Nev Jones PhD
School of Social Work
Department Of Psychiatry
University Of Pittsburgh

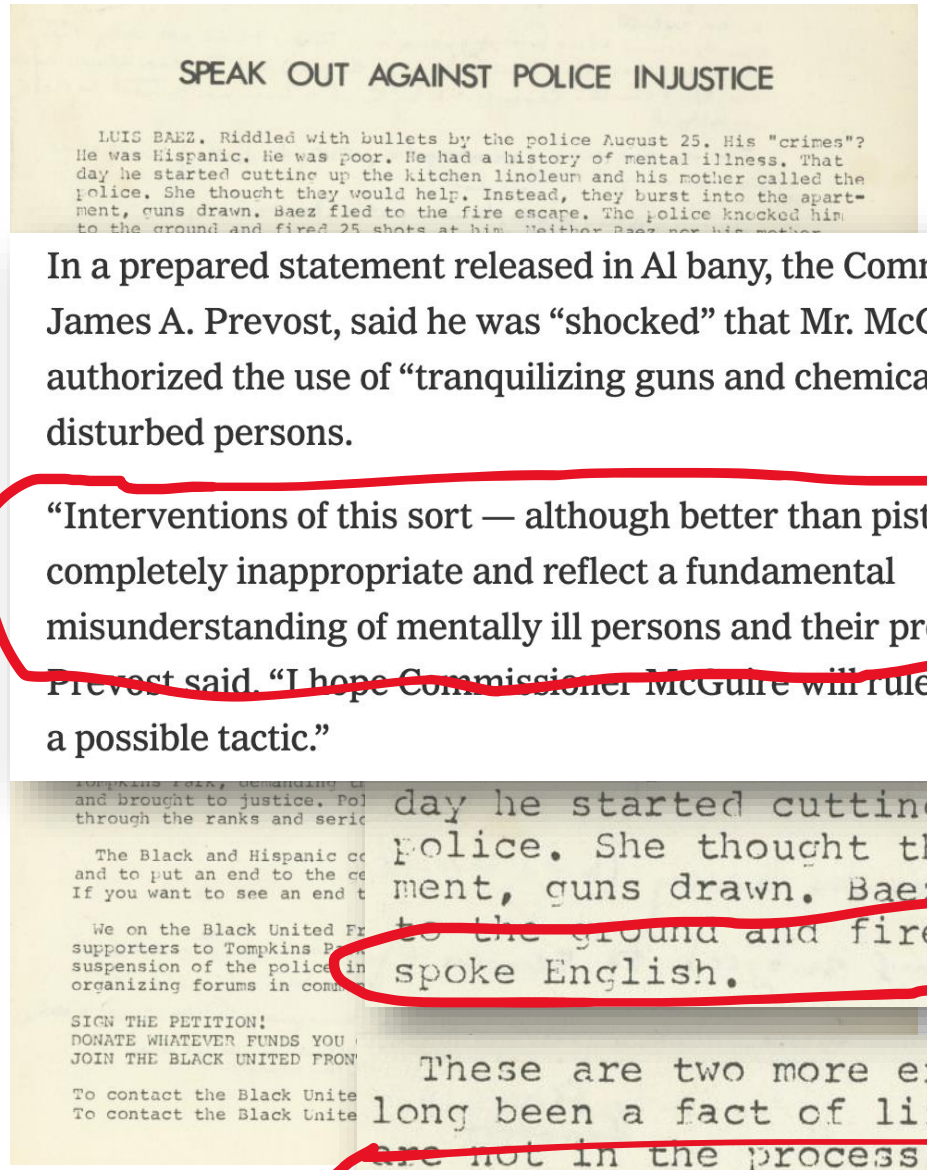
EVIDENCE & EQUITY IN PSYCHOSIS

OVERVIEW OF THE ARGUMENT

- The status quo is unacceptable
- Why are things this way? A few big picture reasons.
    - Case study: Individual placement & support
- To truly embrace equity, inclusion & social justice, we must
    - Be willing to challenge the thinking and structures that inevitably devalue (and punish) disability
    - Move away from research & practice paradigms based on linear causality and instead embrace research paradigms focused on complex systems
    - Base policy on values rather than economics
    -

