

Caring for Persons with Serious Mental Illness: Policy and Practice Suggestions

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ABSTRACT. This article places evidenced-based knowledge of practice within the social context of care and proposes five policy objectives and specific policy and program changes to address care needs of people with serious mental illness. In spite of demonstration programs that provide the basis for proposed policy initiatives throughout the United States, treatment provision for this population remains inadequate and their safety and well-being continues to be at risk. The authors suggest that treatment initiatives need to be tied to stable policies protecting the mentally ill from adverse social context changes. The authors conclude that policies are needed that will enhance housing assistance, independent social functioning, personal empowerment, and treatment engagement. In addition, efforts are needed to make better use of inpatient hospital care, to better understand the role of assisted treatment, and to better develop consistent long-term fiscal support for the seriously mentally ill. They offer specific policy recommendations for changes in HUD

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programs, Medicaid and Medicare funding, and treatment programming that address these needs. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2003 by The Haworth Press, Inc. All rights reserved.]

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There is expanding emphasis on evidenced-based model programs combining psychosocial treatment with the effectiveness of new psychoactive medications in meeting the care needs of people with serious mental illness. This emphasis is reflected in demonstration programs that are the basis for proposed policy initiatives throughout the United States. Nevertheless, in spite of these efforts, both mental health services researchers and various stakeholders concur that treatment provision for this population is inadequate and the population's safety and well-being continues to be at risk (Lamb, 1998; Lamb & Bachrach, 2001; Lamb & Weinberger, 1998; Munetz, Grande, & Chambers, 2001). All involved have an increasing concern for the welfare of the seriously mentally ill—i.e., their deteriorating health and mental health status, their increased involvement with the criminal justice system, and their experience of the consequences of abject poverty and homelessness (Baumohl, 1996; Blau, 1992; Burt, Aron, Lee, & Valente, 2001; Huston & Clapham, 1999). This article places evidenced-based knowledge of practice within the social context of care and proposes five policy objectives and specific policy and program changes to address observed patient care needs.

THE SOCIAL CONTEXT OF TREATMENT

The mentally ill are extremely vulnerable to adverse social context changes and treatment is not robust—i.e., its positive contributions are easily overwhelmed by negative circumstance. The social context of the seriously mentally ill is fraught with negative circumstances.

Serious mental illness frequently leaves people in abject *poverty* and exposes them to all the risks associated with a poverty life style. Perhaps the most adverse consequence of living in poverty is premature death. Early death due to tuberculosis has long been associated with poverty conditions to cite but one example. Many researchers have reported elevated age specific death rates among the seriously mentally ill

along with an unstated assumption that early death is somehow linked to their illness (Tsuang, 1978; Mortensen & Juel, 1990). Yet, one half of this elevation in death rates reported for people with schizophrenia can be attributed to the poverty circumstances in which they reside (Segal & Kotler, 1991).

Poverty and a *lack of affordable housing* are responsible for homelessness among the seriously mentally ill. Deinstitutionalization, per se, is not *directly* responsible for the mentally ill on the streets; rather, it is the way the policy has been implemented (Lamb, 1984; Lamb, Bachrach, & Kass, 1992) or more accurately the way its objectives have been undermined by other policy initiatives and economic priorities. At the outset of deinstitutionalization efforts, there was a surplus of affordable housing (Blau, 1992). The pre-1980 representation of the mentally ill among the homeless population was about 8%; today it is about 33% (Segal & Baumohl, 1988). Thus, a full decade after deinstitutionalization began much of the seriously mentally ill had housing. Housing policies, most notably urban renewal, and the reduction of support for new affordable housing, coupled with their vulnerability have put the mentally ill on the street (Belcher & Deblasio, 1990; Lamb & Bachrach, 2001).

Research supports the observation that mental health treatment programs that have received attention as models of care flourish because of an affordable housing component provided by the program itself (Hurlbert, Wood, & Hough, 1996) or because of their location in areas with affordable housing surpluses. The successes in reintegrating the seriously mentally ill into the community reported in Trieste, Italy, were underpinned by a surplus of housing in the city. Apartments for supervised residential care placements were available at a cost within the purchasing range of service providers and government subsidy grants. Housing provision was also a key component of the successful replication of the Program in Assertive Community Treatment (PACT) in Sydney, Australia (Hoult, Reynolds, Charbonneau-Powis, Weeks, & Briggs, 1983). Affordable housing was readily available in the initial PACT program in Madison, Wisconsin. A randomized controlled study of Massachusetts homeless mentally ill adults in the Boston McKinney demonstration project found that regardless of the original assignment to two housing types, the large majority of clients were able to remain housed and avoid homelessness (Dickey et al., 1996). Thus, with housing, perhaps even of the poverty type available at the outset of deinstitutionalization (i.e., run-down boarding houses or single-room occupancy (SRO) hotels), programs can be successful. As noted above, urban renewal policies have eliminated affordable hous-

ing (particularly SRO hotels) and doomed program efforts without direct housing support.

