

***Mental Health Services: Access,  
Availability and  
Responsiveness***

**Onondaga Citizens League  
2003 Study Report**

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Board of Directors  
2002 – 2003**

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## **Preface**

For 25 years, the Onondaga Citizens League has represented an outstanding example of citizen participation in public affairs in Central New York. Founded in 1978 and incorporated in 1979, OCL is an independent not-for-profit organization that encourages citizen education and involvement in public issues. The OCL's annual study on a topic of community-wide relevance culminates in a report designed to help citizens comprehend the issue and its implications, and give decision-makers recommendations for action.

The Onondaga Citizens League is open to any resident, business or organization in Central New York. While some join to become involved in the study process, many become members to support the concept and practice of citizen involvement in the study and resolution of pressing community issues.

The OCL Board of Directors selected this year's topic because of a deep-seated belief that mental illness has for too long been hidden, and therefore misunderstood and stigmatized by society. It was felt that a public discussion guided by those who knew most about its impact – clients, family members, practitioners, and representatives of the community systems that interact with those suffering from mental illness - would increase understanding and support for mental health services.

Special thanks are extended to the individual and corporate members who support the work of the League through their membership dues and financial donations, and to Syracuse University Continuing Education, which provides substantial administrative assistance to the Citizens League and the study.

*Sandra Barrett*  
*Executive Vice President*

## **Acknowledgements**

I am deeply indebted to all who were involved in the 2003 study. The committee members went far beyond shaping the outline of the study and findings and recommendations of the study report. In addition to the overall planning, each member recruited the panelists and moderated one of the sessions – more than they bargained for when they signed up, I'm sure.

The panelists each contributed generously of their time and expanded the understanding of all in attendance. It was because of their knowledge and commitment to the subject that we had such a successful series of meetings.

I am especially grateful to those who agreed to participate because the study turned out to be an emotionally wrenching experience for many. Almost everyone - study committee members, many of the panelists and those attending the sessions - had had very personal experiences with mental illness. However, that personal involvement highlighted the relevancy of the issue and enriched the sessions.

Sarah Merrick arranged for the sessions to be held in the Community Room of the United Way, which was well suited to our needs. Sandra Barrett, executive vice president of the Onondaga Citizens League, was the sustaining force behind all that we did. Her resourceful guidance kept us all on track.

The skill of our writer Renee Gaduo has been indispensable in creating the permanent record of our findings and recommendations. The written report will serve as our key tool in advocacy efforts for changes that will enable those who experience mental illness to recover and participate fully in their communities.

Helen B. Crouch  
Study Chair

## 2003 Study Topics and Speakers

<p>February 27, 2003  <b>Thursday Morning Roundtable</b></p>	<p>"The Public Mental Health System: Whom Does It Serve?"  <b>James L. Stone, MSW, CSW</b>  <b>Commissioner, New York State Office of Mental Health</b></p>
<p>March 12, 2003  <b>Moderator: Sheila LeGacy</b></p>	<p>"Our Stories: Families &amp; Consumers in the Mental Health Care System"  <b>Laura Peer</b> - Parent  <b>Cindy Lusk</b> - Parent  <b>Carol Puschaver, RN, MS</b> - Consumer Advocate  <b>Judith Bliss Ridgeway</b> – National Alliance for Mental Illness</p>
<p>March 19, 2003  <b>Moderator: Rick Kinsella</b></p>	<p>"The Delivery Process"  <b>David Brownell</b> - Commissioner, Onondaga County Mental Health Department  <b>Alfred Fusco</b> - Executive Director, Mental Health Association of Onondaga County  <b>Eugene Schneider, M.D.</b> - Medical Director for Behavioral Health Services, Excellus, Inc.</p>
<p>March 26, 2003  <b>Moderator: N. Thomas Letham</b></p>	<p>"Access to Emergency Services"  <b>Deborah Welch</b> - Director of Mental Health Services, St. Joseph's Hospital Health Center Mental Health Services  <b>Lisa McChesney</b> - Director, Community Peer Initiative, Transitional Living Services</p>
<p><b>April 2, 2003</b>  Moderator: Joan Durant</p>	<p><b>"Access for Children"</b>  Kristen Riley - <b>Deputy Commissioner, Onondaga County Mental Health Department</b>  Mary Ellen Claussen - <b>Ophelia's Place</b>  <b>Alan A. Andrews, DCSW, Psy.D.</b> - A&amp;R Consulting Services, a provider of EAP services</p>
<p><b>April 9, 2003</b>  Moderator: John Sheets</p>	<p><b>"Access for Adults and the Elderly"</b>  <b>Nancy Calhoun, MSW, CSW</b> - Senior Clinical Social Worker, University Geriatricians, SUNY Upstate Medical University  <b>Sheila LeGacy, MA</b> Director of Family Support and Training, Transitional Living Services of Syracuse, Inc.  <b>Lisa McChesney, MSW</b> - Director, Community Based Peer Initiatives, Transitional Living Services of Syracuse, Inc.</p>

<p>April 23, 2003</p> <p><b>Moderator: Frank Woolever</b></p>	<p>"Access for Special Populations"</p> <p>Rev. Bill Lott - <b>adjunct instructor, Department of Social Work, Syracuse University</b></p> <p>Laurie Sanderson - <b>Social Worker/Therapist, Syracuse Community Health Center</b></p> <p>Kurt Andino - <b>Director, Jail Ministry Office</b></p>
<p><b>April 30, 2003</b></p> <p>Moderator: Hon. Robert Rossi</p>	<p><b>"Interface with Law Enforcement"</b></p> <p><b>Anthony Callisto, Jr.</b> - Chief Deputy &amp; Custody Dept. Commander, Onondaga County Sheriff's Office</p> <p><b>Steve Thompson</b> - Deputy Chief, Syracuse Police Department</p> <p><b>Hon. Jeffrey R. Merrill</b> - Supervising Judge, Syracuse City Court</p>
<p>May 7, 2003</p> <p><b>Moderator: Donna Stoner</b></p>	<p>"The Cost to Employers and Schools"</p> <p>Jeanne Elmer, <b>Director of Student Assistance Programs, Onondaga County Mental Health Dept.</b></p> <p>Dr. James Wright, <b>School Psychologist on Special Assignment to the Syracuse City School District</b></p>
<p>May 14, 2003</p> <p><b>Moderator: Jinx Crouch</b></p>	<p>"Interface with Health, Religion and Social Services"</p> <p><b>David Sutkowy</b> - Commissioner, Onondaga County Department of Social Services</p> <p><b>Rev. Bill Lott</b> - Pastor, Greater Love in Christ Church</p> <p><b>Jef Sneider, M.D.</b> - Syracuse Internist and Past President, Onondaga County Medical Society</p>
<p>May 21, 2003</p> <p>Moderator: Harvey Pearl</p>	<p><b>"Funding and Insurers"</b></p> <p><b>Kathy Hart</b> - Director of Medicaid Services, Onondaga County</p> <p><b>Michael Slade</b> - Excellus, Inc.</p> <p><b>Bob Shear</b> - Syracuse Behavioral Healthcare</p> <p><b>Tom Dennison</b> - The Maxwell School, Syracuse University</p>

**June 11, 2003**

Community Leadership Conference

"Our Mental Health Service Delivery System:  
Problems and Promises"

Michael Hogan – **Chair, President's New  
Freedom Commission on Mental Health**

**Joseph A. Glazer** - President and CEO of the  
Mental Health Association in New York State,  
Inc. (MHANYS)

**Eileen D. Siddell** - Director of Crouse  
HelpPeople Employee Assistance Program

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## OCL Mental Health Study Report Introduction

*disability* “...Americans must understand and send this message: mental disability is not a scandal – it is an illness. And like physical illness, it is treatable, especially when the treatment comes early.”  
--President George W. Bush

In the fall of 2002, the OCL Board selected Mental Health Services: Access, Availability and Responsiveness as the subject of its 2003 study. As its starting point, the League acknowledged significant changes over the last 25 years in our understanding of mental illness and in the delivery of mental health services on the national, state and local scenes. For example, we have seen changes in the movement from long term institutional services to a community-based services orientation, the initiation of new community provider agencies and services, and the development of new pharmaceuticals and therapeutic intervention strategies.

We wondered: How well have the changes served the needs of the mentally ill and their families? What has the shift meant for public and private service providers? How well have public social policy and the mental health services infrastructure adapted to support these changes in the delivery system, as well as the changing needs of individuals requiring assistance?

These concerns paralleled those of President George W. Bush who, in April 2002, named a special commission to study the issue. The President identified primary obstacles to responsive mental health services: stigma surrounding mental illness; unfair treatment limitations and financial requirements placed on mental health benefits in private health insurance; and a fragmented delivery system. Like the President’s New Freedom Commission on Mental Health that spent more than two years researching this issue, the Onondaga Citizens League, in initiating the study, was aware that many barriers stood in the way of obtaining effective treatment for mental illness.

The OCL study, conducted from January to June 2003, included panel discussions, a daylong conference, conversations with other mental health professionals and research into current developments. The process provided an overview of the availability of local mental health services from various perspectives, the funding and public policy influences on the system, and the ability of the system to be responsive to the needs of diverse constituents.

**Our goals included:**

\*Establishing the current status of availability of local mental health services inclusive of the public mental health system and private sector services, access to services for various populations (e.g. children, adults, aging, minority groups), and the availability of appropriate emergency services for both adults and children.

\*Examining the impact on other systems that interface with individuals with mental health issues, e.g., law enforcement, criminal justice, social services, faith-based institutions, schools, employers.

**\*Considering the status of current social policy regarding the funding of mental health services.**

**\*Helping the public gain greater understanding of mental health service accessibility issues.**

**In fall 2003, The President's New Freedom Commission on Mental Health issued its final report. Its vision makes mental health a national priority.**

*We envision a future when everyone with a mental illness will recover, a future when mental illness can be prevented or cured, a future when mental illnesses are detected early and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports – essentials for living, working, learning, and participating fully in the community.*

**Our research revealed numerous parallels to the national study. We learned that the incidence of mental illness is enormous, the many services available are not well coordinated and many are insufficient to serve the growing number of clients and families affected by mental illness. We also heard from passionate health-care providers, public officials, private citizens and consumers eager to improve a system they see as under-funded and fragmented.**

**By fall 2003, encouraging progress was underway locally. The Onondaga County Department of Mental Health reported it was taking steps to broaden participation in its planning process and better coordinate planning between divisions. We believe it is important that the public agency responsible for mental health planning take the lead in increasing public involvement in and awareness of mental health issues and solutions.**

**While there are still concerns about the adequacy and effectiveness of local emergency mental health services, it is greatly encouraging that last spring possible closure of the Comprehensive Psychiatric Emergency Program was averted through collaboration and multi-hospital sponsorship among St. Joseph's Hospital Health Center, Upstate Medical University and Community General Hospital. A new corporation, developed with the assistance of the Hospital Executive Council, will operate CPEP, which continues to serve both children and adults.**

**University Hospital announced plans for an addition that would provide an integrated pediatric care unit. The hospital also hired its first, part-time children's chaplain. Both underscore the community's commitment, highlighted in University Hospital's advertising, that "Children are not just small adults." We hope to see that the commitment extends to serving the special mental health needs of children and adolescents. Also in the fall, Ophelia's Place opened its doors as a safe haven for people battling eating disorders, and filling an urgent need for resources and support for families facing this type of mental illness.**

**In addition, services to children now include referral service operated by CONTACT Community Services and an interdisciplinary mobile crisis team that will take services to the family and to CPEP. In addition, each licensed clinic treatment provider will establish a detailed protocol for responding to mental health crises.**

**Family Court Judge Robert Rossi and the local NAMI/PROMISE support group began meeting to develop a proposal for a local mental health court. It's a system that has worked in other communities, and we applaud the efforts to address the staggering problem of people with mental illness getting caught in the criminal justice system without appropriate care.**

**On the State front, Governor Pataki's proposed 2004 budget did not propose closing Hutchings. The governor proposed creating a bipartisan Commission for the Closure of State Psychiatric Centers. The panel is expected to follow Office of Mental Health criteria to recommend by April 2005 closures that would happen by 2006.**

