will have **absolutely no bearing** on your ability to leave your hard-earned assets in a special needs trust for the benefit of your son or daughter with a disability.

For those of you who may not know, a special needs trust is a trust created for a beneficiary with a disability that is designed to provide for the needs of the beneficiary while permitting the beneficiary to qualify for needs-based government benefits such as SSI and Medicaid. If you have a son or daughter with a significant mental disability, you almost always want to leave your child's inheritance in a special needs trust, as opposed to leaving it to the child directly. Special needs trusts are discussed extensively in our book, **Planning For The Future.**

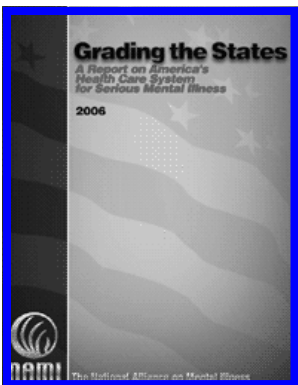
**The Bad News**

In general, the new Deficit Reduction Act of 2005 makes it much harder for parents to obtain Medicaid for their own nursing home care.

*(con't. on page 10)*

(con't. from page 1) **Grading the States**

These factors also make it hard to generalize about the quality of care in the state—because so many decisions happen locally.



**Positives:**

At times, Pennsylvania rises admirably to the vision of being the “Keystone State,” exerting national influence.

- Pioneer in reducing the use of restraints and seclusions.
- Active in building capacity for treatment of co-occurring mental illness and substance abuse.
- An OMHSAS report, “A Call for Change,” was developed with statewide consumer and family participation, consistent with the state’s longstanding support of community support programs (CSPs).

**Negatives:**

Major changes are in progress, but lack an understandable blueprint for stakeholders.

- Hospital closings. Harrisburg State Hospital was recently “closed” . As the number of state long-term psychiatric beds decreases, consumers and family members need to know well in advance the arrangement for community services or transfers to other facilities.

~ full report is available at the state office~

(con't. from page 4) **House Bill Trust Fund**

owned facilities or released into the community, where they receive community-based mental health services.

“Under this plan, any proceeds from the sale of a state-owned mental health facility would be allocated for community-based mental health services, which include emergency and crisis intervention, housing support, and outpatient care,” Frankel said. “Federal cuts to Medicaid and other programs have intensified the competition for state health-care funds. “It is only right that the proceeds of selling former state mental health facilities be used to strengthen the mental health safety net,” Frankel said.

Under Frankel’s bill (H.B. 2654), the dedicated money would go into a new Mental Health Community Services Trust Fund in the state treasury. Any interest or investment gains on the money would stay in the trust fund for use on mental health services rather than being sent to the state’s General Fund.

(con't. from page 9) **Special Needs Legal Planning**

In a nutshell, the new law lengthens Medicaid’s “lookback” period for all asset transfers from three to five years and, most significantly, replaces the beginning of the penalty period for transferred assets from the date of transfer to the date when the person who transferred the assets enters a nursing home and would otherwise qualify for Medicaid but for the transfer. So the real rub is the penalty period will kick in once the applicant has no assets, meaning the applicant will have no money to pay the nursing home for however long the penalty period lasts. Watch out children: In many states that have so-called “filial responsibility laws” the nursing homes may seek reimbursement from the resident’s children for costs incurred during the penalty period if Medicaid refuses to pay. The new law includes other changes as well so it is important that you consult with an attorney knowledgeable about the new rules before you engage in any Medicaid planning.

**What, if anything, should you do?**

First, remember the good news that you can still protect your child’s inheritance by leaving it in a special needs trust. But, that begs the question, “What if I don’t have anything to leave my son or daughter with a disability because my entire estate was spent down for nursing home costs?”

Well, you still have some pretty good options to avoid that problem which should be discussed with your attorney and financial planner:

- If you’re rich, no worries.
- You can purchase good long-term care insurance.
- You can create an irrevocable life insurance trust funded with life insurance on your life and the proceeds fund a special needs trust for your son or daughter.

And, remember, you can transfer property **without a Medicaid penalty** into a trust that is solely for the benefit of a child with a disability. That means, the day before you go into a nursing home you could irrevocably transfer your property into such a “sole benefits” trust for the benefit of your child with a disability and then qualify for Medicaid without a penalty period. The problem is that at that time you might be incapacitated. So, it’s imperative for your estate planning documents (your trust and power of attorney for property) to give the trustee or agent the discretionary power to transfer your assets to such a “sole benefits” trust if you become incapacitated. Further information at [www.specialneedslegalplanning.com](http://www.specialneedslegalplanning.com)

**Eventually,** A poem by Dan Craig  
Time becomes translucent  
Minutes turn hours into days  
The past blends together like  
Watercolors mixing on a page  
The future becomes a stone monument  
To accomplishments not yet achieved  
Until days turn hours into minutes

*(con't. from page 3)* **Executive Director Letter**

Whether you agree or disagree, it is important to hear the voices of families and consumers and to seek ways to work together for system improvement. We have made the report and the assessment available on our Website. We will also print a copy for a nominal fee for those who wish to receive a copy. You may also purchase the report directly from NAMI National. We encourage all to read the report and to join in our efforts to have a meaningful impact on the system that affects our families and consumers.

