The Social Gradient of Health: A Mental Health Services Research Agenda Based on Principles of Economic and Social Justice

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The plight of those with serious mental illness is tragic – not only because we do not know what causes mental illness or how to cure it, but because discrimination and poverty substantially reduce opportunities to lead life to its fullest. The recent NIMH-declared “decade of the brain” brought important advances in our understanding of how the brain works and why it sometimes does not. It has not, however, advanced social and economic conditions of those with mental illness. We cannot wait for the eventual detection of the causes nor assume that the medication-silver-bullet is just around the corner. Instead, it remains important to consider how the lives of those with serious mental illness might be improved sooner rather than later. We need to attend to how people with mental illness are living now – all too often in poverty, neglected and alone.

A strong and compelling case has already been made for the interaction of income and health, also known as the social gradient of health – those less well-off have higher rates of morbidity and mortality. According to the World Health Organization, if you are poor, you will suffer more illness and die sooner.\(^1\) This finding is consistent in every country, regardless of the stage of economic development. However, it is not simply that poverty is detrimental to health, as the report states, but that “the social meaning of being poor, unemployed, socially excluded or otherwise

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stigmatized also matters."

The motivation for this paper has been the persistent exclusion of those most seriously mentally ill. This exclusion is not just because of their disability, but is based on the current social and economic realities in their lives. The stigma of mental illness is deep and broad, complicating the reduction of unemployment, homelessness, lack of health insurance, inadequate treatment, unwarranted involvement in the criminal justice system and involuntary treatment.

The Social Gradient of Health

The onset of serious mental illness starts a downward economic cycle that results in a markedly disproportionate number of individuals with serious mental illness who live in poverty. The cycle begins when symptoms disrupt work patterns, which in turn results in job loss and the interruption of health insurance coverage. Without work or health benefits, many turn to government support programs. These monthly payments are between $443 - $894 per month, at best, subsistence income even if one is also eligible for Section 8 housing vouchers and food stamps. Furthermore, receiving government benefits triggers a complex set of bureaucratic obstacles to gaining additional income through employment in the future. Regulatory income restrictions limit how much a person can earn each month without jeopardizing disability and health benefits despite modifications to government income support plans intended to encourage work. Acceptance of government disability and health benefits means hanging on to a thin safety net that is tied to poverty.

In addition to poverty, there is strong evidence that severe mental illness goes hand in hand with higher than average rates of morbidity and mortality. Dickey et al compared poor Medicaid beneficiaries without any mental illness to those with serious mental illness and found the likelihood of being treated for diabetes and heart disease about three times higher and hypertension, asthma, malignant neoplasms and respiratory disorders about two times higher. These odds ratios likely underestimate the actual disease incidence for those with mental illness because many studies have shown these medical problems go undiagnosed or untreated. For example, people with severe mental illness are sometimes unwilling to seek medical help or may have difficulty in describing their problems to a physician. Psychotic symptoms also may interfere with a patient’s ability to answer questions about the medical problem that brings her or him to the physician.

Of course, more medical disorders lead to higher than expected mortality rates. In Massachusetts, treated Medicaid beneficiaries, age 18-64, with psychiatric disabilities have an age- and gender-adjusted mortality rate three times higher compared to the mortality rate of the general population in the state. It is not just excess medical disorders that lead to higher mortality rates. People with severe mental illness are twice as likely to have rates of externally caused deaths – suicide, homicide, accidents and most commonly, poisoning, either by accident or design. Mortality rates for individuals with dual diagnoses are double that of those without co-morbid substance abuse.
The social gradient of health summarizes the catastrophic end point for many individuals with mental illness who have little control over the complicated and interconnected problems they face. The problem persists despite research that has contributed to policies that improve the delivery of medical and psychosocial treatment for those with the most serious mental illness. In particular, the last ten years have seen increased access to treatment and greater attention focused on housing, case management, assertive community treatment, psychosocial rehabilitation and supported employment. While these improvements are encouraging, deeper questions about exclusion from social, civic and economic life still remain largely unanswered.

To encourage attention to these questions, this paper sets forth a research agenda, informed by the work of Nobel Laureate Amartya Sen. The purpose of this research agenda is to encourage a response to the challenges of inequality and injustice that present such vexing social and economic problems to individuals living with serious mental illness. This agenda is linked to the larger question of how social and economic conditions are related to the course and outcome of severe mental illness.