**While these developments suggest the community commitment to improvements, distressing evidence of the stigma of mental illness remain. In late December 2003, an elected official publicly criticized a plan for a home for people for mental illness in his district. Outraged reaction came quickly from mental health advocates. In a letter to the editor, OCL panelist Carol Puschaver likened the reaction to warnings that a person with leprosy was nearby. "Tragically, some 2000 years later, sentiments of "unclean" and the tendency to ostracize still permeate our society and give rise to stigma and segregation," she wrote. "It is not so much an individual with leprosy who is the present-day lightning rod for prejudice and quarantine, however, but a person beset by serious mental illness."**

**In its conclusion, the New Freedom Commission on Mental Health acknowledges the challenges that lie ahead for mental health care reform. Society, the commission notes, "has a vested interest and a tremendous stake in doing what is right to correct a system with problems that resulted from layering multiple, well-intentioned programs."**

**The National Commission is confident its integrated strategy presents important steps toward transforming the mental health system into one that is accessible to all. "Local innovations under the mantle of national leadership can lead the way for successful transformation throughout the country," the report says.**

**We agree, and the OCL looks forward to facilitating discussions that create change for this pressing problem. May this report be just one step in the local community's commitment to improving the mental health system.**

**2003 OCL Study**  
**"Mental Health Services: Access, Availability and Responsiveness"**  
**Executive Summary**

**The context:**

**Mental illness is pervasive; one in four people has a relative with a diagnosed mental illness. A recent study found that of the 10 leading causes of disability worldwide, five are psychiatric conditions. During the last 25 years, many changes have occurred in the delivery of mental health services; most significantly, deinstitutionalization was mandated without adequate planning or funding for community mental health resources.**

**To determine how well the local mental health services infrastructure has adapted to these changes, the Onondaga Citizens League sponsored a series of discussions between Feb. 27 and June 11, 2003 that provided an overview of the local mental health delivery system and presented the perspectives of a variety of experts. The presentations included consumers' experiences of access to and the responsiveness of local mental health services. The series also covered the impact of mental illness on related community systems, such as law enforcement, schools, employers, social services, and religious institutions. In the final session, speakers addressed the role of funding mechanisms on access to services.**

**The experts included consumers, families, advocates, state and local officials, and mental health providers. Overall, they described a variety of symptoms that indicate a dysfunctional system. The scattered, uncoordinated service delivery and funding mechanisms seem to be growing worse, especially given the serious budget deficits of public agencies. The local assessment parallels the findings of the recently released report from the President's New Freedom Commission on Mental Health. Many of the potential solutions proposed on the national level could be applicable to the local situation.**

**The symptoms:**

**Two recent, narrowly averted local crises - the possible closures of Hutchings Psychiatric Center and of the Comprehensive Psychiatric Emergency Program (CPEP) – reflect a seriously flawed community mental health system, but they are not the only problems.**

- 1. The system includes duplication in some areas and lack of coordination in others.**
- 2. Stigma associated with mental illness limits public concern, elicits shame, promotes ignorance, and affects government spending. Stigma also acts as a barrier to treatment, preventing the client or client's family from seeking help.**
- 3. Some programs are driven more by governmental mandates and funding requirements than the needs of clients.**
- 4. Lack of insurance parity for mental health care severely restricts consumers' access to services.**
- 5. Large populations -- most significantly, children and adolescents -- do not have access to adequate or appropriate services, and the number of child psychiatrists in the community is insufficient to meet the need.**
- 6. Conflicting philosophies and governmental regulations hinder the coordinated treatment of chemical dependency and mental illness.**
- 7. Clients and families across social strata struggle to gain access to the mental health system.**

8. Public awareness is lacking on mental health issues, local programs, services and providers.
9. Emergency services are crucial, but clients consider them inefficient and inaccessible.
10. As a result of cultural, language and economic differences, special populations, such as recent immigrants, minority groups, and people with literacy problems face additional barriers to obtaining mental health services.

**The diagnosis:**

1. A lack of planning, limited resources and an uninformed public have created a fragmented, inefficient system. Without a comprehensive, long-range community planning process involving all the stakeholders, along with a multifaceted public education program, the negative effects of mental illness on related systems will increase. Symptoms that emerge in schools, the criminal justice system (about half the people in the criminal justice system are estimated to have mental health problems), social services, the workplace and among the homeless will continue to go untreated.

2. Mental health problems are immense, and mental health professionals alone cannot provide all the solutions. Critical to a responsive mental health system are diverse, accessible entry points. What does a person do when he is in crisis? Whom does a parent call when her child is out of control? Most will turn first to people they know and trust such as clergy, physicians, school counselors. These professionals and paraprofessionals must receive training to increase early identification of mental health conditions and the skills to refer people to appropriate services.

3. In addition to structural problems, we see the failure to embrace a philosophy of recovery and we challenge the community to adopt a more caring attitude toward mental illness. We acknowledge that many resources already exist ---several participants described Onondaga County as “resource rich” in mental health services ---but the community must improve its efforts to ensure those in need are directed to and can obtain necessary services in a timely fashion.

**The prescription:**

1. While recognizing that the County Department of Mental Health, the agency mandated to be responsible for mental health planning, has already begun work on an improved planning process, we urge that there be public forums with all stakeholders including community leaders and representatives of funding agencies as well as consumers, advocates and mental health providers to develop a blueprint for furthering the goals of the President’s New Freedom Commission on Mental Health in Onondaga County. Once it is developed, the plan should be widely publicized.

2. There should be a continuous, highly visible public education campaign on mental health. The final report of the President’s New Freedom Commission on Mental Health highlights the importance of targeted public education initiatives.

3. In order to be responsive to the growing need for mental health services and the difficulty in accessing services, provide adequate funding so that Onondaga County's 24/7 Information and Referral line (HELPLINE) can be continuously and broadly publicized in print, broadcast and electronic media. The telephone number should be easily found in the phone book and become as familiar to residents as 911.

- 4. New York State must not make a decision on closing Hutchings Psychiatric Center in response to budget problems or architectural issues without considering and addressing how the changes will affect clients. If the state chooses to close Hutchings, it must do so in an orderly, timely manner. Major changes must be coordinated with the long-range community plan for provision of mental health services.**
- 5. The uncertain funding and structure of CPEP make it clear local health care providers must commit to, and local leaders must support, an emergency system that is accessible and includes appropriate children's services and professional staff. Discussions must include consumers, and CPEP should be perceived as one part of the emergency response system, which intersects with a community plan for public and private mental health services.**
- 6. Provide ongoing training for primary care physicians, pediatricians, corrections officers, and school employees to improve identification of mental health problems. Capitalize on the existing work of such agencies as Jail Ministry and the Onondaga Pastoral Counseling Center. Increase training for a broad range of front-line people, such as clergy, teachers, police, social workers, family and friends. This, too, supports a recommendation of the recently released President's Commission on Mental Health.**
- 7. The comprehensive plan should include a commitment to recruit and retain child psychiatrists in our community and increase mental health support services for children. The plan should incorporate psychiatric nurse practitioners and related experts, such as child development specialists. Local health care planners should commit to incorporating psychiatric services for children as one component of the new Children's Hospital.**
- 8. The New York State Legislature should mandate that health care coverage for mental illness is comparable to that for physical illness.**

NOTES ON  
STUDY SESSIONS



**"The Public Mental Health System: Whom Does it Serve?"  
Thursday Morning Roundtable, February 28, 2003**

*"The values of recovery, hope, excellence, respect and safety form the foundation and will shape the future of New York's mental health care system."*

*--James L. Stone*

Speaker: Commissioner James L. Stone, New York State Office of Mental Health

**Highlights: New York State has a massive public mental health system, spending more per capita than any other state. As the system has evolved from an inpatient to an outpatient orientation, it has become more fragmented.**

The New York State Office of Mental Health Commissioner Stone provided copies of 2001 "Progress Report on New York State's Public Mental Health System" and gave an overview of the state's mental health department.

The state Office of Mental Health describes its dual roles as "a major provider of inpatient and outpatient services and as the lead governmental agency responsible for statewide oversight of all public mental health services, including more than 2,500 mental health programs operated by local governments and nonprofit agencies." The public mental health system serves over 400,000 adults and 100,000 children and adolescents each year. According to Commissioner Stone, the OMH has about 4,200 mental health inpatients, down from about 90,000 in-patients 50 years ago. In addition:

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- New York spends \$4.8 billion on mental health, more money per capita than any other state, and the system is larger and more diverse. (for instance, California, three times NY's size, has 55 psychiatric centers to New York's 28).
- The department's mission statement stresses that people can and will recover from mental illness. "They can and do relapse, but we are more focused on recovery," he said.
- OMH includes both state-operated and locally operated services. The department develops, monitors, licenses and directly operates some inpatient and outpatient services for those with severe mental illness. The State runs the state's 28 psychiatric centers, with some assistance from local budgets. Locally, Hutchings is the only center that takes direct admissions; all other centers require referrals. Of the 28 facilities, 17 are civilian hospitals, three are forensics hospitals, six are children's hospitals and two are research institutes.

Commissioner Stone cited Kendra's Law as an example of the state mental health system responding to needs of psychiatric patients. New York State passed the law, which provides for court-ordered treatment for certain people with mental illness, in 1999 after a 32-year-old mentally ill man who resisted treatment pushed Kendra Webdale into the path of a New York City subway train.

The commissioner outlined several reasons for the decrease in the number of patients in the state's mental health facilities since 1940. These include medical breakthroughs, such as new and better medications, and changing community standards. "We are more likely to accept people with mental health disabilities," he said.

Of the current environment, Commissioner Stone said that while a lot of money is spent and the system has a lot of capacity, gaps remain. He cited:

- Need for better allocation of resources
- People with substantial mental health problems who need but resist treatment.
- Evidence links increased risk of untreated drug- and alcohol-related violence (people with addictions 5-10% more likely to be violent.)
- Problems with quality of care; practitioners untrained; low salaries
- Patients see little recovery of life roles
- Lack of flexible, community-based services
- 
- Need to integrate children's services into system
- Fragmented system; people lost in cracks
- Lack of performance outcomes; money for programs focuses on attendance vs. results.

Commissioner Stone summarized the goals and challenges:

- Prevention and early intervention. For example, studies show if you address schizophrenia early on you can make a big difference. People tend to go without treatment for schizophrenia for three to five years while patient refuses to accept the illness or begins to self-medicate. If there are signs in early adolescence, working with the patient to help him and his family understand the illness could prevent problems. The concept is difficult to sell to public because no immediate results are visible.
- Low occurring disorders. System has allowed practitioners to reject some patients. OMH is trying to make the system seamless, including regulatory control.
- Stigma. Project Liberty model, the \$132 million federal program for disaster relief following the 9/11/01 terrorist attacks, helped to address the issue of stigma, as many people begin to develop signs of depression following the crisis. The system needs to understand and address how traumatic events, and not just genetics, affect mental illness and to be able to respond to and treat both.

The Commissioner discussed the effect of proposed state budget cuts to psychiatric centers. Governor George Pataki's 2003 proposed budget included closing Hutchings Psychiatric Center and mental health facilities in Elmira and Middletown. The closings would have saved the state \$18.2 million a year; closing Hutchings was projected to save \$6.6 million. Hutchings inpatients and staff would be transferred to Mohawk Valley Psychiatric Center in Utica. While the number of hospital beds was expected to decrease, the proposal would create 2,000 housing units for mental health clients in New York.

The facilities to close were chosen for their small size and are outdated. Hospitals with fewer than 150 patients are not cost-effective. Twelve years ago, planners forecast the need for 8,800

beds and built and refurbished facilities. “We’ve got acres of vacant wards,” Stone said. “Is it smart to put a lot of money into these to bring them into line with standards?”

For instance, the Syracuse facility built in 1960s for people in long-term care is a townhouse, difficult and expensive to staff. It would cost \$19 million or more to renovate. The Mohawk Valley facility was renovated more recently. The majority of patients in Onondaga County are in outpatient services. None of those programs would be affected under state budget proposal. Stone believes the travel to new facilities should not be a burden for families visiting patients, and that specialized services cannot be expected in every community. The average stay for the first visit to a state hospital is 10 weeks.

