The Debacle of Deinstitutionalization:
History and Politics of Community Mental Health Centers

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Disclosures

- Grant from Magellan to study outcomes of Iowa’s ACT teams

“Whose idea was it that we give our investors full disclosure?”
Overview

- History of CMHCs
- CMHCs in Iowa
- CMHC for Mid-Eastern Iowa
- Role of Psychiatrists
Suffered a debilitating breakdown in her mid-thirties. In hopes of a cure, in 1836 she traveled to England, where she met men and women who believed that government should play a direct, active role in social welfare.
The Indigent Insane Bill

- Promoted a grant of land for the relief and support of indigent, curable and incurable insane

- Provide asylums that would emphasize “moral treatment”
  - Emphasized humane treatment based on compassion and care rather than assigning mentally ill people to jails, poorhouses, or life on the streets
  - Orderly routine with social contact, exercise and work rather than efforts to rid the body of demonic possession and corporal punishment
"If Congress has the power to make provisions for the indigent insane, the whole field of public beneficence is thrown open to the care and culture of the federal government. I readily acknowledge the duty incumbent on us all to provide for those who, in the mysterious order of providence, are subject to want and to disease of body or mind, but I cannot find any authority in the Constitution that makes the federal government the great almoner of public charity throughout the United States."
Asylums Supported by States

- Dix resumes her campaign, state by state, for the establishment of public asylums supported by state tax dollars
- Her advocacy led to the founding of 32 hospitals in 18 states
- Over time asylums changed from small therapeutic programs into large custodial public hospitals
- Concepts of "curability" were replaced by concepts of custody and chronicity
Era of the Asylum
1850s to 1950s

- 100 years of state based approaches
  - Long term institutional care
  - Large hospitals
  - Custody rather than treatment

- By the mid-1950s about 560,000 Americans resided in state supported institutions

- The average length of stay was measured in years
  - Many patients spent their entire lifetime in Asylums
Deinstitutionalization
Late 1950’s

- Many factors led to deinstitutionalization
  - Journalistic exposés
  - Introduction of chlorpromazine which initiated the psychopharmacologic revolution
  - President Eisenhower's major study of the care of the mentally ill population
    - Mental institutions were often viewed as inhuman “snake pits” factories for the manufacture of madness
    - Evidence of social and functional deterioration following long-term care reinforced the notion that institutions caused chronic disorder
Bedlam 1946

- *Life* magazine exposé
  - Pennsylvania's Byberry
  - Ohio's Cleveland State

"All of a sudden America sees these photos that look like concentration camp photos. You see people huddled naked along walls, strapped to benches... and it really is this descent into this shameful moment." - Robert Whitaker, author of “Mad In America”
Several new ideas emerged with military psychiatry

- **Proximity** – treatment should occur as close as possible to where symptoms were exhibited
- **Immediacy** – early identification and treatment lead to better outcomes
- **Simplicity** – the major part of intervention should consist of rest, nourishment, and social support
- **Expectancy** – return to former functioning was possible
Cocoanut Grove Fire 1942

The Boston Post

NIGHT CLUB DEATH LIST 447
BOY ADMITS STARTING FIRE

Match Used to Replace Light Bulb by Youth Under Legal Age of Employment Set Imitation Palm Ablaze—Lax Enforcing of Fire and Building Laws Blamed for Allowing Tinder Dry Decorations—Federal Agents Watch Inquest

LIST OF DEAD

Mass Burials of Victims Not Identified May Be Found Necessary

Tragic Scenes as Loved Ones Are Sought—144 Still Await Names

Photo provided by Bill Noonan  www.firenews.org
Cocoanut Grove Fire
1942

- Deadliest nightclub fire in United States history
  - Killed 492 people and injured hundreds more

- Dr. Erich Lindemann, a Boston psychiatrist, studied survivors and their relatives and published "Symptomatology and Management of Acute Grief"
  - Laid the foundation for research in this area
  - Created the first community mental health center in 1948
The First CMHCs

- The first CMHCs were principally devoted to consultation and education for community agencies.
- Offered treatment to new groups of previously untreated, acutely ill, and emotionally troubled patients.
- Few persons with severe and chronic illnesses were treated.
In 1955 Congress passed the Mental Health Study Act to study the problems of mental illness.