THE STATUS QUO

WHERE HAVE WE BEEN?INTERVENTION'S PAST



SPEAK OUT AGAINST POLICE INJUSTICE

LUIS BAEZ. Riddled with bullets by the police August 25. His "crimes"? He was Hispanic. He was poor. He had a history of mental illness. That day he started cutting up the kitchen linoleum and his mother called the police. She thought they would help. Instead, they burst into the apartment, guns drawn. Baez fled to the fire escape. The police knocked him to the ground and fired 25 shots at him. Neither Baez nor his mother

In a prepared statement released in Al bany, the Commissioner, James A. Prevost, said he was "shocked" that Mr. McGuire had authorized the use of "tranquilizing guns and chemicals" to subdue disturbed persons.

"Interventions of this sort — although better than pistols — are completely inappropriate and reflect a fundamental misunderstanding of mentally ill persons and their problems," Mr. Prevost said. "I hope Commissioner McGuire will rule them out as a possible tactic."

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SIGN THE PETITION!
DONATE WHATEVER FUNDS YOU
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ment, guns drawn. Baez fled to the fire escape. The police knocked him
to the ground and fired 25 shots at him. Neither Baez nor his mother
spoke English.

These are two more examples of a certain type of police murder that has long been a fact of life. The victims are members of minority groups. They are not in the process of committing any major crime. Yet the police "instinctively" shoot to kill. The press can echo the police by labeling the victims "disturbed" to justify their deaths, but the fact remains that if Baez and Mangum had been white, they would be alive today.

- Institutionalization and force
- Excesses of psychoanalytic approaches (e.g. Fromm-Reichmann)
- Psychiatric rehabilitation – employment, social skills, symptom self-management

contemporary outcomes

Functional recovery in schizophrenia☆

*María Alejandra Silva, Diana Restrepo**

Universidad CES, Medellín, Colombia

ARTICLE INFO

ABSTRACT

Due to the severe functional deterioration associated with schizophrenia, the stigma that it generates, the psychosocial difficulties, the poor quality of life, the professional failure and family and social dependence, among other difficulties, it is clear that schizophrenia means more than delusions and hallucinations.[5]

Why Are the Outcomes in Patients With Schizophrenia So Poor?

Robert B. Zipursky, MD

Despite many advances in the treatment of schizophrenia over the past 50 years, the outcomes for many patients with schizophrenia remain poor. While the majority of patients with a first episode of schizophrenia may be able to achieve and maintain a remission of symptoms, only 1 in 7 patients are likely to meet criteria for recovery. These findings could be easily reconciled if schizophrenia could be established to be a progressive brain disease. Results from longitudinal studies of brain structure, cognitive functioning, and clinical outcomes, however, do not support this view. The poor outcomes so commonly observed are likely best explained by poor access to treatment, poor engagement in ongoing care, poor treatment response, and poor adherence together with the cumulative negative impact of substance abuse, comorbid psychiatric disorders, cognitive deficits, and multiple social determinants of health.

(J Clin Psychiatry 2014;75[suppl 2]:20–24)

(9). As Shadish and associates (10) note: "By any reasonable standard, the chronic mentally ill must rank as one of the most needy and disadvantaged groups in American society."

Prevalence, Employment Rate, and Cost of Schizophrenia in a High-Income Welfare Society: A Population-Based Study Using Comprehensive Health and Welfare Registers FREE

Stig Evensen ✉, Torbjørn Wisløff, June Ullevoldsæter Lyst
Erik Falkum

Schizophrenia Bulletin, Volume 42, Issue 2, March 2016, Pa
https://doi.org/10.1093/schbul/sbv141
Published: 03 October 2015

Abstract

Schizophrenia is associated with recurrent hospitalizations, need for long-term community support, poor social functioning, and low employment rates. Despite the wide- ranging financial and social burdens associated with the illness, there is great uncertainty regarding prevalence, employment rates, and the societal costs of schizophrenia. The current study investigates 12-month prevalence of patients treated for schizophrenia, employment rates, and cost of schizophrenia using a population-based top-down approach. Data were obtained from comprehensive and mandatory health and welfare registers in Norway. We identified a 12-month prevalence of 0.17% for the entire population. The employment rate among working-age individuals was 10.24%. The societal costs for the 12-month period were USD 890 million. The average cost per individual with schizophrenia was USD 106 thousand. Inpatient care and lost productivity due to high unemployment represented 33% and 29%, respectively, of the total costs. The use of mandatory health and welfare registers enabled a unique and informative analysis on true population-based datasets.