**Panel #1: “Our Stories: Families and Consumers in the Mental Health-Care System,” March 12, 2003**

*“As for me, you must know I shouldn’t precisely have chosen madness if there had been any choice. What consoles me is that I am beginning to consider madness as an illness like any other and that I accept it as such.”*

*-- Vincent Van Gogh, 1889*

Panel: Laura Peer, parent; Cindy Lusk, parent, Carol Puschaver, consumer advocate; Judy Bliss Ridgway, St. Joseph’s Hospital Health Center. Moderator: Sheila LeGacy

**Highlights: Powerful personal stories set the stage for the year’s study, with clients, parents and mental health professionals touching on the damaging effects of mental illness and providing faces and real stories to pair with the statistics. Patients and their families encounter serious difficulties in identifying services, obtaining diagnoses and overcoming stigma. Panelists urged planning to include an emphasis on community awareness, the need for a centralized referral system, respect for input from clients’ families, peer support for patients and families, and continuing education for professionals.**

**Sheila LeGacy** shared statistics, facts, and definitions she uses in her Supportive Family Training program, which is offered locally through Transitional Living Systems and has become a national program. According to the National Institute of Mental Health:

- There are 100 million first-degree relatives (parents and siblings) of people with mental illness in the United States.
- 41.2 million Americans suffer from a diagnosable mental disorder
- One in four families has a relative with mental illness
- One in every five Americans will suffer from some form of mental illness at some point in their lives.
- 12% of children under 18 suffer from mental disorders such as autism, depression and hyperactivity.
- Over 17 million Americans suffer from a major depressive disorder.
- Over 10 million Americans suffer from serious depression.
- Over 3 million Americans suffer from manic-depressive illness/bipolar disorder.
- 3 million Americans suffer from schizophrenia.
- 23 million Americans suffer from anxiety, phobia, panic disorder, or obsessive-compulsive disorder.
- Persons with mental illness use more hospital beds than those occupied by heart, cancer and lung patients combined.
- \$72.7 billion a year is spent in the U.S. to care for people with psychiatric disorders.
- One-third (200,000) of the 600,000 homeless population of the U.S. suffers from severe brain disorders
- At least 7% of all jail inmates and 14 % of all prison inmates suffer from schizophrenia, bipolar disorder, or major depression.
- Major depression is the leading cause of disability globally. (World Health Organization, 2001)

- 1 million people commit suicide every year; between 10 and 20 million people attempt it.

“Mental illnesses,” LeGacy stressed, “are physical illnesses characterized by, or resulting from, malfunctions of the brain.”

Researchers have found higher levels of acute and ongoing grief in families with a chronically mentally ill child than in families whose child has died. LeGacy, an advocate and the mother of a woman with mental illness, strongly supports education and training for family members. Research shows increase in family participation predicts better outcomes.

**Laura Peer** described her young adult son’s experience with the mental health system.

City police picked him up at CPEP because he violated a protective order. While on the mental health floor in the Justice Center, his condition declined and he became psychotic. After two weeks of solitary confinement, he was transferred to a Rochester psychiatric center, then to Strong Memorial Hospital. Charges were eventually dropped and he was sent to Hutchings Psychiatric Center, where he presented as “a young man who looked like a prisoner of war. ... After a few months my son was able to have a conversation.”

She is a strong advocate for Hutchings: “They brought him back to life,” she said. “He remembers his time at the Justice Center. He was barely human. This because he was unable to comply with the rules.”

**Cindy Lusk** described her experience as the parent of a 22-year-old son with mental illness and her family’s 17-year struggle to find out what was wrong with him. Among her recommendations:

- Improve education in schools to help identify mental illness.
- Recruit more psychiatric doctors to the community.
- Address ignorance about mental illness.
- Take families seriously and recognize their involvement as critical to achieving proper diagnosis and treatment.

**Carol Puschaver** spoke about her experience with mental illness, provided a critique of cultural stigma and biases; her view and experience as an advocate.

“I have twice tried to kill myself,” she began. “I believe I am a mistake. In July 1995, while my cats looked on, I swallowed everything in my medicine cabinet and went to bed. But I made a mistake. I left the phone on the hook.”

Puschaver has earned both bachelor’s and master’s degrees, is a published writer, amateur historian and a member of Phi Beta Kappa, “but there are days I cannot remember how to tie my shoes,” she said. “I panic about turning off the directional signal.”

**Judy Bliss Ridgway**, as a professional (including 20 years as a psychiatric nurse) and family member, described the structure and purpose of NAMI, the National Association for Mentally Ill. She is president of local NAMI/PROMISE. “We’re keeping people out of the hospital by supporting the family members,” she said.

**Panel #2: “The Delivery Process,” March 19, 2003**

*“The goal of treatment we have come to embrace is not just reduction of symptoms, but recovery from the illness, which will enable restoration of a useful and productive life.”*

*-- David Brownell, Onondaga County Mental Health Department*

Panel: David Brownell, commissioner, Onondaga County Mental Health Department; Alfred Fusco, executive director, Mental Health Association of Onondaga County; Eugene Schneider, M.D., medical director for Behavioral Health Services, Excellus. Moderator: Rick Kinsella

**Highlights: A lack of comprehensive planning and the absence of an integrated delivery system hamper the efficient and effective delivery of mental health services. To some extent, New York state regulations, which control local planning processes for public services for chemical dependency, developmental and psychiatric disorders, help to create a fragmented system. In addition, the failure of New York State to reinvest money saved from downsizing of state psychiatric hospitals into community mental health services has created gaps in care. Lack of comprehensive private insurance coverage for mental illness also hinders the delivery process, but insurance providers can be motivated to cover more effective, and therefore economical, services.**

**A. David Brownell:** The County department’s priority is public mental health programs, which serve children and those with severe mental illness. With a \$20 million annual budget, it has responsibility for chemical dependency and developmental disability and psychiatric disorders. Addictions complicate the treatment of people who are mentally ill.

Brownell described community needs as including: case management; psychosocial rehabilitation; short-term inpatient hospitalization for short-term crises; integration of mental health and chemical dependency treatment; consumer, self-help and advocacy; family self-help and advocacy. For services to be effective, they need to be integrated, he said.

**B. Alfred Fusco:** The Mental Health Association offers information and referral and has a database of 300 therapists in private practice. “We get a good earful day in and day out about these people’s problems,” he said. “People call on the phone and say ‘I’m depending on you to help me.’ All too often, when you feel you can’t be of any help it just fuels your anger and your sense of ‘something’s gotta change.’”

About 36 percent of the people who call (2,000 calls a year) are on Medicaid; another 33 percent are uninsured or underinsured.

Fusco blames state policies for creating an ineffective system and sees this playing out in the possible closure of Hutchings Psychiatric Center. “We were going to take money saved from the downsizing of state hospitals and make it available for communities and the communities were to decide for themselves how to use those funds,” he said. “Now we’re talking about using the reinvestment to increase the salaries of vastly underpaid mental health workers. We’re gutting whatever ability a locale may have to decide its own mental health system”.

He acknowledged some planning takes place in Onondaga County, but said that does not happen at the state level. “My idea of planning that we actually sit down together,” he said. “That it’s comprehensive, that providers, clients, family members get to be involved. We’re not getting that.”

Fusco points out problems when people enter the mental health system through law enforcement. “It seems difficult for me to envision how people can recover and make the journey and feel they’ve got a trusting relationship with professionals in the mental health arena when they’ve been handcuffed and put in the back seat of a police car, taken up for an evaluation and put into a facility with other people who are angry because they were forced to be there,” he said. “It doesn’t seem like exactly the most therapeutic environment to begin a recovery.” While Fusco does not oppose all use of medication, he describes the mental health system as drug-addicted.

**C. Eugene Schneider:** The system of insurance is getting more fragmented, he said, and each region is different. He sees a gap in step-down programs and managed care. He described Excellus, the largest not-for-profit Blue Cross/Blue Shield in New York, as attempting to help patients manage their benefits so their coverage provides the most services. (i.e.: Don’t waste two days’ coverage over weekend if patient can be released). He described some model programs in Rochester in which there is coordination among the hospital, patient and insurer. He also said the state lacks a sufficient number of child psychiatrists.

**Panel #3**  
**“Mental Health Services: Access, Availability and Responsiveness: Access to Emergency Services,” March 26, 2003**

*“Individuals are seeking supports for everything from a life crisis to a place to go when they’re feeling out of control and not safe.”*

*--Deborah Welch*

Panel: Lisa McChesney, director, Community Peer Initiative, Transitional Living Services; Deborah Welch, director of Mental Health Services, St. Joseph’s Hospital Health Center.  
 Moderator: N. Thomas Letham

**Highlights: Providing appropriate and available emergency services for those in psychiatric crisis has been a serious challenge for the CPEP program. The panel identified concerns including insufficient number of inpatient beds, lack of services specifically for children, slow and inadequate response by professional staff and the need for complementary peer-run respite services.**

**Lisa McChesney:** McChesney runs the Community Peer Initiative and speaks both from professional and personal experience: she has used peer support, individual and group therapy, psychotropic medications, continuing day treatment, inpatient hospitalization; community self-help groups such as 12-step programs, Anorexia and Bulimia Support Group; educational and vocational supports, group homes and supervised apartments.

“I’ve heard it said by some providers that people accessing services today represent the most difficult of human dilemmas and complexity of issues ever faced before by the community, making it harder for us to respond effectively within our current capacity.”

Examples of challenges people involved in peer support and mental health services such as CPEP see include: those living on the edge of society; painful and life-altering affects of childhood trauma; addictions and addictions with other disabilities; lack of family support, issues with the law, extreme poverty, illiteracy, serious health issues; hopelessness, despair, overwhelming fear, homelessness; stigma and discrimination surrounding a mental health diagnosis.

Some recipients say they were helped at CPEP because of a positive experience with a particular psychiatrist, someone who was comforting, safe to talk with, positive and willing to take into account what the recipients felt they needed in order to get through the crisis and that recovery was possible. Most say they do not want to go back to CPEP, mainly because of long waits and unhelpful responses by staff. But there seems to be no alternative available during crises.

McChesney reported recommendations from consumers who have used CPEP:

- Decrease the long waiting time to be evaluated by staff.
- Offer a comfortable waiting room.
- Privacy
- Improve staff responsiveness and attentiveness

- Use discharge interview practice to determine outcomes and get feedback
- Honor medication refusal; make an effort to accommodate recipient preferences

McChesney advocates complementary services, such as peer-run respite, mobile emergency response and including recipients in the planning process.

**B. Deborah Welch:** “CPEP has become a lightning rod for what the community needs to do better,” she said. CPEP began in 1992 with goal of offering a service with quicker, complete access to intervention. Components include emergency room evaluation and treatment; extended observation beds; mobile crisis outreach; crisis residential service provisions made via agreement with Hutchings Psychiatric Center.

CPEP responded to 6,000 client visits by 4,000 clients in 2002. The service sees an average of 17 to 18 individuals a day. 25 percent of clients are 18 or under; 42 percent are aged 19-40; 27 percent are 40-60 years of age; just 6 percent are over 60. Twenty-four percent arrive at CPEP via family or friend; 26 percent via law enforcement; 24 percent refer themselves; 20 percent enter via the ER.

CPEP gets 100 calls a day from people seeking support and referrals. She outlined these challenges of existing system:

- ER setting is a difficult atmosphere when people feel out of control
- Lack of appropriate children’s services
- Lack of inpatient beds
- Increased drug and alcohol use
- Long waiting list for practitioners
- Complexity of treatment to enable client to return to a productive life.

**Panel #4: “Access for Children,” April 2, 2003**

*“I have had to bandage her wrists as she has cried she doesn’t want to live anymore...but doesn’t want to die either....”*  
*--Mary Ellen Claussen*

Panel: Kristen Riley, Deputy Commissioner, Onondaga County Mental Health Department; Mary Ellen Claussen, Ophelia’s Place; Alan Andrews, private provider for adolescents and children. Moderator: Joan Durant

**Highlights: The same barriers that limit adults’ access to services exist for children. Practitioners committed to the distinct needs of children are needed in the community, and existing systems need to make changes to accommodate children’s special needs. The current emergency system, CPEP, is especially inappropriate for children. Young people with some forms of mental illness, such as eating disorders, suffer additional stigma and face additional barriers to service because of insurance limitations and a pervasive sense of denial about the condition’s health ramifications.**

**Mary Ellen Claussen:** Claussen is the mother of two daughters with eating disorders and founder and director of Ophelia’s Place, a resource center and support group for family and friends of people with eating disorders. Her presentation was based on comments she made at recent congressional briefing on behalf of the Eating Disorders Coalition and mental health parity.

“My daughters have struggled for many years because of their eating disorders,” she said, describing her view of mental illness and its toll on the family. “I have spent many a night sitting by their bedside making sure they keep breathing. I live in fear of the phone ringing, a fear that sometimes is paralyzing. ... I live in crisis mode 24/7, always ready to face the next challenge; I minimize what I feel and maximize what they feel. Then of course there is the guilt, and anger.”