**Research Agenda**

Sen proposed his economic theory of human capabilities in 1978 as an alternative to existing theories of social advantage and resource allocation. Those theories (e.g., welfare economics, equality of opportunity, libertarian rights of non-interference) were inadequate, he argued, to capture what is necessary for each of us to be all that we can be. Substantive freedom, central to his theory, rests on human capabilities — "the ability of people to lead the lives they have reason to value and to enhance the real choices they have." The term capability, as he uses it, conflates two distinct aspects of his perspective of freedom: processes that allow freedom of action and decision-making and opportunities to undertake actions and make decisions. He would say that it is not enough to be educated if you have no opportunities to use that education.

Sen’s approach draws on Aristotle, who in the Nicomachean Ethics noted that “wealth is evidently not the good we are seeking; for it is merely useful and for the sake of something else.” According to Sen, his approach has the advantage of assessing poverty without relying exclusively on measures of income. For example, he observes that African-Americans in prosperous US cities have life spans markedly shorter than China, where average income levels are markedly lower than the average income of poor African-Americans. His interpretation is that discrimination and social class, not just income, have limited the human capabilities of African-Americans, shortening their lives. In this way, substantive freedoms can only be advanced by income when social and economic rights are preserved.

The goal of this paper is to increase the influence of research on policy by inserting macro-ethical concepts into services research. Public policy might be strengthened by more research that links social and economic conditions with course of illness. This is not to suggest that the consequences of poverty and poor health have
not been addressed by health services research. Rather we argue for more research that specifically examines the direct consequences of injustice and discrimination on the lives of people with serious mental illness.

The need for a broader research agenda is illustrated by a recent article which reports that more individuals with serious mental illness are receiving treatment than ever before, despite managed care. While this is good news, it is troubling that those with the most serious mental illnesses, despite increased access to care, remain stigmatized, and are more likely to be homeless or poorly housed, be incarcerated, live in poverty, lack health insurance and employment, be in poor health and die sooner than other Americans. It does not appear that increasing the amount of treatment received has much effect on their everyday lives.

This agenda is guided by the evidence that individuals with serious mental illness are, in Sen’s words, limited in their “ability to do valuable acts” [e.g., participate in civic life] or reach “valuable states of being” (e.g., have satisfying personal relationships), his definition of quality of life. The social and economic domains suggested by this research agenda fall into areas where we, as multidisciplinary health services researchers, bring our special expertise.

**Stigma**

Stigma tops the list because of its pervasive and insidious presence in the conditions that shape the lives of individuals with serious mental illness. It is fair to assume that stigma attached to mental illness pervades almost all the research domains that need our attention. Public policy aimed at improving access to social welfare and health care are important but will not solve the larger problems associated with mental illness as long as institutional and personal prejudice discriminate against the mentally ill.

For more than a thousand years, mental illness has been demonized. Even today, despite its known prevalence and well-publicized treatments, those with mental illness are all too often excluded. Individual prejudice is reinforced and compounded by institutional policies and government regulation that explicitly and implicitly single out the mentally ill for exclusion.

Anyone with mental illness severe enough to engage in behaviors deemed socially unacceptable has experienced rejection. In fact, even the label of mental illness is enough to be stigmatizing in both personal and work lives. It is not just that the stigma of mental illness is demeaning; it has a direct effect on the social integration of individuals with severe mental illness. Integration has been described as important on four levels: participation in civil society, access to social goods, inclusion in social production, and access to normal forms of livelihood. Living life to the fullest includes having the opportunity to participate as an active citizen in one’s community and through expression within one’s personal sphere. Straus and Carpenter wrote 20 years ago: “Who can doubt the devastating impact on a fragile person of perceiving that the entire social milieu regards him (wittingly or not) as subhuman, incurable, unmotivated, or incompetent to pursue ordinary expectations...?”
No matter what form stigma takes, it limits the capacity of those with mental illness to fulfill their potential. Like all forms of discrimination, the roots are deep in misguided beliefs and not easily changed. We know that there are barriers to the full inclusion of those with serious mental illness in our social and civic society but it is less clear how they can be addressed. It might be useful to ask:

What are the characteristics of social environments that reduce stigma and foster self-confidence and optimism in the mentally ill about the future?