The final report (1961 Action for Mental Health issued by The Joint Commission on Mental Health and Illness) states:

- Immediate care be made available to mentally ill patients in community settings.
- Fully staffed, full-time mental health clinics be accessible to all people living in the US.
- Community based aftercare and rehabilitation services for mentally ill individuals be greatly expanded.
In 1961 John F Kennedy became president

- Personal family experience with mental disability

Sister Rosemary Kennedy

- At age 23 her father was told by her doctors that a cutting edge procedure would help calm her "mood swings"

We went through the top of the head, I think she was awake. She had a mild tranquilizer. I made a surgical incision in the brain through the skull. It was near the front. It was on both sides. We just made a small incision, no more than an inch." The instrument Dr. Watts used looked like a butter knife. He swung it up and down to cut brain tissue. "We put an instrument inside," he said. As Dr. Watts cut, Dr. Freeman put questions to Rosemary. For example, he asked her to recite the Lord's Prayer or sing "God Bless America" or count backwards. ... "We made an estimate on how far to cut based on how she responded." ... When she began to become incoherent, they stopped. - James W. Watts

- The lobotomy reduced her to an infantile mentality that left her incontinent and staring blankly at walls for hours and her verbal skills were reduced to unintelligible babble

- She lived out her life in a Wisconsin institution and died at the age of 86
A national mental health program to assist in the inauguration of a wholly new emphasis and approach to care for the mentally ill.

Focus on comprehensive community care.

We need a new type of health care facility; one which will return mental health care to the mainstream of American medicine, and at the same time upgrade mental health services.

I recommend, therefore, that the Congress:

- Authorize grants to the states for the construction of comprehensive community mental health centers.
- Authorize short term project grants for the initial staffing costs.
CMHC Construction Act of 1963

- The Mental Retardation Facilities and CMHC Construction Act signed on October 31, 1963
- Ended 109 years of federal noninvolvement in state services for the mentally ill
- Congress refused to authorize funds to hire staff for CMHCs
- Less than a month later President Kennedy was assassinated
CMHC Construction Act of 1963

- President Johnson signs amendments in 1965 that provide staffing grants
  - Accomplished out of sentiment for JFK
- In 1965 mental health catchment areas of 75,000 to 200,000 people all over the country began applying for federal grants
- Program based on federal seed money grants
  - Local communities applied for federal funds that declined over several years
  - Alternative funds like third-party payments were expected to replace declining federal grants
Rise of the CMHC

- Provide five essential services
  - Inpatient services
  - Outpatient services
  - Day treatment
  - Emergency services
  - Consultation and education services
- Ensure continuity of care between the services
- Be accessible to the general population
- Serve people regardless of their ability to pay
  - “…a reasonable volume of services to the indigent”
In the early 1970’s Richard Nixon tried to discontinue the program but was rebuffed by the Democratic Congress.

In 1974 Gerald Ford vetoed the extension of the Community Mental Health Act.

- Existing centers were supported by congressional continuing resolutions until a new bill could be developed.

In 1975 another extension was also vetoed by Ford on the grounds that it was too expensive but Congress overrode the veto by a wide margin.

- Congress passed amendments that added more requirements for the mental health centers but did not appropriate the funds necessary to pay for the newly required services or to cover even half of the country in the time frame initially envisioned.