Claussen said her family has exhausted financial resources to help their children; the average length of treatment has been 60 days at a cost of \$30,000 per month. She advocates for policies to recognize eating disorders as a serious public health threat, resources for education, prevention and treatment.

An estimated 8 million Americans suffer from eating disorders. Eating disorders cut across race, color, gender and socioeconomic categories. The incidence of eating disorders has doubled since the 1960s and is increasing in younger age groups, in children as young as seven. Eating disorders are commonly associated with substantial psychological problems, including depression, substance abuse, and all too frequently with suicide. They also can lead to major medical complications, such as cardiac arrhythmia, cognitive impairment, osteoporosis, infertility, and death. Anorexia nervosa has the highest mortality rate of all the psychiatric disorders.

Insurance companies routinely limit the number of days they will reimburse, forcing doctors to discharge patients with anorexia too early, she said. Although patients with eating disorders typically require more than six weeks of inpatient therapy for proper recovery, insurance companies reimburse for an average of 10-15 days a year.

**Kristen Riley:** Riley provided these statistics involving children and mental illness:

- 20 percent of children ages 9 to 17 are diagnosed with mental illness
- 70 percent with diagnoses do not receive treatment
- 50 percent of low-income children are at risk for mental illness

Major access issues for clients and families include:

- Not enough public mental health services for children and difficulty recruiting child psychiatrists (currently working with Upstate to re-establish fellowships to recruit and retain child psychiatrists).
- Two to three month waiting list
- Shortage of all levels of mental health workers, including psychiatric nurses and social workers
- Insurance limits who client can see, what treatment and number of visits
- Lack of insurance parity
- Lack of information about services
- Insufficient training for pediatricians, who are often the first contact; many pediatricians misdiagnose or do not understand mental illness
- Many families wait until medical emergency or suicide attempt and then access the system through the emergency room.
- Need better cross-system involvement (probation, social services, and schools)
- Public health system too reliant on state budget
- Need to address conflict between demand for medication as first-level treatment and the results of impact studies/FDA approval for using medications on kids

**Alan Andrews:** The majority of providers are stretched to the limit, work long hours and are compensated poorly. In addition to long waits for some services, roadblocks to service include insurance limitations and poverty. However, even people with financial means must sometimes go out of the area to find available services for adolescents because of lack of qualified practitioners or services locally. Another barrier to treatment is the need for dual diagnosis (e.g. eating disorder AND chemical dependency) in order to qualify for coverage for some treatment programs.

CPEP, he feels, is not effective for children and adolescents: “I would not send my worst enemy to CPEP. I don’t think it’s the place to send a child.” The alternative, he said, is a place where children are received in a warm, loving place, not a hospital emergency room. The community also needs a place people can go when they’re in crisis and not have to worry about how to pay for services. Treating people early would reduce crime and the number of people in criminal justice system with mental health problems.

**Panel #5**  
**“Access and Responsiveness of Local Mental Health Services for Adults and the Elderly,”**  
**April 9, 2003**

*“I didn’t know how to stop being mentally ill, but I suspected it would require no less than recovery. I made up my mind to achieve a full recovery from mental illness ... to recreate a self, my self, that could manage my life on my own.”*

--- Lisa McChesney

Panel: Sheila LeGacy, director of Family Support and Training, Transitional Living Services of Syracuse; Lisa McChesney, MSW, director, Community-Based Peer Initiatives, Transitional Living Services; Nancy Calhoun, MSW, CSW, senior clinical social worker, University Geriatricians, SUNY Upstate Medical University. Moderator: John L. Sheets.

**Highlights: Panelists highlighted the need to overcome stigma and increase public and provider awareness of the latest research to deliver mental health services. They also noted the need to increase the availability and accessibility of services that more effectively engage and involve consumers and families as partners in the service process. Panelists also cited the need to overcome fragmentation of services with wider inclusion of stakeholders in the planning and monitoring of services and through greater coordination in the funding and delivery of mental health and related human services. Better education of health care workers, as well as the general public, is needed for better recognition and understanding of mental illness. Special problems of the elderly should not mean that mental illness is inevitable or acceptable.**

In his introduction, John Sheets asserted the key to improving services include: asking users what they want: relief from symptoms of distress from mental illness; access to desirable housing; opportunity for meaningful employment and education; supportive service relationships; and responsive help in times of crisis.

**Lisa McChesney** - McChesney described personal experience with dropping out of college as a result of mental illness. In her experience, services were generally satisfactory, but she sees room for improvement and says the system is especially difficult for someone new in the community with no contacts. Her recommendations include:

- Adding case managers
- Create service to answer questions/provide referrals
- Expand CPEP to include peer coaching
- Simplify system to get prescriptions

Further weaknesses/recommendations are the result of informal survey of clients in peer support. Service is based not on want, but on availability, she said. There is a lack of recipient choice; and many clients need assistance managing the system, sometimes including money and transportation. Among her recommendations:

- Educate professionals on effective listening.
- Offer genuine choices
- Be creative
- Honor choices of individual
- Create service coordinator program

- Improve coordination among service providers
- Stop painful maintenance mentality

The local mental health system needs to be held accountable to belief that recovery is possible, she said.

**Sheila LeGacy** - LeGacy believes there are not enough psychiatrists, case managers, or residential programs in the community. She advocates a new residential model, a safe house for consumers who don't need ER or CPEP, more supportive businesses like Provisions, and a jail diversion program. The family should be involved in the discharge plan.

**Nancy Calhoun** - Ms. Calhoun described a lack of attention to older patients. Despite conventional wisdom, she said, aging is NOT a time of illness; being depressed is NOT to be expected; being dependent is NOT expected; being demented is NOT expected.

Symptoms of dementia mimic mental illness; dementia increases with symptoms of depression. Dementia is a general complex of symptoms that involve problems of memory and learning plus at least one of the following impairments: ability to communicate; ability to reason; to plan; to manipulate objects in space; to be oriented and alert; to moderate emotions. The community is often indifferent to people who are demented and mentally ill, she said.

Mental health issues and dementia issues are often a continuum. Mental health and physical illnesses are inseparable in older people. She stressed the importance of advance directives, Power of Attorney, Health Care Proxy, Living Wills, and Do Not Resuscitate Orders

Her recommendations include:

- Coordination of program services and money.
- Transportation to non-medical programs through Medicaid
- Recipient/family members should serve on new CPEP board of directors
- Create an Ombudsman to address problems of the mental health system

**Panel #6: “Access for Special Populations,” April 23, 2003**

*“The very mentally ill fall through the cracks.”*  
*--Laurie Sanderson*

Panel: Rev. Bill Lott, adjunct instructor, Department of Social Work, Syracuse University and pastor, Greater Love in Christ Church; Laurie Sanderson, social worker/therapist, Syracuse Community Health Center; Kurt Andino, executive director, Jail Ministry. Moderator: Frank Woolever.

**Highlights:** Falling through the cracks of local services, an increasing number of the mentally ill end up in jail or in other vulnerable situations. While these include individuals of all ages, those at greatest risk are youth with physical, emotional or developmental disabilities. Some positive interventions are taking place in our Justice Center; however, greater collaboration is needed among social service, mental health and faith-based organizations, with cultural sensitivity and language skills to assist the increasingly diverse population. The trend toward more incarceration speaks to a lack of meaningful alternatives.

**Rev. Bill Lott:** Although Syracuse and Onondaga County have many mental health resources, they do not necessarily address the needs of special populations. Barriers include fee scales, hours of operation, location, and intake process and forms, lack of cultural sensitivity, and language issues. More culturally diverse staff is needed.

Recommendations:

- More inpatient and outpatient services for young people;
- Community and home-based mental health to overcome barriers of location and hours;
- Family-oriented services;
- Building treatment on strengths not weaknesses;
- Greater collaboration among social service, mental health and faith-based organizations.

**Laurie Sanderson:** Sanderson adds developmentally disabled to list of special populations. Her list of barriers to mental health services includes long waiting lists, uninsured and underinsured not getting services; insufficient number of practitioners who speak other languages, including Spanish and those of other immigrant groups; lack of case management; lack of psychiatrists; lack of psychiatrists who are sensitive to cultural differences; lack of training in alternative therapies.

**Kurt Andino:** “When all else fails, they end up in jail,” according to Andino. He cited the following statistics for mentally ill inmates:

- 53 percent committed a violent offense
- 50 percent receive medication
- 41 percent receive counseling
- 8 percent more likely to know the victim (who is often the caregiver);
- 15 percent more likely for victim to be 12 years old or younger;
- 52 percent chance has been in jail three times or more;
- more likely to have been abused previously (36 percent vs. 12 percent)
- likely to serve 15 months longer than a person who is not mentally ill.

While people “age out” of criminal behavior; the reverse is true of mentally ill. Mentally ill prisoners are often there because they violated orders of protection, harassment or contempt of court. Because of their illness, they do not define these structures the same way nor do they respond to the threat of incarceration.

Andino points to the success of the Justice Center’s Clean and Sober Pods and Jail Ministry’s role in assisting with anger management and 12-step programs. His recommendations to improve the system include:

- exit plans for mentally ill inmates;
- attention to the extra challenges for mentally ill/chemically addicted;
- improved connections between Justice Center staff and Mental Health Department.

**Panel #7: “Interface with Law Enforcement,” April 30, 2003**

*“The crime is that you often have to commit a crime  
to enter the mental health system.”*

*--Hon. Robert J. Rossi*

Panel: Anthony Callisto Jr., chief deputy and Custody Department commander, Onondaga County Sheriff’s Office; Steve Thompson, deputy chief, Syracuse Police Department; Hon. Jeffrey R. Merrill, supervising judge, Syracuse City Court. Moderator: Hon. Robert J. Rossi.

**Highlights: Many mentally ill people enter the system through the criminal justice system. CPEP is an important resource for law enforcement officers who encounter mentally ill people who are charged with offenses. A mental health court using the Drug Court model to divert mentally ill people from the regular criminal justice system should be investigated. Other recommendations include developing a trauma team of officers and mental health officers to respond to calls and ensuring necessary funding to maintain and refine critical services in the justice center.**

**Hon. Jeffrey Merrill:** “The way New York State dealt with mental health issues during the Carter administration was awful,” he said. “It was cynical and done to save money.”

Merrill supports the DWI diversion program and oversees Drug Court. Of the 350 people are in treatment court; Merrill estimates half are also mentally ill. While unified treatment for those with both substance abuse and mental illness is preferable, dual diagnosis is difficult to deal with because of lack of services;. He urges an expansion of providers to offer broad services. “We’ve been trying to help people with mental health issues for years, but not in a structured way,” he said.

Judge Merrill feels the Drug Court model could work for mental health clients as well. He offered the Office of Court Administration’s help to promote this.

**Steve Thompson:** Chief Thompson reported that police officers encounter 1,200-1,500 mentally ill people each year: calls come from homes, merchant complaints, doctors, and CPEP, among other places. The Department does 500 transfers to mental health facilities each year. Each transfer ties up two officers for at least two hours; if CPEP closes, response time of officers will increase, he said.

Officers are trained on how to deal with people who are mentally ill, but he said that population has changed. “We used to see in the 1970s a lot of people who were schizophrenic or bipolar,” he said. “Today we most often come in contact with people with dual diagnoses. Many facilities won’t accept those people if they’re intoxicated.”

The community needs a facility for immediate triage. He supports a trauma team of officers and mental health professionals to respond to calls.

**Anthony Callisto:** “Short of CPEP or ER, we provide the highest level of mental health services in the community,” he said. Services offered at jail include substance abuse management in the Clean and Sober Unit and Behavioral Health Unit. There are 50 beds for males (average of 48 in use); 14 beds for women (average 11 in use).

The Justice Center has 20 hours a week of psychiatric services contracted by the county department of mental health and 24/7 coverage by on-call psychiatrists. Every inmate is interviewed by a psychiatric social worker. These services are not mandated, but are local policy decisions, he said.

In Chief Callisto's view, the Justice Center needs crisis intervention services, counseling, case management, and better programs to provide transition back to community. Obstacles include funding, the struggle with day-to-day crises of suicide attempts and out of control behavior, and staff recruitment.