Unemployment

The elimination of stigma is a necessary but not sufficient action to bring those now excluded into our everyday social world. Becker and Drake tell us that “most people with mental illness identify competitive work as one of their primary goals” and that supported employment is the best avenue to reach that goal. Work, they say, is consistent with taking control of one’s life and having “meaningful activities that reinforce a sense of purpose and accomplishment.” With work comes identity and a sense of agency and well-being. From Sen’s perspective, agency and well-being are key to having the freedom to accept responsibilities which changes relationships in the direction of reciprocity, rather than dependency. While these attributes are an important end in themselves, work has the added benefit of producing income, perhaps lifting the person not only out of the misery of poverty but also, if work is therapeutic, the shadow of mental illness.

However, despite widespread agreement that working is key to the goal of well-being, it is the means of achieving that goal that remains if not controversial, at least a low public priority, if one uses as a measure, dollars spent on accomplishing the goal of competitive work. Although one version of evidence-based supported employment, Individual Placement and Support (IPS) has been around for more than 10 years, most people with serious mental illness do not have access to IPS or other supported employment programs. One reason for the few programs available has been attributed to the attitude of some mental health professionals which view working as a “dangerous experiment.”

If supported employment is available, admission is usually highly selective. This screening helps to ensure program success, but leaves many potential workers outside the workforce, looking in. A survey of unmet needs found 61% needed help in getting or keeping a job. Obtaining competitive employment is possible with the help of programs like IPS, but all vocational rehabilitation programs have found that maintaining employment is difficult. This has remained a puzzle until Gold et al, in a large clinical trial, found that neuropsychological performance mediated the likelihood of long-term employment. This is a good example of how carefully designed multidisciplinary studies might improve services targeted to overcome special problems.

How would public policies have to change to make employment a realistic goal for people disabled by psychiatric illness?
In Focus

Homelessness

It is shocking to learn that the number of homeless people has grown by 40% in the last 10 years, at a time when the US is the richest and most powerful country in the world. The best and most recent count for the US comes from the Urban Institute, which estimated the number of homeless people from interviews in 1996, conducted in a representative sample of rural and urban areas. The estimate was derived from data gathered from people who were using some type of homeless service, and thus the estimate can be considered a lower bound: an annual prevalence between 2.3 and 3.5 million people. Of these, it is thought that about one quarter have a serious mental illness and about half have a history of substance abuse. Virtually no one believes that increasing the number of shelter beds is the way to end homelessness.

Improving housing outcomes, then, means rethinking the function that shelters perform and understanding the cost of homelessness to society.

The expenditures are high and except for a few specific programs designed to reduce or alleviate homelessness, are devoted to paying for the consequences of homelessness rather than prevention. The financial and social burden to families and friends who provide shelter is significant. Brendan O’Flaherty lists several other “costs” of homelessness, among them the spread of tuberculosis, the problem of fires and the use of public spaces by the homeless. Another example is from Lindblom who estimates annual clean-up costs of transit centers used by homeless people in New York City as $20 million.

In searching for the roots of homelessness, several authors have made compelling arguments based on economic theory. There is widespread agreement that the ravages of mental illness, inpatient commitment laws, inadequate community mental health resources and ubiquitous substance use contribute to homelessness but are vulnerabilities or risk factors, rather than “causes.”

Martha Burt is one of several researchers that has pointed to macro-economic injustice, rather than deinstitutionalization as the root of homelessness. Burt’s analyses target economic restructuring which has led to the loss of unskilled or semiskilled jobs, lack of affordable housing units, demolition of lower-cost single room occupancy replaced by gentrified urban communities, income inequality, and reduction in the purchasing power of public benefits.

Research on homelessness needs to include research on housing options for people with very low income and mental disabilities. There are many reports of their preferences, but there is much less on how to bring about a greater supply of adequate housing, especially in cities, to meet their needs. Micro-economic cost studies that have been published can be improved upon by following individuals longer after they have been housed and by expanding the range of costs to be included.