The mentally ill are extremely vulnerable to *the vicissitudes of the policy process*. For example, the Mentally Ill Offender Crime Reduction Grant outpatient program, a recently enacted piece of California legislation (AB2034), aims to reduce crime, jail crowding and criminal justice costs associated with mentally ill offenders. Through June 2004, the California Board of Corrections will have awarded a total of approximately \$87.5 million to 30 demonstration projects. This is an excellent attempt to bring comprehensive integrated care services to the criminal justice involved and homeless mentally ill. Its reliance on the grant mechanism for continued funding, however, instead of general budget increases with appropriate utilization review, makes the long-term nature of this effort tenuous at best and subject to cyclical changes in public policy population interests. The ephemeral nature of such efforts are illustrated by the limited duration of several other model program efforts proceeding it (Wright-McCorquodale-Bronzan Act, 1988) and the past use of financial incentives to foster reduced hospitalization (California Mental Health Services Act, 1984). The latter incentives, designed to allow the investment of inpatient care savings in outpatient programs, were subsequently eliminated leading to reductions of over 50% of California State general fund investment in the care of the seriously mentally ill (Okin, 1992). *The grant mechanism for funding treatment efforts contributes to a lack of program continuity and the failure to support programs that are not "new and innovative."* Utilizing this type of discontinuous funding disrupts the process of ongoing beneficial change and negatively affects the mentally ill in the long run.

The State, perhaps most in response to fiscal incentives included in the Federal Medicare/Medicaid legislation, has effectively *abandoned the responsibility for the mentally ill*, placing it on the shoulders of increasingly desperate family members who are exasperated with the often disjointed, limited and resource poor efforts of the system to help their family members in times of greatest need—i.e., before they become dangerous to themselves or others. The "IMD exclusion," which limits federal funding for the mentally ill in many settings including state hospitals and other facilities considered "institutions for mental disease" (IMDs), has created fiscal incentives for states to move patients out of mental hospitals. This *legislation* along with the federal subsidies of nursing homes and board and care (via Supplementary Security Income (SSI)) *has created a residential care calculus that makes the use of mental hospitals, regardless of how appropriate they may be for patient*

care, a fiscally unsound decision. It has contributed to homelessness through premature release of patients from mental institutions (Segal, Watson, & Akutsu, 1998) and to the use of incarceration as an alternative to hospitalization (Geller, 2000). In fact, the elimination of the IMD exclusion would in all likelihood correct the adverse transfer of care incentives in the Medicare/ Medicaid legislation and complete the transfer of fiscal responsibility for the seriously mentally ill (initiated with the passage of Medicare/Medicaid and SSI) from the State to the Federal government.

The origins of the State Mental Hospital in the Dorothea Dix campaign was an effort to provide protection for the vulnerable mentally ill from the vicissitudes of the negative social environments where they were housed, i.e., in the unsegregated populations of jails and poorhouses. We have returned to nineteenth century unsegregated care provision in corrections facilities and poor houses (now called homeless shelters) with all of its attendant abuses. At Rikers Island alone, of the 133,000 inmates admitted in 1997, 15,000 were treated for mental illness (Butterfield, 1998). This is more than the population of Puritan State Hospital (the largest state mental hospital) at its peak. For some time now, the Los Angeles County jail has been viewed as the “de facto largest mental institution in the country” (Torrey, 1998).

POLICY AND PRACTICE OBJECTIVES

Treatment does not occur in a vacuum. Serious mental illness is often so devastating that target outcomes must address the individual’s total life situation. There is no mind-body separation in treatment outcomes for the seriously mentally ill, and generally medically necessary treatment is a fully integrated bio-psychosocial program. Medical outcomes not only include reduced symptoms, but also involve avoidance of adverse experiences (death, violent crime, criminal detention), improved quality of life (not just satisfaction but both independent and assisted social functioning) and personal empowerment (enhanced control over one’s life situation) over the long-term (for this is a long-term condition). In order to achieve such broad-based outcomes, however, medically necessary treatment cannot be tied to efforts to simply reduce symptoms and/or prevent hospitalization; it must be anchored in policies that address the total life situation of the seriously mentally ill. Therefore the following policy and practice objectives are proposed:

Objective 1: Support efforts to give the mental health consumer an active role in decisions about their own care both within professional helping relationships and through self-help programs.