**Panel #8: “The Cost to Our Employers and Schools”, May 7, 2003**

*“Youth are experiencing the same stresses adults are experiencing.  
They are also witnessing how adults deal with stress.”  
--Jeanne Elmer*

Panel: Jeanne Elmer, director of Student Assistance Programs, Onondaga County Mental Health Department; Jim Wright, school psychologist/mental health coordinator, Syracuse City Schools.  
Moderator: Donna Stoner

**Highlights: The high cost of providing mental health services to businesses and schools results from avoidance and/or ignorance of the issue and insufficient early diagnosis and treatment. Mental illness affects business in lost work time and increased health care costs. The barriers and effects are similar for children: disruption in learning, insufficient early intervention and diagnosis, inconsistent access to treatment, and stigma.**

**Donna Stoner** set the tone by reading excerpts from recent edition of “Workplace Visions,” a publication of the Society for Human Resources Management. A recent study found that of the ten leading causes of disability worldwide, five are psychiatric conditions: depression, alcohol use, bipolar disorder, schizophrenia and obsessive-compulsive disorder.

Depression costs US employees almost \$44 billion per year. It is the number one cause of disability in developed countries and it is associated with more annual sick days and higher rates of short-term disability than any other chronic condition, including hypertension, diabetes, heart disease and arthritis.

A recent study found that total medical expenditures for employees with mental disorders was 45 times higher than for those without. Studies also found the costs of physical medical care are higher for people with mental disorders.

Indirect costs of mental health impairments outweigh the direct costs. Combined costs of absenteeism and lost productivity related to depression are much higher than the direct costs. Cost of mental health conditions extends to employees who are spouses, parents, siblings, children or friends of mentally ill.

**Jeanne Elmer** described the Student Assistance Program, which has been operating 20 years in Onondaga County, serving 14 schools in seven districts in the city and county. It is modeled on Employee Assistance Program and is funded by OASAS, schools and the county. The services (including substance abuse evaluation and mediation) are free and confidential, and the program uses a strength-based approach to counseling.

How pervasive are mental health issues in schools? Counselors see a lot of substance abuse, but less dependence, she said. Typical issues are relationship problems, concerns about friend or relative’s substance abuse, eating disorders, disconnectedness, anxiety, depression and sense of isolation

Recommendations:

- an emotional health campaign that emphasizes effects of poor emotional health;
- a campaign and attitude changes to address stigma;

- more home-based, wrap-around, flexible services that empower clients with choices of how, when and where they receive services;
- more individualized treatment;
- emphasis on strength-based approaches;
- continuum of care with no barriers to next level;
- more child psychiatrists; and
- respite services for families.

**Jim Wright** said mental health programs in city schools are considered support services rather than essential services. This is complicated by vague definition of “emotional disturbance.” Many emotional needs of kids in schools cannot be met because of lack of funding and because they are not part of traditional mandate, he said.

Research indicates 18 to 22 percent of the public school population may meet diagnostic criteria for at least one psychiatric disorder, he said. He sees a scarcity of effective programs and services for students with intensive mental health and behavioral needs; poor coordination of existing services and barriers between systems. (Regulations of schools are different from those in mental health care system.)

Wright advocates expanding services for “high-needs” children; creating and maintaining updated online directory of community mental health services; and community coordination of mental-health efforts across systems.

**Panel #9: “Interface with Health, Religion and Social Services,” May 14, 2003**

*“I say to a patient who is depressed: ‘You have insurance, call this 800 number and see what you can get covered.’ That’s not a very satisfying answer.”*

*--Dr. Jef Sneider*

Panel: David Sutkowy, commissioner, Onondaga County Department of Social Services; Rev. Bill Lott, clinical social worker, pastor, Greater Love in Christ Church, director of mayor’s task force on youth violence; Dr. Jef Sneider, private physician. Moderator: Helen Crouch

**Highlights: Mental health professionals are not the only providers of mental health counseling, referral and treatment. Clergy, physicians, and others who are part of the system need training and support to recognize mental illness and properly refer people to the mental health system. Better coordination and a holistic approach to diagnosis and treatment are required. Health insurance restrictions are a barrier and Medicaid has been stretched to cover some services, but has restrictive guidelines and children, in particular, are shortchanged by this system. Special care must be taken to address the needs of people with language, culture, or economic differences.**

**Rev. Bill Lott:** “There is a connection between people who struggle with mental health and their concept of spirituality,” he said. Many people look for “someone who will understand my religious beliefs and won’t think I’m crazy,” he said.

He described a shift in the mental health system to better communicate with the religious community (one example is a social work course that focuses on spirituality). Clergy are often the first people to be aware of people’s emotional pain; they see people at their best and worst, but not all pastors are trained in psychotherapy. Both clergy and psychotherapists bring something to mental health treatment; both need to be sensitive to the other perspective, he said.

The mental health/spirituality piece has been missing from community efforts to address violence, Lott said. “Kids are fatalistic; there is no hope,” he said. “They are not afraid to die. We have to give them a reason to live. That’s the spiritual piece.”

**David Sutkowy:** A major issue in the mental health field is the inadequacy of resources. The state is paying a price and losing flexibility by converting services to Medicaid, the public funding system that covers many mental health programs. The child welfare system deals with mental health by default but many children have dual diagnoses, which makes it harder to find and fund services.

**Dr. Jef Sneider:** the lack of money and reimbursement results from insurance definitions of mental health. Primary care doctors treat mental health issues; diagnosing depression is very common. General practitioners may be the largest prescribers of psychiatric drugs, and drugs are heavily marketed to physicians. Some patients take the easy way out and take the medicine but do not get recommended counseling, he said, while some refuse to take medication, fearing it’s unsafe or addictive. Sneider advocates a team approach and collaboration with client.

**Panel #10: “Funding and Insurers,” May 21, 2003**

*“Mental health services in the United States evolved in large measure apart from the medical care system; the organizational and financing dynamics are very different in mental health care”.*

*--Tom Dennison*

Panel: Tom Dennison, Maxwell School, advisor to Health Services Management and Policy Program; Bob Shear, former president of Syracuse Behavioral Healthcare (Syracuse Brick House Inc.), member, Onondaga County Criminal Justice Advisory Board, former director of state Division of Alcoholism and Alcohol Abuse; Kathy Hart, Onondaga County assistant commissioner for Medicaid and Adult Services; Michael C. Slade, behavioral health treatment program development administrator, BlueCross/BlueShield of Central New York. Moderator: Harvey Pearl, Ph.D.

**Highlights: Suggestions to improve mental health services include: increasing inpatient services and reimbursement for children and youth; more creative collaboration among insurers, providers and clients; more county responsibility for long-range planning; and an overhaul of the current Medicaid system.**

**Tom Dennison:** Mental health services historically were largely a state and local concern and responsibility with relatively little funding coming directly from the federal government. The large inpatient psychiatric hospitals that were prevalent until the 1960s were the venue for much of the care and the cost of mental health.

More than half of mental health costs are borne by state and local governments. The federal government, apart from its share of Medicaid, contributes very little. Approximately 3 percent of total mental health spending is direct federal dollars.

Federal public financing mechanisms, such as Medicare and Medicaid, initially imposed limitations on coverage, particularly for long-term care, of “nervous and mental disease” to avoid a complete shift in financial responsibility from state and local governments to the Federal government.

Medicare has continued these restrictions. Medicaid has become a major source of payment. Private health insurance was traditionally more restrictive in coverage of mental illness than in coverage for somatic illness. This was motivated, in part, by the fear that coverage of mental health services would result in high costs associated with long-term and intensive psychotherapy and extended hospital stays.

Some private insurers refused to cover mental illness treatment; others simply limited payment to acute care services. Those who did offer coverage chose to impose various financial restrictions, such as separate and lower annual and lifetime limits on care (per person and per episode of care), as well as separate (and higher) deductibles and co-payments. As a result, individuals paid out-of-pocket for a higher proportion of mental health services than general health services and faced catastrophic financial losses (and/or transfer to the public sector) when the costs of their care exceeded the limits.

There is a movement, slow but sure, to ensure parity between mental health care and general medical care. A parity mandate requires all insurers in a market to offer the same coverage, equivalent to the coverage for all other disorders.

**Bob Shear:** A key element of recent trends has been the conversion of services previously financed through discretionary state/county support into Medicaid/entitlement funding. This puts the federal government on the hook for a portion of the costs.

The choice of how to spend money lies at the heart of the discussion, he said, and privatization challenges the constitutional commitment to care for mentally ill. As services are “Medicaidized,” discretionary money decreases and state’s commitment declines, he said.

He faults the planning system for providing limited information about how money is spent. State office of mental health captures information about where programs they fund get the rest of their money. “The failure of the government at county and state level to confront this as public health problem is biggest problem of the system,” he said, adding that treating the mentally ill must be a public sector choice.

A state moratorium on licenses for mental health services creates a roadblock that keeps chemical addiction facilities from offering mental health services, he said.

Shear believes the county should take more responsibility for long-range planning. “Planning for the closing of Hutchings is legally the county’s job,” he said. “They don’t seem inclined to do so.”

**Kathy Hart:** Hart outlined the very complicated system of eligibility standards for public health insurance.

Medicaid started out in the 1960s as a program to help low-income families access medical care. Now there are 20 eligibility levels or programs and five types of applications under the state department of health’s Medicaid program. These are statewide benefit programs covering most health benefits similar or greater than private insurance.

The confusing system of applying may cause some recipients not to see the care and benefits they need, she said. Providers complain of low payment rates, complicated billing process and slow claims payments. “In short, the public health insurance program needs a complete overhaul, rather than continuing to add programs and benefit levels to the current system,” she said.

**D. Michael Slade:** Slade outlined some of the ways providers and Excellus in the Rochester area make flexible use of benefits to maximize service, for instance, shorter hospitalization and transfer to less intense services when appropriate. He offered suggestions to improve the mental health services:

- More inpatient services for children and adolescents
- In-between programs, partial hospitalization (currently no step-down from inpatient care)
- Increased reimbursement for children and adolescents
- Eating disorders treatment
- Telnet program so doctors can network, particularly in rural areas
- Reduced co-payments
- Case management/benefits management/flex benefits
- In-home crisis intervention



**Community Leadership Conference, "Our Mental Health Service Delivery System: Problems and Promises," June 11, 2003**

*"Incremental reform of the system isn't a viable option anymore. We need a much more fundamental transformation."  
--Michael F. Hogan*

Speakers: Michael F. Hogan, chair, President's New Freedom Commission on Mental Health; Eileen Siddell, director, Crouse HelpPeople Employee Assistance Program; Joseph A. Glazer, president and CEO, Mental Health Association in New York

**Highlights: Hogan's advance look at the President's New Commission Report on Mental Health highlighted numerous issues raised in local panel discussions. The national mental health system is fragmented, focuses more on supporting those with mental illness than encouraging a philosophy of recovery, and marginalizes mental illness instead of integrating it into the health-care system. Hogan's recommendations, supported by the national report, include promoting mental health as good health, early mental health screening, and using technology to improve access to services. Other speakers emphasized that mental illness reduces productivity in the workplace and that New York State failed to appropriately plan and implement a community-based mental health system after deinstitutionalization.**

**Michael F. Hogan**, chairman of a presidential commission looking at ways to fix the U.S. mental health system, provided a glimpse of the forthcoming President's New Freedom Commission on Mental Health. Hogan, who has a doctorate from Syracuse University and a bachelor's degree from Cornell University, is director of the Ohio mental health department.

Dr. Hogan stated that the country's system of mental health care is "so fragmented people don't know where to get help." There are 42 federal programs for adults and children with mental illness; each has different eligibility criteria, is administered by a different government agency and has different forms to fill out, he said.

The government pays out more than \$20 billion annually in Social Security Income and Social Security Disability Income to people with mental illness-related disabilities, suggesting a lack of commitment to recovery. "Our deal with them is, "If you stay disabled, we will send you this check and give you health care. Try to recover and we are cutting you off," Hogan said.

Mental health providers and clients describe different goals. Providers often focus on making sure patients take their medicine and stay out of the hospital; clients hope to live, work and participate fully in their communities, according to Hogan. "We have not created a set of supports and a community attitude about this."

Hogan advocates a system in which mental health care is an integral part of health care. "Think of another illness for which you have a county department or a state agency taking care of it," he said. "We used to have that for tuberculosis and leprosy. Today, it's mental health. We have not established this as part of the mainstream."

Mental illness, he said, remains hidden. “These are still problems that are out of sight and out of mind,” he said. “We’re comfortable to put them aside. The places we put them lead to suicide, homelessness, poverty, jail.”