At the macro level, we are only just beginning to understand the housing market and how it is related to homelessness – surely this deserves more attention, as do the dynamic economic forces of our current prosperous environment and how they increase, rather decrease homelessness.

If housing is a substantive freedom,
what economic mechanisms and political strategies will ensure that psychiatrically disabled adults have safe and adequate housing?

Inadequate Health Insurance

Volumes have been written about the current state of health care costs and the fragmented system of benefits. Although most individuals with serious mental illness are covered through public health benefit plans, 25% have no health insurance at all.14 For those who qualify for disability, requirements related to these plans include waiting periods that may prolong a period with no insurance at all. If eligible for Medicare or Medicaid, access to basic health benefits may be limited by the design of the benefit packages which all too often restrict treatment to certain preconceived notions of what is needed and how much.

And “health benefit” is defined as treatment that is medically necessary. The human service needs of this population are significant and rarely covered by health insurance. For example, treatment guidelines for schizophrenia include several recommendations for services not deemed “medically necessary” such as supported employment and case-management.

Even if we accept the ‘medically necessary’ definition of health benefits (leaving the provision of human services to other agencies) there are gaps between these agency “silos.” The lack of integration of medical and human services may increase the likelihood of serious problems secondary to mental illness – homelessness, mothers separated from their children, and physical or sexual abuse that goes unnoticed or unreported.

If access to health care is a fundamental right, as Sen has argued, can we design and test a comprehensive health and human service plan that has the following characteristics:

- Prepaid to encourage flexibility, efficiency and innovation
- Includes of all those disabled by serious mental illness
- Has incentives to provide all the necessary services but no more?

Inadequate Quality of Care

Review of medical practice in the community has shown wide-spread variation and disappointing levels of adherence to standards of care.32-34 For example, there have been a number of studies of the use of antipsychotic medication recently that, with one exception, found that the treatment fell short of what is recommended and one author concluded that “for nearly all of the recommendations the level of practice conformance...[was] modest at best.”13,35-39

Even if you discount these discouraging findings, there remain questions about how to set standards that can inform professional service and teaching. A wide variety of interventions have been tried, ranging from academic detailing for physicians to harsh financial penalties for failure to conform, with modest success in changing behavior. This is a complicated problem because it has been common for physicians to assume that industry studies of efficacy are synonymous with studies of medication effectiveness (i.e., better outcomes in clinical practice).40
Work in other fields suggests that, with people who are poor and in poor health, a combination of compassion and additional human services are essential for treatment to have its maximum effect. Paul Farmer makes this point from his social justice perspective. Based on his work in Haiti, he argues that success in treating poor people with tuberculosis rests on more than providing state of the art medical treatment – good outcomes are achieved only when treatment is conceived within a broader social problem: “...the spirit in which these services are delivered makes all the difference. Service delivery can be just that – or it can be pragmatic solidarity, linked to the broader goals of equality and justice for the poor.” Mental health professionals who deliver care that is technically adequate but which lacks compassion and understanding of the social implications of poverty is not sufficient for the attainment of substantive freedoms.

Donebedian was perhaps the first of modern proponents of measuring quality of care to point out that the best treatment is not just technically adequate, but also must include a strong relationship between clinician and patient. Other than efforts to measure patient “satisfaction,” that relationship has been much less well studied. Work by Ware and colleagues, who have reported on patient relationships with clinicians, suggests that the nature of the relationship may have much to do with personal interactions that result in strengthened belief in self and a sense of agency.

How much of the shortfall in treatment receipt or outcome improvement can be attributed to the social and economic conditions of the patients and how much to physician technical and interpersonal competence?

Justice System

The sometimes overlapping missions of state agencies responsible for health care and justice run head on into each other when someone with mental illness is picked up by the police. Fisher has pointed out that depending on police training, the flexibility of judges, organization of the court system and the progressiveness of the department of mental health, contact with the law can result in anything from inappropriate incarceration to (all too rarely) the initiation of humane and clinically sound care. Fuller Torrey has reported that more people with mental illness in California are housed in the LA county jail than in California psychiatric hospitals. About 15% of all inmates, nationally, are thought to have a mental illness and of those, three-quarters have co-occurring substance abuse.

