

NAMI

Where Did It Come From?
Where Is It Now?
Where Is It Going?



E. Fuller Torrey, M.D.
June 30, 2006

Talk can be downloaded
at www.psychlaws.org

I. Where Did NAMI Come From?

- 1976—San Mateo Co. families organized with the help of Dr. Richard Lamb
- 1979—1st NAMI national meeting in Madison, WI
- Focus on severe mental illness
 - schizophrenia
 - schizoaffective disorder
 - bipolar disorder
 - major depression, esp with psychotic features

I. Where Did NAMI Come From?, cont'd

- Major issues
 - **Causes:**
families being blamed
 - **Treatment:**
grossly inadequate
 - **Services:**
discharged from hospital without follow-up care

II. Where Is NAMI Now?

1. Support groups for families and consumers
2. Educating families and consumers
3. Educating the public
4. Improving insurance coverage
5. Decreasing stigma
6. Research issues
7. Improving services for individuals with SMI who are aware of their illness
8. Improving services for individuals with SMI who are not aware of their illness

II. Where Is NAMI Now?

1. Support groups for families and consumers



- This is the historical core
- Support, advice, support, education, support
- The local group leaders and organizers are the heart of NAMI

II. Where Is NAMI Now?

1. Support groups for families and consumers **A+**
2. Educating families and consumers
3. Educating the public
4. Improving insurance coverage
5. Decreasing stigma
6. Research issues
7. Improving services for individuals with SMI who are aware of their illness
8. Improving services for individuals with SMI who are not aware of their illness

II. Where Is NAMI Now?

2. Educating families and consumers



- Family-to-Family and Peer-to-Peer
- Helpline
- National Provider Education Program
- NAMI Advocate
- State NAMI meetings
- National NAMI convention

II. Where Is NAMI Now?

1. Support groups for families and consumers **A+**
2. Educating families and consumers **A**
3. Educating the public
4. Improving insurance coverage
5. Decreasing stigma
6. Research issues
7. Improving services for individuals with SMI who are aware of their illness
8. Improving services for individuals with SMI who are not aware of their illness

II. Where Is NAMI Now?

3. Educating the public



- Teaching in schools and colleges
- Educating police, jail officials, shelter operators, judges, etc.



II. Where Is NAMI Now?

3. Educating the public, cont'd

Problem:

Educating the public about what?

- “severe mental illnesses”: schizophrenia, schizoaffective disorder, bipolar disorder, severe depression with psychosis
- “severe mental disorders” (1993 NIMH Advisory Council): the above, plus autism and severe forms of panic disorder and OCD

II. Where Is NAMI Now?

3. Educating the public, cont'd

Problem:

Educating the public about what?

- “mental illnesses”
 - borderline personality disorder
 - anorexia and bulimia
 - PTSD
 - ADHD
- “mental disorders”
 - adjustment disorder
 - mathematics disorder

II. Where Is NAMI Now?

3. Educating the public, cont'd

Problem:

Educating the public about what?

- “mental health problems”
 - adolescent adjustment
- promotion of “mental health”:

“Have you hugged your child today?”

II. Where Is NAMI Now?

1. Support groups for families and consumers **A+**
2. Educating families and consumers **A**
3. Educating the public **C**
4. Improving insurance coverage
5. Decreasing stigma
6. Research issues
7. Improving services for individuals with SMI who are aware of their illness
8. Improving services for individuals with SMI who are not aware of their illness

II. Where Is NAMI Now?

4. Improving insurance coverage **B-**
 - Parity: All mental illnesses except drug and alcohol abuse should be covered, just as all physical illnesses are covered
 - DSM-IV:
 - disorder of written expression
 - hypoactive sexual desire
 - dependent personality disorder
 - narcissistic personality disorder

II. Where Is NAMI Now?

4. Improving insurance coverage, cont'd

- "... a name and number for every untoward feeling or behavior" (Paul Chodoff, M.D.)
- DSM-V: new diagnosis of "the human condition"

II. Where Is NAMI Now?

1. Support groups for families and consumers **A+**
2. Educating families and consumers **A**
3. Educating the public **C**
4. Improving insurance coverage **B-**
5. Decreasing stigma
6. Research issues
7. Improving services for individuals with SMI who are aware of their illness
8. Improving services for individuals with SMI who are not aware of their illness

II. Where Is NAMI Now?

5. Decreasing stigma **C**

- NAMI Walks
- "Nothing to Hide: Mental Illness in the Family" book and exhibit
- 1999 Surgeon General's Report on Mental Health: Stigma against mentally ill persons compared in the 1950s and 1990s

II. Where Is NAMI Now?

5. Decreasing stigma, cont'd

- 1950s: 13% said that mentally ill persons are likely to be violent
- 1990s: 31% said that mentally ill persons are likely to be violent
- "The perception of people with psychosis as being dangerous is stronger today than in the past." (Surgeon General's Report, p. 7)

II. Where Is NAMI Now?

5. Decreasing stigma, cont'd

- What was different in the 1990s compared to the 1950s?