His recommendations for transforming the mental health system:

- Make it a national goal to establish mental health as essential to good health.
- Provide consumer- and family-centered care. Put resources and choices in the hands of consumers.
- Eliminate disparities in mental health care. (such as access to racial and economic minorities)
- Encourage early mental health screening and treatment across lifespan
- Strengthen link between science and services (shorten time it takes to get new treatment into the mainstream.
- Capitalize on communication and information technology in such areas as electronic records and telemedicine. (This indirectly will ease access problems.)

**Elaine Siddell:** From the employer’s perspective, mental illness affects productivity. It also can spur workers compensation, family leave, and Americans with Disabilities Act provisions for ill person and relatives affected by a mental health crisis. Although she sees a shift toward more openness about mental illness, it’s still difficult to address in the workplace. Behavioral issues left unresolved lead to more problems.

“We have to give people permission to talk about their issues,” she said, adding that providing information on mental illness and issues such as stress can help normalize response.

**Joseph Glazer:** “Essential to recovery is the issue of self-worth.” Glazer described concerns in 1978 about Willowbrook (NYS children’s developmental disabilities center) as the catalyst for deinstitutionalization. Lawsuits over treatment there led to state leaders’ agreement to revamp mental health services for the developmentally disabled. Since then, the state’s Office for Mental Retardation and Developmental Disabilities has improved significantly, while the mental health system has not.

The state law requiring a five-year plan for mental health care is not followed, he said. “It is possible to create a comprehensive system of community-based care,” he said. That plan should follow the path of OMRDD, he said, by creating, funding and supporting smaller programs and community living models/outpatient care. That system would be:

- Inclusive (built on recognition of the right to live in the community.)
- Include a broad range of services
- Serve multiple populations
- Use multiple practitioners
- Meet individuals’ needs
- Jail should be a last resort
- Broad range of services



## APPENDICES

### GLOSSARY (Source: Family Support and Education, Transitional Living Services)

**Affective disorder:** A mood disorder. In bipolar affective disorder, a person fluctuates between depression and mania.

**Antidepressant:** Medication used to treat depression

**Antipsychotic:** A drug that reduces the symptoms of psychosis; also called a neuroleptic.

**Behavioral therapy:** Direct treatment of behavior by conditioning and related techniques based on learning theory principles

**Bipolar disorder:** Brain disorder characterized by manic and major depressive episodes with periods of recovery generally separating mood swings.

**Borderline personality:** Instability in a variety of areas, including interpersonal relationships, behavior, mood and self-image; impulsive and unpredictable behavior may be physically self-damaging and may be marked by changes from normal mood to inappropriate intense anger or control of anger. Can include uncertainty about self-image, long-term values or goals; feelings of emptiness or boredom; brief episodes of psychosis.

**Brain disorder:** A severe mental illness, such as schizophrenia, panic disorder, obsessive-compulsive disorder, bipolar disorder (manic-depressive illness), and major depression.

**Bulimia:** Disorder characterized by compulsive eating binges followed by some effort to counteract possible weight gain.

**CPEP:** Comprehensive Psychiatric Emergency Program: an emergency and short-term facility for people in crisis. The agency is undergoing restructuring to address concerns about financing and effectiveness.

**Delusion:** A false belief persistently held despite indisputable and obvious proof to the contrary. The belief is not typically accepted by members of the person's culture and may include delusions of grandeur or of persecution.

**Dementia:** Degeneration of central nervous system functions, such as memory and learning capacity.

**Denial:** Psychological defense in which a part of external reality is rejected.

**Dissociation:** An idea, affect, or part of the personality is split from the main personality and thrives as a separate entity.

**Dopamine:** A chemical messenger in the brain that appears to play some role in brain disorders such as schizophrenia.

**Dual disability:** A person affected with more than one impairment, such as mental illness and mental retardation, or mental illness and substance dependency.

**Dsythymia:** A chronic, mild to moderate depression.

**Extra-Pyramidal Symptoms (EPS):** Motor side effects of neuroplectics, such as shuffled gait, slowed movements or tremors, or rigidity.

**Hallucination:** The false perception of a sight, sound, taste, smell, or touch when no actual stimulus is present. Also refers to the imaginary object apparently seen or heard.

**Labile:** Rapidly shifting emotions; unstable.

**Major depression:** A brain disorder characterized by profound depression – loss of interest or pleasure in activities, sadness, and feelings of helplessness. Common symptoms include weight gain or loss, insomnia or excessive sleepiness, slowed or agitated movement, intense feelings of guilt or worthlessness, diminished ability to concentrate; and recurring thoughts of death or suicide.

**Mania:** A symptom of bipolar disorder characterized by irritability, expansiveness, elation, talkativeness, hyperactivity, and excitability.

**NAMI PROMISE:** A support group for families and friends of people with psychiatric disabilities

**Neurological disorder:** Disorder pertaining to the nervous system.

**Neurotransmitter:** A brain chemical that carries an inhibiting or a stimulating message from one brain cell to another via the synapse between them. Examples are serotonin, dopamine, norepinephrine, and GABA (gamma-Aminobutyric acid,) which often are affected by psychiatric medication.

**Obsessive-compulsive disorder:** (OCD) A brain disorder characterized by recurrent and persistent thoughts, images, or ideas perceived as intrusive and senseless (obsessions) and by stereotypic, repetitive, purposeful actions perceived as unnecessary (compulsions.)

**Panic disorder:** A brain disorder characterized by sudden, inexplicable bouts or attacks of intense fear and strong physical symptoms, such as increased heart rate, profuse sweating, and difficulty breathing.

**Parity:** Equal health insurance coverage for brain disorders and mental illnesses as other physical disorders.

**Personality disorder:** A deeply ingrained, inflexible, maladaptive pattern of relating, perceiving and thinking serious enough to cause distress or impaired functioning. Includes antisocial, borderline, compulsive, histrionic, dependent, narcissistic, paranoid, passive-aggressive, schizoid and schizotypal disorders.

**Phobia:** An obsessive, persistent, unrealistic fear of an object or situation, such as acrophobia (fear of heights,) agoraphobia (fear of leaving familiar setting of home,) claustrophobia (fear of closed places) and xenophobia (fear of strangers.)

**Psychoactive and psychotropic:** Something that produces effects on thought, mood, and emotions.

**Psychosis:** A mental state characterized by severely impaired thinking and perception. It is a prominent symptom of schizophrenia.

**Psychotherapy:** A range of therapies used to treat brain disorders, including cognitive and behavioral therapy.

**Schizoid:** A sensitive, shy, isolated detached and emotionally shallow state.

**Schizophrenia:** A brain disorder characterized by disturbance of cognition, hallucinations, and impaired emotional responsiveness.

**Serotonin:** A neurotransmitter that may be involved in depression and anxiety disorders.

**Sociopath:** Antisocial-type personality, pleasure-seeking, remorseless, and not bound by law code, trust, or friendship

**Synapse:** The space between the membrane of one nerve cell and another. A neurotransmitter carries an impulse, chemically or electrically, through the synapse.

**Tourette's syndrome:** a neurological disease with symptoms including lack of muscle coordination, involuntary movements, tics, and incoherent verbal noises.



## List of local mental health services and agencies

(provided by Alfred A. Fusco, executive director of the Mental Health Association of Onondaga County, Inc.)

### 1. Adult inpatient units

Community General Hospital  
 Four Winds Hospital  
 Hutchings Psychiatric Hospital  
 St. Joseph's Hospital  
 SUNY Upstate Medical Center  
 Veterans Administration Medical Center

### 2. Adult outpatient clinics

ARISE  
 Hutchings Psychiatric Center  
 Onondaga Pastoral Counseling Center  
 St. Joseph's Hospital  
 SUNY Upstate Medical Center  
 Veterans Administration Medical Center

### 3. Advocacy

Legal Services of Central New York  
 Mental Health Association  
 Mental Hygiene Legal Services  
 Mental Patients Liberation Alliance  
 NAMI-PROMISE

### 4. Case Management

Mental Health Association  
 Onondaga Case Management

### 5. Child/Adolescent Inpatient units

Four Winds Hospital  
 Hutchings Psychiatric Hospital

### 6. Child/Adolescent outpatient clinics

ARISE  
 Hutchings Psychiatric Center  
 Onondaga County Department of Mental Health  
 Onondaga Pastoral Counseling Center  
 St. Joseph's Hospital  
 SUNY Upstate Medical Center

### 7. Child/Adolescent day treatment

Hutchings Psychiatric Center  
 Onondaga County of Mental Health  
 St. Joseph's Hospital

**8. Continuing day treatment programs**

CNY Services  
 Huntington Family Services  
 Hutchings Psychiatric Services  
 St. Joseph's Hospital

**9. Counseling services**

ARISE  
 Catholic Charities  
 Dunbar Center  
 Jewish Family Services  
 Onondaga Pastoral Counseling Center  
 Salvation Army  
 Syracuse University Goldberg Center  
 Syracuse University Psychology Department  
 Veterans Administration Medical Center

**10. Emergency psychiatric services**

Comprehensive Psychiatric Emergency Center

**11. Family support**

Catholic Charities  
 Hutchings Psychiatric Center  
 Mental Health Association (STRIVE)  
 NAMI-PROMISE  
 Salvation Army  
 Spanish Action League

**12. Housing**

Catholic Charities  
 CNY Services  
 Hillside Children's Center  
 Hutchings Psychiatric Center  
 Liberty Resources  
 Loretto Geriatric Center  
 St. Joseph's Hospital Health Center  
 Salvation Army  
 Transitional Living Services  
 YMCA  
 YWCA

**13. Peer services/self-help**

Mental Health Association  
 Mental Patients Liberation Alliance  
 NYS Office of Mental Health CNY Field Office  
 Onondaga Case Management  
 Peer Networking Group  
 Transitional Living Services

**14. Information and referral**

CONTACT

Mental Health Association

Onondaga County

**15. Intensive psychiatric rehabilitation**

Hutchings Psychiatric Center

St. Joseph's Hospital Health Center

**16. Psychosocial clubs**

Hutchings Psychiatric Center

St. Joseph's Hospital Health Center

**17. Residential treatment facility**

Hillside Children's Center

**18. Supported education**

Transitional Living Services

**19. Telephone counseling**

CONTACT

**20. Vocational services**

ARISE

CNY Services

Hutchings Psychiatric Center

Onondaga Case Management

OCM BOCES

RLS Career Center

St. Joseph's Hospital Health Center

Transitional Living Services

Unity Employment Services

VESID



## **Summary of Study Panel Discussion Themes**

A number of themes emerged in discussions at the ten study panel sessions, which were attended by many interested members of the community representing clients, families and mental health and social service professionals. They have been organized according to the theme of the OCL Study: Mental Health Services – Access, Availability and Responsiveness.

### **Access:**

1. Increase public knowledge of mental illness and its impact. Continue to provide resources for information and treatment through public education.
2. Provide better education and mandatory steps for schools to help identify mental illness.
3. Coordinate continuum of care with no barriers to levels between children's services and those for adults.
4. Remove barriers between systems, e.g. school regulations differ from those in mental health care system.
5. Improve education, prevention and treatment for those with eating disorders.
6. Address roadblocks that limit treatment because of insurance or poverty.
7. Create services that eliminate barriers to special populations: Fee scales, hours of operation, clinic location, language difficulties.

### **Availability:**

1. Determine cause of lack of psychiatrists in community.
2. Increase services designed for children and young adults.
3. Provide more supportive housing and greater availability of supportive employment.
4. Provide greater variety of client services through use, for example, of those home-based, or which offer greater flexibility.
5. Expand services for 'high-need' children.
6. Provide separate emergency services for children and adults.
7. Increase mobile-team services – expand hours, staff and availability.

### **Responsiveness:**

1. Address problems of misdiagnosis or missed diagnosis, especially by school staff and physicians.
2. Emphasize more individualized treatment.

3. Offer respite services for families.
4. Protect programs and services for students with intensive mental health and behavioral needs.
5. Improve coordination of existing mental health services, especially with chemical dependency treatment.
6. Services for older adults with dementia should consider mental health concerns.
7. Greater range of treatment options should be available, excluding medication where possible, and offered without 'force'.
8. Encourage practitioners and service providers to direct families to NAMI/PROMISE.
9. Create/maintain database of local services.
10. Advocate long-term planning for mental health services (e.g., possible closing of Hutchings; the funding of CPEP).
11. Advocate for temporary 'safe-house' model.
12. 12. Encourage CPEP to include peer coaching.
13. System to obtain prescriptions should be more flexible.
14. Criminal Justice System should: Support NAMI's proposal for jail diversion; explore using Drug Court as model for mental health clients in Criminal Justice System; create and maintain a trained Trauma Team of police officers and mental health professionals to respond to those calls where emotional/mental health concerns are an issue.