The person with serious mental illness is not a passive recipient of therapeutic intervention. They are often intelligent individuals who can and do objectively evaluate proffered care, have a good sense of what has and has not worked for them, and of their ability to carry out a treatment plan. In order to successfully implement this objective we first, when at all possible, need to help the person retain responsibility for themselves and help them become maximally involved in decisions regarding their own care (Lamb & Bachrach, 2001). This objective is achieved with interventions targeted primarily at the promotion of independent social functioning with a lessor focus on assisted social functioning. Aggressive social casework, similar to the Program in Assertive Community Treatment (PACT), was effectively employed in California, Wisconsin, Michigan, New York and other states during the late 1960s and early 1970s. Long before the Stein and Test (1980) demonstration, it was the type of social casework practiced by the Bureau of Social Work in California and the Dutchess County Unit at Hudson River State Hospital in Poughkeepsie, New York throughout the late fifties and 1960s. The results of such efforts are primarily gains in assisted functioning. That is, reductions in the use of hospitalization, made possible by mediated service provision that keeps the individual out of the hospital or in more recent studies, reduces homelessness or criminal justice detentions. The latter outcomes are made possible by staff facilitation of housing access or intercession with criminal justice officials. The value of such assisted outcomes should not be underestimated—they make life livable for this population. These outcomes, however, do not signal an end to the individual's vulnerability or the curing of his/her condition. They exist as long as they are guaranteed by program effort and once eliminated, unless progress is made in the independent functioning area, they leave the individual vulnerable to the same social situation. Several studies of the withdrawal of PACT services have documented the loss of such gains supporting the observation that the benefits of PACT come from mediated efforts on behalf of the patient. For many such mediated efforts may be a lifetime requirement. At the same time, greater efforts need to be made in identifying those for whom fuller integration in the community is a feasible goal (Salyers, Masterton, Fekete, Picone, & Bond, 1998) and in individualizing programs to pro-

mote independent functioning to the fullest extent possible for each individual.

Since, in the past 30 years, it has been difficult to depend on the State to insure continued professional treatment or environmental supports, it is important to engage the mentally ill as actively as possible in achieving their own positive outcomes, especially the enhancement of their independent functioning.

Second, when at all possible, we need to encourage consumer led self-help programs that involve network support and participant decision-making responsibility. The shift to managed care has increased the difficulties of providing comprehensive care to all but the “gold card” patients who incur excessive hospitalization costs. Limited by medical necessity criteria, community mental health agencies have, in Northern California, developed a division of labor with consumer-lead services. The latter provide the social support care and the former the medication, treatment and case management service. The extensiveness of this partnership has become increasingly evident in a recent study’s results on service utilization at co-located self-help and mental health service agencies (Segal, Hardiman, & Hodges, 2002, in press).

Self-Help Agencies provide extensive services including social support networks and vocational opportunities. The process of this service provision enables people with mental illness to participate in meaningful decision-making that enhances personal empowerment.

Objective 2: While many will need assisted involuntary treatment, the use of imposed interventions should be carried out with caution and only after underwriting efforts to fully involve the patient in treatment plans to the maximum extent possible.

The objective of treatment is to provide quality care, the definition of which lies with the various stakeholders’ perspectives in the interaction. The mental health professionals’ perspective emphasizes technical quality in the therapeutic interventions; the patient’s perspective, personal involvement in the decision process regarding their own care; and the administrative perspective, efficiency in service delivery. From the perspective of therapeutic interventions, treatment objectives include the provision of medications, psychotherapy, as well as social role supports, supplements (financial and other material assistance), and alternative residential environments. These interventions require the person with mental illness to offer sound information for accurate diagnosis and active participation in the treatment regimen. Noncompliance with

the treatment regimen or inaccurate information on the client's past experiences leads to treatment failure.