**Advocacy Verses Adversary.** Being an advocate is difficult and as some would put it, not everything it is built up to be. An advocate raises questions and expresses concerns which are not always understood or welcomed. Advocates are not always right. We do not claim to have all the answers. We focus on issues, educate ourselves, work to have input on policy issues and to improve the mental health system designed to care for our loved ones. Adversary by definition means to have antagonistic parties or opposing interests. NAMI PA is an organization of advocates. We recognize and respect different points of view. We believe strongly in our position on issues. However, our focus is on the issues. We seek to find common ground and to work with those in authority while supporting those whose voices must be heard. We encourage our members and friends to contemplate these two definitions so that there can be a better understanding of our role.

**NAMI PA Announces new Board Member**

NAMI PA is pleased to welcome a new Board Member: Edward A. Kramer, Vice President of Sovereign Bank.

Mr. Kramer will be inheriting the seat of Pat Heard, who is finishing her six year tenure as Secretary of the Board. Special thanks goes to Pat for her dedicated years of service to the cause and mission of NAMI Pennsylvania.

Mr. Kramer is a family member from Dauphin County and attended our Family to Family Course.

"The statistics on sanity are that one out of every four Americans is suffering from some form of mental illness. Think of your three best friends. If they're okay, then it's you." Rita Mae Brown, Writer

**IDEA (Individuals with Disabilities Education Act) Parent Guide**

There is a new IDEA Parent Guide available from the National Center for Learning Disabilities (NCLD). This guide takes you through the special education process - a process that is the same regardless of a child's particular difficulties or disabilities.

Within the guide, special emphasis is placed on the category of specific learning disability. The guide includes parent perspectives, terms you'll find helpful to know, and practical materials for parents such as Checklists, Sample Letters, Charts, and Questions to Ask.

Find the IDEA Parent Guide online at: <http://www.nclد.org/content/view/902/456086/>

**COMMUNITY-BASED CARE LEADS TO MEANINGFUL IMPROVEMENT FOR CHILDREN AND YOUTH WITH SERIOUS MENTAL HEALTH NEEDS**

Children and youth with serious mental health needs make substantial improvements at home, at school, and in the community when served through systems of care that provide community-based services. Data released May 9th by the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) at a Capitol Hill briefing show that children and youth in systems of care spend less time in inpatient care, experience fewer arrests, make improvements in their overall mental health and do better in school than before enrollment.

A system of care for children's mental health is a coordinated network of community-based services and supports that are organized to meet the challenges of children and youth with serious mental health needs. Families and youth work in partnership with public and private organizations so services and supports are effective, build on the strengths of individuals, and address each person's cultural and linguistic needs.

"Children and youth with serious mental health needs and their families deserve the best care available," said SAMHSA Administrator Charles Curie. "The systems of care approach is a proven approach that not only helps children thrive in their homes and communities, it is a wise investment of scarce resources."

The SAMHSA data suggest that systems of care save taxpayers money when compared to the traditional mental health service delivery systems. On average, systems of care save public health systems \$2,776.85 per child in inpatient costs over the course of a year, and save juvenile justice systems \$784.16 per child within the same time frame.

These and other data related to key outcomes, such as reductions in suicide-related behaviors and reductions in juvenile detentions or incarcerations can be found by visiting <http://www.systemsofcare.samhsa.gov>.

The Capitol Hill briefing was led by the Federation of Families for Children's Mental Health, the National Mental Health Association (NMHA) and the National Association of Social Workers (NASW) and the National Alliance on Mental Illness (NAMI) as part of the first-ever National Children's Mental Health Awareness Day. This day is slated to become an annual event celebrated during the first full week in May, which is Children's Mental Health Awareness Week. May is also Mental Health Month.



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**NAMI PA Membership/Contribution Information  
 THANK YOU!**

**Please make checks payable to NAMI PA and mail to:  
 2149 N. 2<sup>nd</sup> Street, Harrisburg PA 17110**

I'd like to join NAMI PA at the following annual membership level:

Individual/Family Membership \$35.00

Open Door Membership. This Goodwill Offering of \$3.00 is recommended, however, donor may gift anything from \$0.00 to as much as you wish. Full membership benefits.

Professional Membership \$50.00

VIP Membership \$200.00

I would like to support the work of NAMI PA. I enclose my tax-deductible contribution in the amount of \$\_\_\_\_\_.

I'm interested in designating NAMI PA as a beneficiary of my estate. Please contact me with information about planned giving opportunities.

I am moving. The following is my new address:

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 COUNTY \_\_\_\_\_  
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A copy of our official registration and financial information may be obtained from the Pennsylvania Department of State, Bureau of Charitable Organizations, by calling 1 (800) 732-0999 (toll-free within PA only).

Registration does not imply endorsement