## **Testimony on the Proposed Closing Of Hutchings Psychiatric Center, March 20, 2003**

**Onondaga County Executive Nick Pirro** made the following statement March 20, 2003 to the New York State Assembly Committee on Mental Health, Mental Retardation and Developmental Disabilities regarding the proposed closure of Hutchings Psychiatric Center. It is available online at [www.ongov.net](http://www.ongov.net).

Testimony: Good morning. I am Nick Pirro, the County Executive for Onondaga County.

First, I want to thank Mr. Rivera and Members of the Assembly Committee on Mental Health and Developmental Disabilities for coming to our community, once again, to hear our concerns about the proposed closure of Hutchings Psychiatric Center.

By way of background, let me say that I understand that the post 9/11 aftershocks to our already struggling economy have created a very serious financial crisis for government at all levels. Health Care, Pension and Medicaid are just a few examples of budget areas that are out of control and in need of serious reform. In Onondaga County, we accept and encourage thoughtful changes in our spending that lead to the right balance between service levels, productivity enhancements and tax adjustments. In fact, we have enacted a dramatic, bare-bones budget for 2003. But we cannot achieve this balance without the support and collaboration of State government. Continued State mandates that are unfunded or spending cuts that present additional pressure on local property taxes will not produce a better County or a robust State.

The Proposed Budget for the State Office of Mental Health includes a plan to address a budget gap through the closing and consolidation of three State Psychiatric Centers in July of this year. Included in the proposed Executive Budget are the relocation of inpatient beds for children and adults from Syracuse to Utica and the transfer of all other services currently provided by Hutchings Psychiatric Center to Mohawk Valley Psychiatric Center. The result will be a complete closure of the Hutchings Psychiatric Center.

Hutchings Psychiatric Center has, for the past 25 years, provided approximately 40% of the public mental health services in Onondaga County. A range of services is provided including inpatient services for children and adults, clinic and day treatment programs, a social clubhouse program, community residences, and a sheltered workshop. Ninety percent of the people served live in Onondaga County. It is a major part of our service system and because of its downtown location is very much a community-based organization.

The first and most obvious impact of the proposed closing is the loss of jobs. As you will no doubt hear from others this morning, the potential adverse economic impact is significant. I don't have precise data because it has not been made available; however, the estimated number of jobs to be eliminated or moved to Utica is 350. The estimated payroll of these jobs is eight million dollars. Over time fewer and fewer employees of Mohawk Valley Psychiatric Center will reside in Onondaga County.

We have been told that a 10 week hospital stay in Utica should not be a hardship on families, their family members "could not be forgotten" in that timeframe. Further, we have been told that it is unreasonable for every urban community to have

specialty services such as cancer centers, heart specialists and long-term psychiatric inpatient care. We disagree. There is a major impact and hardship to families and service providers of traveling 60 miles or more to Utica to visit those in the hospital and to participate in discharge planning. I am particularly troubled by the impact on children, their families, and the full range of child welfare and education services that will now have to travel to Utica. Many people are attracted to Syracuse because of our excellent access to quality specialty health care. We are known nationally for our cardiac surgery and cancer treatment and have a first class regional trauma center. Accessibility to mental health care should be no different.

Transportation to Hutchings Psychiatric Center is frequently provided by law enforcement agencies or by ambulance. Traveling to Utica will be a substantial burden and will come at a high cost. Relocation of inpatient services to Utica is a step backwards and contradicts State policy of ready access to services.

The third impact is more subtle but no less important. During the past 15 years State government policy and budgetary goals have supported community based services including elements such as ready access to services, coordination of care, strong local authority, and more recently, a single point of entry and accountability. Our current system is fragmented and confusing to recipients and providers. Moving the headquarters for the administration of 40% of our system is a step in the wrong direction and contradicts current State initiatives.

For the past eight years, the State has provided resources to the communities impacted by a facility downsizing and closure. My understanding is that the now expired Reinvestment legislation supported approximately \$70,000 per closed bed for the development of community-based services. The current budget clearly states, and I have been told by the Commissioner of the State Office of Mental Health, that there will be NO reinvestment for the closure of the centers being closed this year, while funds will become available for those closed next year. The State should provide all center closures with the same reinvestment into the communities that have lost this valuable resource for the community.

Let me turn directly to my request. I think we have learned that the journey toward improved health care does not always have to begin in Albany or Washington. All health care is local and frequently the best plans are those developed through a local planning process.

As the Chief Executive of an 836 million dollar corporation, I can understand and accept the need to reduce costs and reallocate funding. This proposed plan may look better to some from a distance.

The Mental Hygiene Law strongly supports local planning as a foundation for the development of public mental health services. The current plan is not consistent with either the letter or intent of the current statute.

My specific request is that the State Legislature rejects the current proposal and that the proposed closure be put on hold pending the development of an alternative plan that will meet the financial goals of the current plan but avoid the adverse impact I and others have identified.

I am confident that a better plan can be developed. Thank you.

**Dr. Mantosh Dewan** is chair of psychiatry at SUNY Upstate Medical University. Following is his March 20, 2003 testimony to the Assembly in support of Hutchings Psychiatric Center.

Thank you for this opportunity to address you on this very important topic. My name is Mantosh Dewan and I am the Chair of the Dept of Psychiatry at Upstate Medical University. I have also been on the Board or a consultant to the Board of the local NAMI affiliate for over a decade.

The Governor proposes to close all of Hutchings inpatient services while retaining outpatient services. Clearly, this plan will hurt the community economically and lay off 124 staff. It will hurt families in their attempts to care for their loved ones. It will hurt our police and ambulance services, which will be tied up transporting our patients to Utica on a routine basis. But these hurts are minor compared to the real harm we will knowingly perpetrate on our patients. Put bluntly, there are plans to move our patients to Utica, to provide walls and windows and a roof, period. Yes, there is something missing; I am most concerned that there are no plans to provide adequate treatment. There is no discussion of the quality of care. Please let me elaborate.

- At HPC, the adult units currently have 7 psychiatrists for 110 patients i.e., 1 psychiatrist for every 15 patients. At Utica, it is approximately 1 psychiatrist for every 50 patients.
- At HPC, the Children and Youth Services' inpatient unit has 2 child psychiatrists for 16 patients i.e., 1 for every 8 patients. At Utica, there is 1 child psychiatrist for 35 patients [and he plans to retire next year].

Let me say that I have great respect for Dr Kordylewska and her very dedicated staff in Utica for the work they do against these odds. It will be crippling and unsafe to add 100 adult patients and 16 children to their workload without any increase in psychiatrists. Unfortunately, it is unlikely that any of the HPC psychiatrists will go to Utica, and one child psychiatrist has already announced that he will leave for the private sector. Utica does supplement their psychiatrists with general physicians; please note though that it requires 4 years of training to become a psychiatrist and an additional 2 years to become a child psychiatrist.

HPC attracts psychiatrists and child psychiatrists because it is in Syracuse and affiliated with a medical school i.e., staff can have faculty appointments, the medical director sits on the Department of Psychiatry Executive Committee, and there are child fellows, residents, medical students to work with. In contrast, it is very difficult to recruit to any of the peripheral State hospitals, including Utica. Specifically, both State hospitals in Utica - Mohawk Valley Psychiatric Center and Central New York Psychiatric Center - have never been fully staffed. Given the many opportunities in Syracuse still available, it is unlikely that any HPC psychiatrist will move to Utica.

We may be able to transport patients to Utica, we may be able to provide walls and a roof; but we never have, do not now, nor will we be able, to provide the same level of expertise and treatment. Based on this simple fact, I would suggest that it was a bad idea to move our patients to Utica when first suggested two years ago, it is a bad idea now, and it will remain a bad idea when it is raised again in a couple of years. In planning for the long term, if we want to provide psychiatric patients with the cheapest **housing**, then Utica or Ogdensburg would be good options [this horrific image does reverse the clock 100 years, when our patients were hidden away in

huge warehouses in far-away communities with little or no treatment]; however if we want to provide much needed **treatment**, then Syracuse is the only viable option.

Eliminating inpatient beds at HPC will also spill over and negatively impact all psychiatric services in Syracuse. For adults, there are 110 beds at HPC plus 24 at UH plus 30 at St. Joseph's and 25 at Community General for a total of 189 beds. It would be devastating to eliminate 110 – about 60% of the beds - which accounted for 225 admissions last year. Not all of these patients could be sent to Utica. Therefore there would be longer stays on all our units, units that already run pretty full now would always be full, acutely ill patients would be remain in ERs for lack of a place to admit them, and ERs would need to close more often to all patients, which is already a major problem in our community. The other concern is that there will be more of our patients diverted to jails or out on to the streets.

For children, the already severe shortage will worsen. HPC has 16 beds and Four Winds has 40, for a total of 56. These are always full. Eliminating 16 beds will leave children in ill-equipped ERs for long periods of time waiting for a bed; Upstate, with the only dedicated pediatric ER, is likely to be especially hard hit and will have to close to all patients more often.

The loss of Hutchings would clearly hurt our patients and our community. I want to take a moment to comment on what HPC has meant to this community. Building it downtown in garden-style units signaled one of psychiatry's first attempts at the "welcoming home" of our patients and their respectful, yet active, treatment aimed at reintegrating them into our community. For years it has provided excellent care; more recently it has been inexplicably chronically under-supported, with predictable results. Today, compared to the other psychiatric units in Syracuse, HPC has the most difficult physical layout, the worst nursing staffing ratio, and the most ill patients. For instance, they will accept patients that other units cannot handle. We send them our most needy patients, then expect miracles and are perpetually disappointed and critical. I would suggest that we commend the HPC staff for doing an impossible job very well and work to level the playing field so that they can continue to provide the best care for our desperately ill patients.

Besides providing excellent care, Hutchings is also a primary affiliate of the SUNY Department of Psychiatry for its educational programs. Our general psychiatry residents, child psychiatry fellows and medical students receive invaluable training at HPC. Less well known is the fact that it is the site for very important research that is competitively funded by the National Institutes of Health and the State to the tune of hundreds of thousands of dollars each year.

To summarize, hospitalizing our patients in Utica on a routine basis without the provision of adequate treatment is unacceptable...Rather than merely reject the Governors plan, I would like to see the community work with the State to design better services for these severely ill patients. I suggest that we:

1. Design and present a plan to enable a significant number of these patients to transition into the community.
2. Implement state-of-the art, community-based treatment for these patients. For instance, better outpatient treatments focused on family psycho-education, Assertive Community Treatment teams and enriched housing (all of which are inadequately represented in Syracuse). This will reduce the need for intermediate beds.

3. Close beds/units at HPC only after, not before, patients successfully transition into the community.

4. Maintain a small number of intermediate beds that must continue to be funded by the State. Unfortunately, despite our best clinical efforts, there will be a need for such a safety net.

Studies indicate that if we follow these steps sequentially and successfully, we will provide improved treatment and more functional lives for our patients, be better able to maintain them in the community, markedly decrease the need for State hospital beds, and thereby save the State some money.

While not directly connected to HPC, the Department of Psychiatry at Upstate is keenly invested in the well-being of all the psychiatric patients in our community. Recently, to address an acute shortage of child psychiatrists in Syracuse, we have been proactive and effective in resurrecting both a division of child psychiatry and a child psychiatry residency. We currently partner in efforts to improve emergency services for both children and adults. With the State and the County, we are working to improve psychiatry services in our jail and prisons. Joint recruitment with Hutchings has added expertise in research and clinical areas. The Department of Psychiatry at Upstate is very concerned about the predictable harm that the closure of Hutchings will knowingly perpetrate on the most seriously ill patients in our community and we remain fully committed to joining any community effort at providing the best care to our patients.

Thank you.



