

8. “It ain’t over ‘til it’s over!”

Yogi Berra was right — never assume the legislative session is over until the session ends.

9. Follow through with accolades.

Thank legislators who supported you. Run newsletter articles. Ask grassroots to make final thank you contacts. Give awards and run an article in legislators’ local newspapers.

10. Whether you “won” this year or not – keep on keeping on.

Next session is uncertain until it is over, so get ready. Keep educating, talking and pressing for the right treatment at the right time that enables recovered lives. Develop more grassroots contacts (use I Vote I Count Campaign name and data collection work all year every year at every event). Start a testimony/story bank on successes with appropriate medication – possibly stories proving the opposite.

Conclusion - Tips On What To Beware

This time around we should not focus on likeness to all other biological disorders, but the uniqueness of the only organ affected by medications which controls choice, behaviors, and all the human qualities essential for compliance and recovery. Prior authorization may inconvenience persons with serious illnesses, but for people with brain disorders, treatment delayed is treatment denied and ER costs, crisis care costs, inpatient care costs and corrections costs far outweigh the cost of appropriate medication.

Be sure to mention that our people are doing their part to save dollars in every other medication they may need, and often that is an extensive list. But NOT on their mental health medications, delays and restrictions cost lives as well as greater budget deficits.

Don’t let the access be limited to only the very few, based on newer, more rigidly defined state SPMI definitions. Statistics show harm to self, particularly suicide, is predominately MI/depression driven and the populations most at risk for suicide currently are not necessarily SPMI, for example. To truly “do no harm,” all mental illness merits proactive treatment – not public apologies after a tragic event.

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The Nation’s Voice on Mental Illness

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A Political Primer on Assuring Access to Appropriate Medications

Perfect Storm Conditions are Upon the States

There has been a dramatic deterioration in state fiscal conditions over the last year. Rapidly declining tax revenues have led state policymakers to implement significant reductions in public services.

The short-term outlook for state fiscal conditions is bleak, as a number of states have recently increased their estimates of budget deficits in 2003, and some states have begun to forecast significant shortfalls in 2004.

States managed to maintain a small amount of spending growth in 2002 by relying heavily on one-time budget balancing measures such as spending down "rainy day" funds and using tobacco settlement funds. But those funds are now depleted.

Feeding the Storm – Rising Prescription Drug Costs

As governors and state legislatures struggle to balance their budgets for 2003, many are turning to reducing projected spending for their Medicaid programs. Medicaid represents one of the largest cost centers for states – and the fastest growing item within state budgets. Specifically, states are reporting that uncontrolled growth in Medicaid prescription drug costs could threaten efforts to balance their budgets and other social priorities.

Most states have implemented several programs to limit their spending on prescription drugs. But with more budget bad news developing each day in which states did not anticipate, policymakers are considering arbitrary ways to control their Medicaid prescription drug spending.

These strategies include:

- Using preferred drug lists
- Requiring supplemental rebates from drug companies
- Placing certain drugs on a list requiring prior authorization before dispensing
- Limiting the number of prescriptions per month a patient can fill without prior authorization
- Requiring mandatory substitution of generic drugs

What is at Risk for Mental Illness Treatments?

These strategies pose significant health threats for Medicaid recipients with mental illnesses trying to access medications prescribed by their treating physicians. Access to quality care and recovery is at risk when battles over cost containment and medication pricing occur.

We have made significant progress in discovering effective treatments for mental illnesses, and we have made progress in developing services that help people with mental illnesses to achieve recovery, independence, and dignity in their lives. We cannot go backwards due to economic and budget considerations.

The indirect economic costs and social and medical consequences that come from inadequate and denied treatments for people with serious mental illness are staggering:

- Over \$100 billion in lost productivity (e.g., absenteeism from work and school and disability), including \$11 billion in Social Security Disability Insurance benefits to 1.3 million persons and \$11 billion in Supplemental Security Income benefits to 2.0 million persons.
- Mental illness ranks first in terms of causing disability in the United States, Canada and Western Europe. Mental illness accounts for 25% of all disability across all industrialized countries. Heart disease and cancer account for 5% and 3% respectively.
- \$12 billion in lost productivity due to premature death, including suicide. Up to 90 percent of all persons who commit suicide suffer from a treatable severe mental illness.
- \$6 billion to incarcerate more than 283,000 persons with mental illnesses in jails and prisons. This is four times the number of people with these illnesses being cared for in hospitals.
- 50-75% of youth in juvenile justice facilities have a diagnosable and most often untreated mental illness.
- Suicide is the third leading cause of youth in the 15 to 24 year-old age group, preceded only by homicide and accidents, and as many as 90% of children and adolescents who commit suicide have a mental disorder.
- Approximately one-third of the nation's 600,000 homeless persons suffer from severe mental illnesses.
- Many people with severe mental illness die prematurely or experience disproportionately high rates of medical illnesses because of neglect or disregard by health care systems of their medical symptoms.

The indirect costs and consequences of not supporting mental illness recovery are clear and must be considered even in times of state fiscal pressures. The costs of not treating consumers with serious mental illnesses will make it even more difficult for states to control costs due to increased hospitalizations and more ER and physician visits.

Strategic Steps for Advocates

Proposals to control pharmaceutical utilization will appear in legislation, appropriations bills or regulations developed by Medicaid programs. Advocates must be mobilized politically to fight proposed limits to access of prescription drugs.

1. Get ALL the information.

Who is sponsoring the bill? What exactly is being proposed in your state? Preferred formulary lists?

Prior authorization (which may have fail-first language such as patient must “demonstrate” need for a medication other than restrictive “preferred” drug)? or co-pays? The basic Ws – who, what, when, where and how.

2. Develop a coalition.

Hopefully a broad stakeholder-based coalition for mental health already exists in your state. If not, call a meeting! Community MH providers, advocacy groups, community and state hospital personnel/administration, associations (with lobbyists) like psychiatrists, psychologists, nurses, social workers, medical society, MH & Aging groups and others. Don’t go in alone if you can go in greater numbers! You may carry the message, but decision-makers will understand you represent the many – not the few.

3. Do the statistical and philosophical homework.

Prepare valid materials to show that access to medications is crucial for people w/ MI and denial is financially catastrophic compared to the cost of appropriate treatment.

4. Be real people. Legislators are.

Find the driving forces; the author of the bill, leaders in state budget work. Ask them their thinking and listen. Be sure and listen well.

5. Then talk, from the heart and mind.

Prove the argument from your homework. If no compromise comes quickly, do not fear – you have more options!

6. Initiate grassroots contacts.

Voters from each legislator’s district calling at home. E-mails to ALL committee members when decisions are being considered. You have to get the contact info on lawmakers and educational bulleted points made quick and simple. You are responsible for empowering the grassroots and uniting their efforts. Don’t over tax them. We carry enough daily stresses and strain. Alert them at strategic times with specific direction on successful advocacy work. They are the power.

7. Be ever present.

Be sure you show up every time the bill or provision is discussed publicly. Give formal testimony. When the opportunity opens up to work that understanding of a compromise, or help a committee in deliberation understand about brain disorders, medications and research data, they should know you are there to help with expertise and compassion. Those moments in hallways may turn into decisions for good.