Despite the evidence that many inmates suffer from mental illness, they seldom receive adequate treatment and in many sites, no treatment. Advocates for the mentally ill have argued that their mental illness has become criminalized, leading to unnecessary involvement in the criminal justice system, triggering mechanisms for the social control, rather than treatment, of mental illness. While this description of the path that many inmates follow is surely accurate, the argument for change assumes that law enforcement and the justice system are able to distinguish
between symptom-induced behavior, drug or alcohol-induced behavior and criminal behaviors that are neither symptom-driven nor chemically-induced. It also raises the question of how offenders should have their case adjudicated as prescribed by law, even if they are also mentally ill.

In response to concerns about the deleterious effects of incarceration on those with serious mental illness, some states have instituted programs designed to reduce prison time and at the same time provide adequate treatment services. Mental health courts, modeled on drug courts, seek to find solutions to the complex problems presented by individuals charged with an offence and who have a mental illness and usually co-occurring substance abuse. These courts aim to intervene quickly in the justice process, typically in cases of misdemeanors, to obtain treatment as an alternative to incarceration. Because the courts are part of the criminal justice system, they can use the leverage of the system to prescribe sanctions if treatment is not followed.\(^{49,50}\) No systematic research has been published about the effectiveness of mental health courts. A recent report of a national multi-site study of jail diversion programs indicated that they did not improve mental health nor decrease criminal justice recidivism for those diverted compared to other mentally ill inmates.\(^{51}\)

When police contact is made, how can the mental health, judicial and correction systems work together to reduce inappropriate incarceration and increase a clinical presence in the lives of those who are caught up in all three systems?

**Involuntary commitment**

One of the thorniest problems in the mental health field is how to balance individual rights with those of society.\(^{52}\) Inpatient commitment can occur if a person is determined to be in imminent danger of doing harm to themselves or to others. Although commitment policies have been revised to narrow the definition of dangerousness and ensure due process, it remains an option when a person is deemed dangerous, refuses treatment and is not competent to determine what is in their own best interest. In the case of imminent danger to others, the community has a responsibility to provide compassionate care and ensure public safety. But just what constitutes “imminent danger” is open to interpretation and it is this point that has led to opposition to any form of involuntary commitment. Many critics see this as blatant abuse of civil liberties while others argue that, once treated and better able to speak for themselves, those committed are better off. There have been some efforts to establish outpatient involuntary treatment to avoid institutional commitment, but the research findings have been limited in their effect on shaping policy.\(^{53-56}\)

Perhaps the most common and controversial use of involuntary commitment is with people who are both seriously mentally ill and homeless. In a famous case a decade ago in New York City, Mayor Koch announced “morally and legally we have an obligation to help those who can’t or won’t help themselves.”\(^{57}\) City workers identified street people who were in “foreseeable danger” and hospitalized them against their will. The first person so identified brought a lawsuit against the city (with
the help of the ACLU), and after the suit worked its way through the courts, her release from Bellevue Hospital was obtained almost three months later.

What can be learned from states that rarely rely on involuntary inpatient commitment to ensure public safety? What is the threshold that allows those with mental illness to remain citizens of the community, despite behaviors that seem to threaten their own safety and that of others?

Discussion

Generating a list of research topics is much easier than considering the challenges that make research on these topics so difficult. After all, if it were easy to do this research, it would be done. It is not just that there are substantive methodological problems to overcome, but also complex and competing public and personal incentives that discourage researchers from asking these hard questions: moving into the larger more politically-charged arena of social justice risks unfunded research and denial of promotion and tenure. Furthermore, the links between research findings and policy-making remains tenuous despite the NIMH initiative to bring health services research and policy into closer relation. Little effect on policy can be found until the mass of evidence reaches the ‘tipping point’ when not changing a policy carries greater political risks than maintaining it.

Research Challenges

More than one experienced researcher has floundered when trying to undertake field research that examines the lives of individuals in the course of their daily activities. Nothing can move forward in research until questions about the benefit and costs to human subjects are answered. Institutional Review Boards (IRBs) and the Health Insurance Portability and Accountability Act (HIPAA) are increasingly successful in protecting patient privacy, clearly warranted, but tightening up procedures for approving and monitoring research protocols has inadvertently created problems for investigators carrying out health services research. But the history of human protection in research studies is embedded in the clinical, not health services world, the world from which IRB members have usually been drawn. Bolstering this clinical perspective are medical schools that pass on to their students the belief that the randomized clinical trial model is the gold standard for research design. The result is a pervasive, if not explicit, clinical paradigm that colors assessment of the benefits and costs of policy research.