- Services for children, the elderly, and chemically dependent persons as well as rehabilitation, housing, and preventive services.
Failure to Meet Goals

- After 1975 no new construction was attempted due largely to prohibitive costs
  - Actual federal dollars were reduced while inflation more than doubled the cost of construction and staffing costs
- Most CMHCs were focused on primary and secondary prevention programs
  - Crisis clinics and hot lines to prevent mental illness
  - Staff more interested in insight oriented psychotherapy than in case management and rehabilitation
- Severely mentally ill persons leaving state hospitals did not receive follow-up services necessary to live in the community
Between 1955 and 1980 the population of state mental hospitals dropped from 558,000 to 140,000. Were these people better off out of state hospitals? Funds from the states that were supposed to follow patients from the hospital into the community did not provide sheltered housing and treatment. Poverty, homelessness, and criminalization resulted.
Community Support Programs

- CSPs were the NIMH’s response to the unmet needs of the CMI
- By 1982 most of the states had received some sort of community support planning help for CMHCs
  - Case management
  - Psychosocial rehabilitation
  - Supported living
  - Supported working
  - Crisis care
- New evidence-based practices (EBP)
  - Assertive Community Treatment
Reassessment of the CMHC Program

1977 Presidential Commission on Mental Health chaired by First Lady Rosalyn Carter

- Persons with chronic mental illness who had been deinstitutionalized lacked the basic necessities of life including adequate housing, clothing, and food

- Half of the people released from large mental hospitals were being readmitted within a year of discharge
National Mental Health Systems Act of 1980

- An effort to reinvigorate the CMHC program and redirect it to those with chronic mental illness
  - Restructure federal, state, and local relationships allowing the states more control of the management and distribution of federal funds coming to local programs
  - Give priority to vulnerable groups such as the chronically mentally ill, children, adolescents, and the elderly

- Signed one month before Carter lost the election to Reagan
Withdrawal of Federal Government

“New Federalism”

- Reagan promises to reduce government waste and regulation and to return responsibility for many social programs to the states

- The Omnibus Budget Reconciliation Act of 1981
  - Repealed the Mental Health Systems Act of 1980
  - Eliminated all of the federal initiatives of the previous 18 years
  - Eliminated all of the 10 federal regional offices of NIMH
    - Lack of capacity to supervise and provide technical assistance to surviving federal CMHCs
Withdrawal of Federal Government

- OBRA 1981
  - Withdrew direct federal grant support from CMHCs and replaced it with block grants to the states
  - Returned primary authority to states to decide how and to whom mental health services should be provided
  - Ceased to make official use of the term “community mental health center” to describe a unique entity
    - Only 754 of a possible 1,500 eligible catchment areas nationwide had applied for and received funding for CMHCs
- CMHCs increased fees and reduced staffing and services
- Waiting lists developed
- Service quality decreased
Medicaid

- Created in 1965 to provide health insurance for low-income parents, children, seniors, and people with disabilities

- Supplemental Security Income established in 1972 provided welfare to those disabled due to mental illness

- By the 80's all CMHCs switched to Medicaid and away from block grant money
CMHCs of Today

- CMHCs have survived but service priorities and the locus of control have changed
- CMHCs remain the only option for mental health treatment for low income uninsured people
- CMHCs have had to use revenues from a patchwork of funders to cover the costs of caring for uninsured and underinsured
  - Paying patients
  - Federal governments
  - State governments
  - Local governments
  - Fund raising
- Availability of services have steadily decreased in the last twenty years
- Individuals often sit on waiting lists for extended periods or are turned away
CMHC programs and deinstitutionalization were implemented without evidence of effectiveness of treatments and without a social welfare system for the disabled mentally ill.

- Communities lacked availability of:
  - Supported housing
  - Community treatment approaches
  - Vocational opportunities
  - Income supports

- Many became homeless

- Many became incarcerated
CMHCs could not handle the huge numbers of patients who had been released after spending months or years in the large institutions.

“Nowhere in our society is the debacle of deinstitutionalization felt more than in our criminal justice system. America’s jails and prisons are now surrogate psychiatric hospitals for thousands of individuals with the severest brain diseases.”