THE JOURNAL OF CLINICAL PSYCHIATRY

Schizophrenia and Schizoaffective Disorders

The Economic Burden of Schizophrenia in the United States in

Martin Cloutier,
Agnihotram V. R
PhD; Susan N. L

Results: The economic burden of schizophrenia was estimated at $155.7 billion ($134.4 billion-$174.3 billion based on sensitivity analyses) for 2013 and included excess direct health care costs of $37.7 billion (24%), direct non-health care costs of $9.3 billion (6%), and indirect costs of $117.3 billion (76%) compared to individuals without schizophrenia. The largest components were excess costs associated with unemployment (38%), productivity loss due to caregiving (34%), and direct health care costs (24%).

Conclusions: Schizophrenia is associated with a significant economic burden where, in addition to direct health care costs, indirect and non-health care costs are strong contributors, suggesting that therapies should aim at improving not only symptom control but also cognition and functional performance, which are associated with substantial non-health care and indirect costs.

Neuropsychiatr Dis Treat. 2013; 9: 787–798.
Published online 2013 May 30. doi: 10.2147/NDT.S41632
PMCID: PMC3682806
PMID: 23785238

The cost of schizophrenia in Japan

Mitsuhiro Sado,[1] Ataru Inagaki,[2] Akihiro Koreki,
Kimio Yoshimura[4]

The societal burden caused by schizophrenia is tremendous in Japan, similar to that in other developed countries where published data exist. Compared with other disorders, such as depression or anxiety disorders, the direct cost accounted for a relatively high proportion of the total cost. Furthermore, absolute costs arising from unemployment were larger, while the prevalence rate was smaller, than the corresponding results for depression or anxiety in Japan.

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CARE COURT IS ANOTHER TOOL FOR OPPRESSION. CARCERAL COURTS DON'T CARE.

June 28, 2022 by Jonathan — 1 Comment

TLDR: Newsom's CARE Act (SB 1338) weaponizes care (read: conservatorship) against poor and Disabled people, doubles down on racist and classist systems at the expense of community-based treatment programs and real, affordable housing.

RESEARCH ARTICLE | PUBLIC OPINION
HEALTH AFFAIRS > VOL. 38, NO. 10: VIOLENCE & HEALTH

Evolving Public Views On The Likelihood Of Violence From People With Mental Illness: Stigma And Its Consequences

Bernice A. Pescosolido, Bianca Manago, and John Monahan
AFFILIATIC

PUBLISHED:

National Stigma Studies. The studies gave respondents one of three vignettes describing people who met clinical criteria for mental disorders or one describing a person with nonclinical "daily troubles." Perceptions regarding potential violence and support for coercion generally rose over time—significantly so for schizophrenia. By 2018 over 60 percent of respondents saw people who met criteria for schizophrenia as dangerous to others, and 44–59 percent supported coercive treatment. Sixty-eight percent saw people with alcohol

WHY?
SUPERFICIAL POLICY CHANGE

- Changes in policy, practice and research have been largely superficial
  - No real shift in the degree to which psychosis/ppl with psychosis are pathologized, and objectified
    - Primary object of intervention is therefore “biological disease”
  - No real shift in attention to ableism within society and social structures/institutions
    - Interventions fundamentally targeting ‘biological disease,’ implemented at the level of individuals / families
    - Avoidance of/unwillingness to recognize the role of extractive capitalism
      - Privatization of health and social care
      - Neoliberal responsibilization of individuals
      - Narrow focus on social value through the lens of “productivity” within a neoliberal economy
      - Psychosis that cannot be “rehabilitated” is either
        - a drain on society -> carceral management
        - a threat -> segregation and punishment
  - Internalization of neoliberal economic values, unacknowledged by researchers/clinicians

OVER-SIMPLIFYING COMPLEX SYSTEMS

- "*a dynamic and constantly emerging set of processes and objects that not only interact with each other, but come to be defined by those interactions*" Cohn et al., 2014
  - Characteristics include
    - Multiple & interacting contexts that shape what opportunities are open or closed to any given person
    - Multiple, differently positioned stakeholders, with diverse goals and values
    - Programs and systems that influence and are influenced by other systems
    - Complex and shifting fiscal and policy constraints
    - Feedback loops
    - Ongoing adaptation to circumstances by those impacted
      - Context-dependent decision making