Furthermore, current research studies that rely on administrative data may encounter lingering institutional confusion about how research and patient privacy are affected by HIPAA. Data confidentiality may present the most difficulty to IRBs when reviewing health services research protocols, in part because IRB members may narrowly interpret HIPAA regulations that restrict access to identifiable medical information gathered as part of the treatment documentation and reimbursement processes. Varying interpretations of fed-
eral regulations result in differences in how IRBs distinguish research from other data collection activities, what constitutes identifiable information and what level of confidentiality protection is adequate.60

Once IRB approval is obtained, launching the study has challenges. The very setting of field studies may create so much noise that the signal sought by the research team may go undetected.61 Enrolling and keeping enrolled individuals willing to participate. This is especially difficult in population-based studies that use a representative sampling-frame. Further, within the agenda we have posed, questions lead to sampling frames which include the least likely research subjects – those who see little personal benefit from participation, who are unable to unwilling or sustain long-term participation if it is required, or who have more general antisocial or inhibited tendencies.

For the principal investigator, ingenuity and persistence are perhaps the key ingredients; ingenuity is free, but persistence often translates into considerable and costly level of effort. Whether it is gathering data about the treatment of prison inmates or testing the effect of health benefit or payment changes on access to care, the barriers are more than most of us would attempt to overcome.

The active dissemination of results to policy-makers, rather than the passive publication in scientific journals, has had mixed results, at best. A prime example is the recent count in New York City of homeless adults living on the streets. This annual count was supplemented by Hopper and colleagues to improve the estimate obtained.62 The count takes place one winter night between 1-4am through the city, including documented areas where homeless people gather. Sending out 120 graduate students on the night of the count with instructions to identify themselves as “plants” if approached by counters, Hopper et al. would use the percentage of plants counted as a proxy for genuine homeless who were counted. About 20% of the students were not approached during the count, thus allowing Hopper to assume that the city estimate was under-counted by 20%.

Funding Challenges

If the research is challenging, the funding of such work is equally difficult. Despite growing budgets at NIMH for extramural research, especially in the realm of quality of care, there remains a bias in study sections toward the selection of projects that present the fewest risks. Federally funded research is desirable because it implies a certain level of confidence in the underlying science whereas research projects funded by industry or advocacy foundations tend to be viewed with some skepticism. While it is easy to make the argument that federal (or state) research monies ought to be parcelled out according to our democratic (i.e., social and economic justice) ideals, the ideals of democracy also contain the role of public dialog and its interplay with policy. Public funding for research goes hand in hand with public priorities, priorities in the current political and social climate that are more likely to emphasize change in the direction of less rather than more substantive freedom for those who live on the margin of our society.
Academic Disincentives

There is an old and tired argument about the conflict between challenging existing paradigms, trying to get money to do leading edge research, and the increased risk of losing faculty promotion and tenure. This argument probably still holds, but shouldn’t stand in the way of the few who have the rare combination of intellectual gifts, a sense of urgency about social justice and some uncommon amount of moxie. It surely is the role of tenured faculty to lead the way in supporting younger investigators in taking on risky but promising research.

Conclusion

The goal of this paper is to outline a research agenda that would directly address the relation between the social and economic environment and the course of mental illness. Even though the accumulated evidence of the social gradient of health identifies the consequences of the growing gap between the rich and poor, this approach falls short of capturing the scope of problems that beset those with serious mental illness. The theoretical work of Amartya Sen has helped to expand that scope. In setting quality of life as the standard for resource distribution rather than income, his work helped to set a research agenda that included direct threats to the quality of life of individuals with mental illness. These threats, coupled with poverty and increased morbidity and mortality, represent an almost insurmountable social gradient. Nevertheless, health services researchers can, and must, work harder at shedding light on questions that result in policies that improve the quality of the lives of those with serious mental illness so they too can benefit from the privileges and responsibilities of citizenship.

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