Treatment Advocacy Center Briefing Paper.
Criminalization of individuals with severe psychiatric disorders. 4/2007

10-16% of US inmates have serious psychiatric illnesses like schizophrenia, bipolar disorder and disabling depression.
Hindsight

I KNEW I SHOULDN'T HAVE BROUGHT THE TERMITES
“Many of those patients who left the state hospitals never should have done so. We psychiatrists saw too much of the old snake pit, saw too many people who shouldn't have been there and we overreacted. The result is not what we intended, and perhaps we didn't ask the questions that should have been asked when developing a new concept, but psychiatrists are human, too, and we tried our damnedest.”

Dr. Robert H. Felix, past director of the NIMH and a major figure in the shift to CMHCs
"The psychiatrists involved in the policy making at that time certainly oversold community treatment... the policies were based partly on wishful thinking, partly on the enormousness of the problem and the lack of a silver bullet to resolve it, then as now."

Dr. John A. Talbott, past president of the American Psychiatric Association
Hindsight

“The result was like proposing a plan to build a new airplane and ending up only with a wing and a tail... Congress and the state governments didn't buy the whole program of centers, plus adequate staffing, plus long-term financial supports.”

Dr. Jack R. Ewalt, directed the staff of the Joint Commission when it was founded in 1955
CMHCs in Iowa
Iowa is a prime example of what President Bush's New Freedom Commission on Mental Health meant when it reported that the nation's mental healthcare system is "fragmented and in disarray." It must be among the most convoluted mental health systems in the country.
For individuals who are not Medicaid eligible, the state's 99 counties provide services, through a combination of state funds and county funds, derived primarily from local taxes.

Iowa's counties follow a policy known as "legal settlement" which requires that individuals be county residents, and free of the need for mental health services for at least a year before their new county is responsible for paying. These restrictions often lead to inordinate, potentially catastrophic delays in getting services when they are needed.

Iowa's mental health system is in serious trouble. The state needs to move forward with a bold restructuring of its mental health system...
We have 99 counties making 99 different decisions.

- Some provide little or no mental health assistance short of institutionalization.
- Some provide a significant and inclusive array of services.
- The result is grossly unfair, with service based on geography rather than need.
Who is Eligible for County Funded Mental Health Services?

- Counties fund services at CMHCs for low income uninsured people

- Counties designate Central Point Coordinators (CPCs) to serve as single points of entry into the mental health system
  - Determine who is eligible for county funded services
  - Determine which services will be provided
  - One of the only state mandated services for those with mental illness is inpatient treatment
    - Outpatient psychiatry, psychotherapy and medications are optional

- Each county has different criteria for determining who is eligible for services
  - Clinical Criteria
  - Financial Criteria
  - Legal Settlement Criteria
Clinical Criteria

- Primary diagnosis of
  - Mental Illness
  - Chronic Mental Illness
  - Mental Retardation
  - Brain Injury
  - Developmental Disability

- Does not include a primary diagnosis of substance use disorder
Financial Eligibility Criteria (Johnson County)

- Income that is equal to or less than 250% of the federal poverty level
  - Single person $26,000/year
  - Two person household $35,000/year
- Resources that are equal to or less than $2,000 for a single-person household or $3,000 in for a multi-person household
Legal Settlement Criteria

- Must have legal settlement in a County to get County funding
- If a client does not have legal settlement in the County where they reside, services can still be funded
  - County of legal settlement will be billed
  - Or
  - State payment program will be billed
What does Johnson County Cover?