INEQUALITY & COMPLEXITY

- Stratification & inequality result from (and are reinforced by) multiple, interacting vectors that include
  - Place / geography
  - Access to opportunities (education/work)
  - Family and community capital
  - Exposure to individual trauma and adversity
  - Structural discrimination / structural violence (historic & contemporary)
  - Identity and how diverse identities are taken up

MENTAL HEALTH SYSTEMS & COMPLEXITY

- *"The world moves quickly; baselines shift; technologies crash; actions are (variously) constrained; and certainty is elusive. The gap between the evidence-based ideal and the political and material realities of the here-and-now may be wide. Decisions must be made on the basis of incomplete or contested data. People use their creativity and generate adaptive solutions that make sense locally.* ***The articulations, workarounds and muddling-through that keep the show on the road are not footnotes in the story, but its central plot****. They should be carefully studied and represented in all their richness."* -Greenhalgh et al., 2018

HEALTHCARE COMPLEXITY AND THE LIMITATIONS OF TRADITIONAL CLINICAL RESEARCH METHODS

- *"These core characteristics of complex systems suggest that the randomised controlled trial (in which the effects of context are 'controlled for') will address only a fraction of the unanswered questions relating to healthcare organisations and systems [12, 13, 17]. Because the system is dynamic (turbulent, even), the conventional scientific quest for certainty, predictability and linear causality must be augmented by the study of how we can best deal with uncertainty, unpredictability and generative causality. For this, we need research designs and methods that foreground dynamic interactions and emergence – most notably, in-depth, mixed-method case studies that can act as concrete, context-dependent exemplars, including powerful ethnographic narratives paying attention to interconnectedness and incorporating an understanding of how systems come together as a whole from different perspectives"*

RELIANCE ON LINEAR, OVER-SIMPLIFIED RESEARCH METHODS

'Primary' outcomes may not even be those that matter most to patients (or the patients of today, or the patients in X context)

- And different outcomes matter to different people in context dependent ways

Interventions designed for narrow "effectiveness" often fall prey to *suboptimization*

- Fixation on achieving narrow performance markers in ways that undermine more fundamental goals – "quick fixes"

In spite of statistical "controls" for context, measure validity, intervention effectiveness in fact established in context-dependent ways

- Yet then generalized/scaled without regard for local difference & intra-group heterogeneities
- Used for decades, disregarding changing social & political conditions

INATTENTION TO REAL-WORLD COMPLEXITY FUELS PROVIDER RESENTMENT

- "Sub-optimization" targets tends to reflect the priorities of academicians writing federal grants
  - And reinforcement by reviewers / funders
- These priorities normatively fail to map onto
  - the priorities of front-line clinicians
  - their perceptions of what their clients need most
  - The flexibility in fact needed to meet diverse & shifting needs
  - The realities of operating under complex and shifting fiscal and policy constraints
  - The capitalist ecosystem – e.g. if there are lower paid providers who have mastered EBPs, hired them in the private sector with higher pay
- Managed care and managerialism "collude" with over-simplified linear-causality-science as a means of limiting care in order to control costs

IN ADDITION

- Evidence mapped from one area to another, without an understanding of dynamic interactions, can lead to myriad adverse consequences
  - Limiting access to needed care by rendering many ‘ineligible’
  - Inadvertently “suboptimizing” care for originally-privileged groups & contexts
  - Discouraging organic adaptation & innovation
    - Fidelity criteria, funder restrictions
  - Conservation of the status quo (funders avoiding R&D in areas in which an entrenched EBP exists)

CASE STUDY: INDIVIDUAL PLACEMENT AND SUPPORT

SOCIOECONOMIC STRATIFICATION VIA IPS/CSC

- Background
  - Individual placement & support (IPS) was developed in the 1980s as an alternative to sheltered work & excessive 'train-then-place' employment models
  - IPS stresses rapid placement
  - Many dozens of studies attest to IPS' success in achieving "rapid placement"
    - Jobs that are generally minimum wage
    - Part-time, non-benefitted and/or contingent
    - Average tenure is short
    - Poverty amelioration has not been investigated in any US IPS study
    - *Quality* of work is rarely studied
  - On the basis of rapid job placement rates, IPS is considered a "gold standard" EBP, the only model SAMHSA will support under its supported employment grant program