Deinstitutionalization

- Most people with severe psychiatric disorders are not violent. A small number, who are not being treated, do become violent.

II. Where Is NAMI Now?

1. Support groups for families and consumers A+
2. Educating families and consumers A
3. Educating the public C
4. Improving insurance coverage B-
5. Decreasing stigma C
6. Research issues
7. Improving services for individuals with SMI who are aware of their illness
8. Improving services for individuals with SMI who are not aware of their illness

II. Where Is NAMI Now?

6. Research issues C

- Earlier years: B
NARSAD
NAMI Research Institute
Annual review of NIMH grant portfolio
Dr. Brownstein's removal at NIMH
- Last 10 years: D
1999, *A Mission Forgotten* (NAMI and Stanley Research Programs)
2000, *Mission Impossible* (TAC)
2003, *A Federal Failure in Psychiatric Research* (TAC and Public Citizen, available at www.psychlaws.org)

II. Where Is NAMI Now?

6. Research issues, cont'd

- Only 29% of NIMH grants have any relationship to severe mental illnesses
- Only 6% are clinically relevant, meaning "reasonably likely to improve the treatment and quality of life for individuals presently affected"

II. Where Is NAMI Now?

1. Support groups for families and consumers A+
2. Educating families and consumers A
3. Educating the public C
4. Improving insurance coverage B-
5. Decreasing stigma C
6. Research issues C
7. Improving services for individuals with SMI who are aware of their illness
8. Improving services for individuals with SMI who are not aware of their illness

II. Where Is NAMI Now?

7. Improving services for individuals with SMI who are aware of their illness B

- Emphasis on PACT teams (1998, the PACT model)
- State rating of services
1988, *Care of the Seriously Mentally Ill*
1990, *Care of the Seriously Mentally Ill*
2006, *Grading the States*

II. Where Is NAMI Now?

7. Improving services for individuals with SMI who are aware of their illness, cont'd

- Emphasis on services to restore all affected individuals to their best possible level of function ("the recovery model")

II. Where Is NAMI Now?

7. Improving services for individuals with SMI who are aware of their illness, cont'd

- **Marks off:** Promotion of "recovery model" as indicating full recovery. Full recovery from schizophrenia at the end of 3 years is 12%, based on 210 studies (Miettunen et al., Recovery from schizophrenia, *Schizophr Res* 2006;81:183)
- **Marks off:** Failure to aggressively focus on the Institutions for Mental Disease (IMD) exclusion

II. Where Is NAMI Now?

- | | |
|--|----|
| 1. Support groups for families and consumers | A+ |
| 2. Educating families and consumers | A |
| 3. Educating the public | C |
| 4. Improving insurance coverage | B- |
| 5. Decreasing stigma | C |
| 6. Research issues | C |
| 7. Improving services for individuals with SMI who are aware of their illness | B |
| 8. Improving services for individuals with SMI who are <u>not</u> aware of their illness | |

II. Where Is NAMI Now?

8. Improving services for individuals with SMI who are not aware of their illness

F

- Anosognosia (lack of awareness of illness) as a fact of life (www.psychlaws.org)
- One-third of the homeless are SMI and untreated
- 10-15% of those in jails and prisons are SMI and untreated

II. Where Is NAMI Now?

8. Improving services for individuals with SMI who are not aware of their illness, cont'd

- NAMI surveys: 1991: 40%
2003: 44%
- 5-10% of all homicides in the U.S. are committed by SMI who are untreated

II. Where Is NAMI Now?

8. Improving services for individuals with SMI who are not aware of their illness, cont'd

- NAMI survey, 1991: 11% had harmed another person in the past year
- California:
 - 75,000 SMI homeless
 - 9,000 SMI in county jails
 - 32,000 SMI in state prisons
 - 120-240 homicides/yr committed by SMI not being treated

II. Where Is NAMI Now?

8. Improving services for individuals with SMI who are not aware of their illness, cont'd

- Victimization of untreated SMI
 - robbed
 - raped
 - killed by law enforcement
 - unnecessary surgery
- Housed in human warehouses
- NAMI's abolition of its Networks
 - Forensic
 - Homeless and Missing Mentally III

II. What Is NAMI's Overall Grade?

1. Support groups for families and consumers A+
2. Educating families and consumers A
3. Educating the public C
4. Improving insurance coverage B-
5. Decreasing stigma C
6. Research issues C
7. Improving services for individuals with SMI who are aware of their illness B
8. Improving services for individuals with SMI who are not aware of their illness F