- Initial psychiatric or therapy evaluation and as many therapy and psychiatry appointments as needed for 90 days

- After 90 days
  - One psychiatric visit per quarter for medication management
  - Up to two therapy sessions per month

- **Generic** medications in six classes
  - Anticonvulsants
  - Antidepressants
  - Antipsychotics
  - Parkinson’s medications
  - Sedative-hypnotics
  - Stimulants

- Lab work not covered
CMHCs in Iowa

- Number of CMHCs in Iowa = 32-42?
- Definition of a CMHC
  - CMHCs provide local outpatient services to mentally needy individuals residing or working in a catchment area
  - No clearly defined mandated or core services
Community Mental Health Center for Mid-Eastern Iowa

507 E. College Street

505 E. College Street
CMHC for Mid-Eastern Iowa

- 40th Anniversary
- Private non-profit agency
- Serves Johnson, Cedar, and Iowa Counties
- Serves 2,500 individuals, couples, and families
CMHC for Mid-Eastern Iowa
List of Services

- Psychiatry - 3.5 FTE’s
- Counseling and Psychotherapy
- Intensive psychiatric rehabilitation services
- Play therapy
- Homeless Outreach (PATH)
- School Liaison Program
- Supported Community Living
- Clubhouse
- Family Services (PACE Program)
- Emergency Services
- Consultation and Education
33% services covered by Johnson County
33% Medicaid
23% Private insurance
20% Medicare
9% services covered by the State Payment Program
8% services covered by other counties
CMHC for Mid-Eastern Iowa
Diagnoses of Clients

- Depressive Disorders 49%
- Anxiety Disorders 16%
- Bipolar 11%
- ADHD 8%
- Schizophrenia & Psychotic Disorders 6%
- Schizoaffective Disorders 3%
- PTSD 2%
- Autistic Spectrum 1%
- Impulse Control 1%
- Other 4%
Role of the Psychiatrist at CMHCs
Role of the Psychiatrist

- At first, CMHCs were primarily directed by psychiatrists
  - CMHCs led by psychiatrists
    - 1971 >50%
    - 1980 <20%
    - 1985 < 8% (Knox 1985)

- Emphasis at CMHCs put on prevention and social engineering
  - “Psychiatrists were considered too elitist, too expensive, and too removed from the realities of social change” Sharfstein, S. S. (2000).

- Relegated to medication management
Role of the Psychiatrist

- Numbers of psychiatrists, psychologists and nurses decreased
- Numbers of master's level workers increased
- By the 80’s a number of changes led to a moderate increase in psychiatrists at CMHCs
  - Discharged mentally ill patients needed psychiatric evaluations and adequate treatment
  - Growth of psychopharmacologic treatment
  - Medical issues
Role of Psychiatrists Today

- Medication checks
  - 15-30 minutes

- Leadership
  - Grant to support Medical Directors

- Psychiatric shortage
  - Telemedicine
  - Circuit Riders
Resident Rotation

- Started July 2007
- Residents rotate half day/week for 6 months in the 3rd year at Mid-Eastern Iowa CMHC
- Exposure to the CMHC environment and team
- Community Psychiatry Track
Conclusions

- The CMHC program was developed to
  - Provide mental health services to all who need them regardless of financial means
  - Provide care to the seriously mentally ill leaving state hospitals

- CMHCs were unable to meet the demands of deinstitutionalization due to
  - Inadequate funding
  - Lack of coordination with state mental hospitals
  - Absence of a support system for the chronically mentally ill

- Today CMHCs continue to be the mental health safety net for the uninsured and underinsured in designated catchment areas

- Funding for services comes from a complicated patchwork system of insurers including federal, state and local government agencies

- CMHCs and care of the mentally ill are at the mercy of the politics of the era

- The CMHC system in Iowa is no exception
  - Funding of services at CMHCs varies significantly by county
  - No set of core services at CMHCs are mandated
Change We Can Believe In?

- Identify core safety net services and require that CMHCs provide those services in order to be accredited
- Remove county property tax dollar caps and determine funding responsibility for safety net services
- Implementation of EBPs
- Emergency Mental Health Crisis Service System
- Address Workforce Shortage
References