IPS IN US EARLY PSYCHOSIS PROGRAMS

- Qualitative interviews with N = 29 CSC clients & families, N = 15 clinicians
  - Additional interviews (to date) with N = 31 CSC clients, N = 5 SEES
- Clients from higher SES, college-educated families are disproportionately encouraged to pursue higher education
  - Family resource cushions allow providers to encourage higher ed without recourse to disability, income and housing benefits (and associated dependencies)
- Clients from low SES (and disproportionately minoritized) families are disproportionately encouraged to obtain low wage, non-career-ladder jobs
  - Lack of family resource cushion may render disability, income & housing benefits essential
  - Lack of resources, access to quality secondary education, etc. reinforce 'rapid placement' driven provider identification of easily obtainable, broadly undesirable positions such as gas station attendant, Amazon warehouse worker, in-home aide, janitorial / laundry staff
    - These jobs are often highly stressful, leading clients to seek out benefits of various kinds (if they hadn't already)

IPS AS "WORKFARE"- CONSISTENT, NEOLIBERAL POLICY

- Focus on the individual with minimal attention to bias/discrimination/ableism among schools and employers
- Employment assumed to matter more than quality of life / alternative potential avenues for flourishing
    - Particularly when we look at the uptake of "supported employment" and other forms of vocational rehabilitation in national policy
- Provides powerful alibi for inaction on structural issues, including institutionalized ableism

INTERPRETATION

- Decades ago, bar was set low (any job, no matter how low-paying)
  - Oriented toward middle aged to older adults with substantial, long-term disability
- Intervention models became fixed (fidelity, increasingly top-down financing mandates)
- Poverty amelioration in a substantive sense not even a goal
- Alignment with neoliberal workfare policy unacknowledged
- No adaptation for
  - Radical social, cultural and economic changes
  - Career development beyond short term placement
  - Alternative social mattering / flourishing
- ”Effectiveness” nevertheless reified through narrow research paradigms/ reliance on RCTs

WAYS FORWARD

STRUCTURAL AND POLITICAL CONSCIOUSNESS / COMPETENCY

- Ability and commitment to
  - Recognizing the fundamental problems inherent in our
    - Fixation on psychosis as a “neurobiological disease” or ”disorder”
    - And primary focus on individual-level intervention
  - Recognizing sociostructural drivers of ‘poor outcomes’
  - Recognizing the dominant social and political assumptions in fact driving mainstream mental health ‘solutions’
- Interventions/policies that
  - Visibilize and work to dismantle the above

RESEARCH GROUNDED IN COMPLEX SYSTEMS

- Mixed methods case studies for complex healthcare systems
  - Make policy decisions based almost entirely on distant RCTs a relic of the past
- Participatory practice based knowledge generation via continuous learning systems
  - Learning that leverages adaptation, innovation
  - Mult-stakeholder involvement and centering of the perspectives of those most impacted by interlocking systems of oppression (race – class – disability)
- Equity analysis and standards
  - Policies and practices that we would reasonably anticipate to fuel inequality should be subject to extensive public scrutiny
    - Eligibility criteria
    - “Poverty trap” interventions likely to harm those who already most structurally vulnerable

VALUES-FIRST POLICY MAKING

- ”You can’t be neutral on a moving train”
    - Our feigned neutrality in fact functions as acceptance of status quo neoliberalism / extractive capitalism
- We must explicit in our concerns and criticisms
- And ground our alternatives in alternative social and political values

SO WHAT CAN WE DO?

- Generate learning differently!
  - Unapologetically equity oriented knowledge generation
  - Knowledge generated in real-world complex systems
  - Orientation to a pragmatic understanding of how to
    - Dismantle inequality
    - Meet the needs of always diverse, heterogeneous, differently positioned clients & families
    - Empower local programs and stakeholders to effectively identify what is and is not working locally, in equity terms
      - 'De-implement' outdated or harmful practices
      - Innovate & work across programs, systems and sectors