## **Reflections on the Community Mental Health System 1967-2003**

### **By John McCrea, February 2003**

From shortly before the Civil War until the second part of the 20<sup>th</sup> century, New York citizens with a "mental illness" or "mental retardation" label were housed in state institutions, most of which were located in rural areas. Their basic daily living needs were met in large congregate dining halls, bleak day rooms, and ward-like sleeping quarters. Anything approaching privacy was unknown to them. Their need to contribute to the lives of others was curtailed not so much by their "mental limitations" but by the lack of opportunities provided them in these institutions. Near the end of the era of the big state institution some fortunate few were allowed to help state employees with their duties in return for cigarettes. Psychiatric treatment was, for the most part, custodial in nature.

At the start of the second half of the 20<sup>th</sup> century, newly discovered psychotropic drugs enabled doctors to improve the behavior of their patients to the extent that they could function without being overwhelmed by the more debilitating consequences of their psychiatric condition. However, these medications all too often produced side effects that made it difficult, if not impossible, for them to function in the community without significant help. But, since it would be less expensive to have these patients live outside the institutions, the state began discharging them from psychiatric centers in great numbers with little or no preparation for community life. In most cases, they went from a very large institutional setting to a merely "large" institutional setting such as an adult home, boarding home or an older hotel that would admit them in order to stay in business. Some few had access to generic vocational services that were never meant to serve their special needs. Psychiatric treatment, usually limited to medication, was not consistently provided to most of those who left the institutions.

The public outcry over the horrible living conditions of persons with developmental disabilities at the state developmental center on Staten Island, called Willowbrook, led Governor Hugh Carey in 1975 to sign the historic "Willowbrook Consent Decree." By that act, Carey committed the state to the closure of that facility, and by extension, others like it. More importantly, he committed the state to a community-based system for all of its institutionalized citizens. Adequate community services must provide:

1. Housing and the concomitant daily living skills needed to live independently in the community.
2. Vocational training.
3. Adequate clinical psychiatric services

What has happened to the mental health system in New York State and Onondaga County since May 1975? More importantly, what must be done to achieve the full promise of the Willowbrook Consent Decree?

#### **A. Critical State Milestones**

1. In 1977 the state legislature enacted Chapter 978, creating the Office of Mental Health (OMH) and the Office of Mental Retardation and Developmental Disabilities (OMRDD) within the existing State Department of Mental Hygiene. This meant that each office would have its own commissioner and its own funding base. OMRDD, in large measure because of a strong, family-based constituency, outstanding internal

leadership, and a very favorable government, has evolved into what is arguably the best large, community-based service system in the world.

2. On June 15, 1978, OMH got off to a good start with the "Morgado Memorandum," in which Robert J. Morgado, secretary to Gov. Carey, formally stated that Carey was determined to implement a balanced service system for both the mentally ill and the mentally retarded populations. This system would maximize both public and non-public resources. At that time, the practice, and as far as most could see, the promise for the future was to provide these community-based services using local not-for-profit agencies – agencies that would presumably have the trust and confidence of the local community. No state jobs would be lost in the transition. State workers from state institutions would be retrained for community service and would work alongside workers from the voluntary sector. State workers would retain all their benefits. Voluntary workers might not enjoy the same benefits as state workers, but salaries for both groups would be moderately comparable.

3. To achieve the goal of a balanced service system for persons with a psychiatric label, Carey appointed Dr. James Prevost, the director of Hutchings Psychiatric Center, as the first OMH commissioner. Hutchings was, at the time, arguably the most advanced stage community mental health operation in the world. Due in great part to his positive experience in Onondaga County, Prevost, during his tenure as state commissioner, was a strong advocate for a balanced service system. For Prevost, the balanced service system was based on the principle of recipient choice. It sought to integrate clinical treatment, rehabilitation services, and residential programs into a unified whole. There were then (as there are today) many powerful individuals at OMH who wanted OMH to concentrate exclusively on clinical services and stay out of the "housing and vocation business." The irony is that up to that time, all the state really provided for persons with a psychiatric label was housing, albeit institutional in nature. "Clinical services" consisted mostly of medications to control patients, not to help them recover.

4. In 1983, Acting Mental Health Commissioner William Morris, working with the Association of Community Living, improved the existing certified community residence program by virtually doubling the resources the state would make available for each individual participant in that program. This was called the "New Residential Model," and it enabled OMH, for the next several years, to provide residential services that were comparable to the residential services OMRDD was providing to its consumers.

In addition, in the 1980s, the OMH sponsored a number of experimental vocational and socialization programs specifically designed to meet the needs of persons in recovery. Until the end of the decade, the state Division of the Budget worked cooperatively with private providers to enable them to pay adequate wages. Commissioner Richard Surles embraced a policy that emphasized full inclusion of recipients of services. Families of persons with psychiatric issues became better organized at the national, state, and local levels.

5. During the last decade of the 20<sup>th</sup> century, the state did all in its power to acquire federal Medicaid dollars for community services. OMRDD was very successful, not only in acquiring large amounts of Medicaid dollars, but doing so in such a way that a cost of living adjustment for community workers was built in. OMH did acquire Medicaid dollars as well. But it acquired relatively smaller amounts. COLAs for OMH-sponsored community services were usually not built in. OMRDD moved forward with a very aggressive policy of closing its institutions, coupled with a reasonably well-financed system of community-based services. OMH floundered. There was little

agreement among mental health policymakers, families, and recipients about how to continue to develop the system. While the population of state psychiatric centers was reduced from a high of over 93,000 people in the 1960s to about 5,000 individuals by the close of the century, few institutions were closed. Government began to rely on a policy of developing a cadre of case managers, whose job it was to enable recipients of service to negotiate a community-based mental health system that quite simply did not exist. Generally, families favored some kind of involuntary outpatient treatment; but most recipients were opposed, arguing that not only did involuntary outpatient treatment jeopardize their basic human rights, but it was also almost certain to be ineffective. Mental health advocates continued unsuccessfully to lobby government to force insurance companies to provide mental health coverage to the same extent that they provide health coverage.

6. OMH continues its efforts to define a role for itself at the start of the 21<sup>st</sup> century. The state legislature has now required OMH to develop a form of involuntary outpatient treatment throughout the state. This program is called "Assisted Outpatient Treatment." New York remains at the top of the list of states in per capita spending for mental health, but finds itself near the bottom of that list when it comes to spending for community-based mental health services. OMH has not provided its constituents with anything close to a positive vision for the improvement of its services. In 2002, The New York Times brought to the public's attention the many clusters of persons eligible for OMH services living in extremely poor conditions in New York City adult homes as well as in nursing homes in other states. On the other hand, with Gov. Pataki's leadership, OMRDD is now operating under the policy of "New York Cares," which guarantees all needed services for all eligible OMRDD consumers.

#### Critical County Milestones

1. In 1974, then-County Executive John Mulroy wrote "I think it is incumbent upon all of us to try to educate the public and private sector as to the needs of the people who are attempting to make the change from an institutional environment back to their respective communities." Mulroy received the full support of Nicholas Pirro, who was then the chair of the county legislature's health committee. This was a full four years before Governor Carey's "Morgado Memorandum."

2. Margo Northrup chaired a study of the local mental health system during the 1970s. One of the study's recommendations was that a comprehensive planning process was needed to respond to the state policy of deinstitutionalization. Commissioner Dr. Donald Boudreau assigned Michael Kipp to work with recipients of service, parents, and providers to develop this planning process. A number of "Planning Cluster" were formed to provide a forum for community mental health planning dialogue and offer advice to the county commissioner of health. One of the first things done was to get local providers to agree to a community residence site selection process to keep the number of persons served in each site to a minimum and to make certain that no one neighborhood would become saturated with these residences. This planning cluster process is still operating and has received an award for excellence from the National Association of Counties. Michael Kipp went on to head the state planning process for OMH. It would take the state 10 years to inaugurate its own major study of the mental health system (Governor's 1984 Select Commission on the Future of the State-Local Mental Health System) ... to pass a law (Padavan Law) whose objective was to prevent neighborhood community residence saturation. ... and to mandate a local planning/advisory process. Consideration was given to having the clusters sponsor regular forums to enable the public to

participate in the process. It was determined that the "Mental Health Roundtable," which was sponsored by University College and modeled after the Thursday Morning Roundtable, was meeting this goal.

3. In the 1980s, as a result of a new state policy, acute inpatient services provided by Hutchings Psychiatric Center, were moved to the general hospitals. Hutchings would convert to a facility providing care for people needing longer inpatient stays. Following this, a Comprehensive Psychiatric Emergency Program (CPEP) was developed at St. Joseph's Hospital in order to centralize these emergency services. In addition, the state Mental Health Commission, Richard Surles, mandated that state psychiatric centers (including Hutchings) could no longer serve people with an organic brain syndrome because this was not a mental illness. This meant, for example, that many families of persons with such conditions as Alzheimer's disease would now have to seek help from a standard hospital emergency room at one of the general hospitals. Under the leadership of County Mental Health Commissioner David Brownell, Onondaga County continued to maintain a system of services that was second to none in the state. Due in large measure to the advocacy of PROMISE (the local family-based advocacy network), and the support of Senator Tarky Lombardi, Provisions, an innovative vocational program specifically designed to meet the needs of persons being served by the mental health system, opened in Armory Square.

4. The 1980s were characterized by a determined effort by the state not only to maximize federal Medicaid dollars but to move the entire mental health system into some form of managed care to keep expenses to a minimum. Onondaga County geared up for this change, but a wholesale conversion to managed care never materialized. The wage disparity between state workers and workers employed by the not-for-profit workers increased to a point where individual not-for-profit workers were receiving 50 percent of the wages being awarded to their state counterparts. The state, however, continued to require the same degree of regulatory accountability for both sectors. Perhaps the most hopeful aspect of the 1990s was the fact that OMH continued to emphasize the need for recipient-based programs. Unique Perspectives (a program in which recipients of mental health services provide support to each other and help one another negotiate the system) came about as a result.

5. The 21<sup>st</sup> century has already seen a controversial state plan to close Hutchings, the need to convert CPEP from a one-hospital to a three-hospital program, and the continued erosion of the financial base required to provide adequate community-based services.

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### Suggested resources

President's New Freedom Commission on Mental Health, Final report, "Achieving the Promise: Transforming Mental Health Care in America." Fall 2003

Progress Report on New York State's Public Mental Health System. NYS Office of Mental Health, 2001.

Interim report, President's New Commission on Mental Health, October 29, 2002.

"Mental Health: A Report of the Surgeon General," 1999,  
[www.surgeongeneral.gov/library/mentalhealth/home.html](http://www.surgeongeneral.gov/library/mentalhealth/home.html)

"Cruellest Choice Faces Parents of Mentally Ill," *New York Times*, February 16, 2003

"Losing Joshua," Jennifer Gonnerman, *The Village Voice*, October 29, 2003.

"Parents forced to give up mentally ill children to foster homes," Shaila K. Dewan, *New York Times*, Feb. 23, 2003.

"Don't shed tears – pass parity for mental health insurance," Alfred Fusco, op-ed, *The Post-Standard*, May 28, 2003.

"What Do Consumers Say They Want and Need During a Psychiatric Emergency?" *Journal of Psychiatric Practice*, January 2003

"Mental Health Parity," *Contemporary Rehab* Volume 59, No. 2. April 2003. p. 11-.

"Making the Business Case for Improving Mental Health Care: How to Maximize Corporate Resources," National Health Care Purchasing Institute, September 2002.

"The Unfinished Promise of Willowbrook: Twenty-five Years of Unnecessary Despair for New Yorkers Living with Mental Illness," MHA in New York State, Inc., October 18, 2002.

"For the Clergy, Flock's Troubles Become their Own," Elizabeth Bernstein and Peter Landers, *The Wall Street Journal*, July 31, 2003.

"Mental Health Trends," *Workplace Visions*, No. 2-2003.

Testimony of Joseph A. Glazer, president/CEO Mental Health Association in New York State, Inc., to the New York State Assembly Committee on Mental Health, Retardation and Developmental Disabilities, March 20, 2003.

"Mental Health Court discussed," Jim O'Hara, *The Post-Standard*, December 8, 2003.

"Police play vital role in broken system; Nation's mental health system is in crisis, but how can it be fixed?" Heather Frye, *Lewiston Morning Tribune*, Oct. 12, 2003.

"Mental Health: Pay Now – or Later," *BusinessWeek Online*, May 24, 2003.

"A model for mental health programming in schools and communities," Nasts, B.K., *School Psychology Review*, 27, 165-174. 1999.

NAMI website: [www.nami.org](http://www.nami.org) (includes comparison of state mental illness parity laws.)

[www.KeepHutchingsOpen.com](http://www.KeepHutchingsOpen.com)