II. What Is NAMI's Overall Grade?

1. Support groups for families and consumers A+
2. Educating families and consumers A
3. Educating the public C
4. Improving insurance coverage B-
5. Decreasing stigma C
6. Research issues C
7. Improving services for individuals with SMI who are aware of their illness B
8. Improving services for individuals with SMI who are not aware of their illness F

II. What Is NAMI's Overall Grade?

1. Support groups for families and consumers A+
2. Educating families and consumers A
3. Educating the public C
4. Improving insurance coverage B-
5. Decreasing stigma C
6. Research issues C
7. Improving services for individuals with SMI who are aware of their illness B
8. Improving services for individuals with SMI who are not aware of their illness F

Where Is NAMI Going?

III. Where Is NAMI Going?

1. It must define its mission
"severe mental disorders," as defined by NIMH in 1993 special report to Congress
 - schizophrenia
 - schizoaffective disorder
 - bipolar disorder
 - severe forms of depression
 - severe forms of panic disorder
 - severe forms of obsessive-compulsive disorder
 - autism

III. Where Is NAMI Going?

2. It must define the responsibilities for local, state, and national levels

- **Local**—support groups and education
- **State**—improvement of mental health services (problem: co-opted by state)
- **National**—pressure on federal programs
 - NIMH
 - CMHS
 - Protection and Advocacy
 - Medicaid: IMD exclusion

III. Where Is NAMI Going?

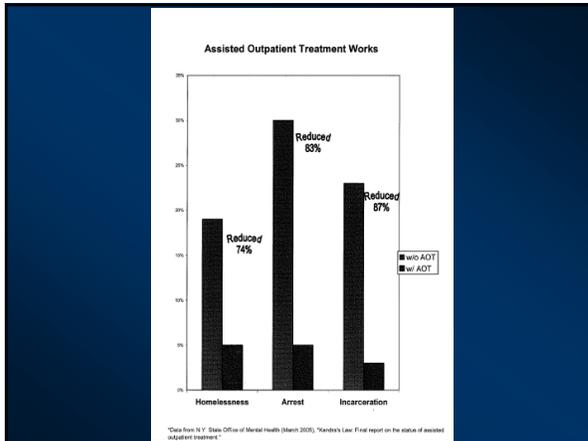
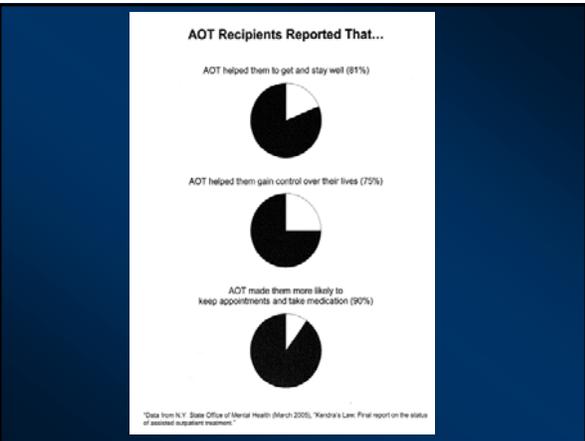
3. It must use the strengths and passion of its members with special interests

- Families of children with severe mental disorders
- Veterans
- Missing persons and homeless network
- Forensic network: jails and prisons

III. Where Is NAMI Going?

4. It must advocate for those who are sickest and those who cannot advocate for themselves

- For example, NYS adult homes: 12,000 individuals
- 500+ SMI NYS residents illegally placed in nursing homes in NJ
- Assisted outpatient treatment



Misunderstanding Civil Liberties

Uninformed calls to protect civil liberties betray a profound misunderstanding of that term. There is nothing "civil" about leaving people lost to disease to live homeless on the streets, suffering rape and victimization. There is nothing "right" about leaving someone untreated and psychotic, rendering them incapable of discerning whether they are attacking a CIA operative or their own mother.

Mary Zdanowicz
Executive Director,
Treatment Advocacy Center

III. Where Is NAMI Going?

5. It must become fiscally responsible

- Fundraising for what?
- Reduce rent
- Reduce staff
- Reduce dependence on pharmaceutical company money

The Future of NAMI: What Face Will It Wear?

"The nation's largest grassroots mental health organization"
or...
"The nation's meanest and most effective grassroots mental health organization"

A follower
Very concerned about political correctness
Says: "ba-a-a"



A leader
Not concerned about political correctness

Says: "They say, 'nothing can be done here.' I reply, 'I know no such word in the vocabulary I adopt.'"

Dorothea Dix



**The choice
is up
to each
of you.**

**The slides for this talk
are available on the
website of the
Treatment Advocacy
Center (TAC) at
*www.psychlaws.org***