Ways to ameliorate this unsatisfactory situation include validating and incorporating the experiences, values, and personal goals of patients into the planning process and developing and evaluating highly individualized treatment plans (Bachrach & Lamb, 2001; Sartorius, 1992; Heinessen, Levendusky, & Hunter, 1995). For the most severely mentally ill (expressly, those with multiple co-morbid psychiatric conditions), we need to reevaluate the scientific basis of needs assessment methodologies and therapeutic intervention (Langle, Renner, Gunther, & Buchkremer, 2000). The most pervasive finding in all services evaluation research is that proper engagement of the client and highly individualized treatment plans lead to better outcomes.

This engagement is reflected, to cite a few examples, in the power of individual involvement in the choice of their own residential care facility in influencing positive functioning outcomes (Segal & Aviram, 1978), the importance of patient engagement in psychiatric emergency service (PES) outcomes (Segal, Egley, Watson, & Goldfinger, 1995), and the general role of client involvement in self-help agency decision making (organizational empowerment) in predicting self direction in one's life (personal empowerment) and improved functioning (Segal & Silverman, 2002). In county general hospital psychiatric emergency service (PES) units, research has reported that quality of care was related to patient outcomes. Most notably, appropriate patient engagement was associated with a lower probability of retention and improved functioning at time of PES exit even after controlling for the severity of entry problems (Segal, Egley, Watson, & Goldfinger, 1995). At the same time, there are significant numbers of individuals who do not appreciate the extent or danger of their disability. However, we have a long way to go before we can successfully distinguish such individuals from those who have experienced repeated system failures (i.e., by way of inappropriate, inadequate, and aversive care). Such individuals are frequently unwilling to risk another attempt at system interaction. For example, we know that the attitudes of people toward the mental health system are often shaped during their initial evaluation in psychiatric emergency services, the site where most civil commitments are initiated. A bad initial experience can deter future help seeking as people often avoid treatment for fear of civil commitment (Campbell & Schraiber, 1989). Also, for some patients who have been involuntarily hospitalized, attitudes' toward hospitalization do not become more pos-

itive even after later acknowledging they needed it (Campbell & Schraiber, 1989; Gardner et al., 1999).

The PES under the dangerous standard can be a model of care giving if properly supported (Segal, Lauri, & Segal, 2001). Using coercive detention at other points in the civil commitment process has been less consistent and poorly studied. Further, we have very limited understanding of involuntary outpatient civil commitment (IOPC), i.e., we don't know whether such procedures will enable people with serious mental illness to benefit from available treatment or avoid adverse outcomes over the long-term (Swartz et al., 2000; Steadman et al., 2001; Hoge & Grottle, 2000; Stein & Diamond, 2000; Allen & Smith, 2000). The benefits and costs of IOPC need to be better understood (Draine, 1997).

Objective 3: Develop a full spectrum of State sponsored housing supports including independent living, supported housing, supervised housing and group care facilities for the seriously mentally ill. These facilities need to include true alternatives to hospitalization (as opposed to rented rooms at single room occupancy hotels) as well as permanent supported housing arrangements.

Despite all service efforts, serious mental illness will leave a significant number of individuals in need of long-term supervised residential care. Long-term supervised residential care for the seriously mentally ill leads to reductions in psychiatric symptoms, improved general health, and improved assisted social functioning (i.e., functioning mediated by the efforts of others) (Segal & Kotler, 1993). This is a big positive for those truly unable to meet their own basic needs. Yet, this comes at the cost of reductions in independent social functioning and concomitant increases in institutional and or supported environment dependencies (Segal & Kotler, 1993; Segal & Moyles, 1979). Again, these outcomes should be acceptable for many who cannot make it on their own (i.e., they are a good trade-off given the improvements in quality of life the person accrues). The dependencies and reductions in independent social functioning, however, contribute to increased vulnerabilities to the social context that can be devastating in an unstable policy environment that fails to support necessary housing and comprehensive integrated treatment alternatives. We, therefore, have an increased obligation to those in need of long-term care or supervised residential placement to insure the stability of that placement during their period of need and to provide for transitional supports that enable them to cope with the re-

quirements of independent living for independent functioning ability at the time they are ready for a transition out of a supervised care environment.

Objective 4: Stop using hospital retention as a negative indicator, for many the later is a necessary lifesaver (Munk-Jorgensen, 1999).

There remains an important role for hospital inpatient care, at least in the absence of adequate alternatives (Lamb & Bachrach, 2001; Draine, 1997). Some evidence suggests that severe cognitive impairment in people with schizophrenia, specifically, in executive functioning, effects rehospitalization and time in the hospital (Greene, 1996; Jackson, Fein, Essock, & Mueser, 2001). Follow-up studies have showed that early release from a post psychiatric emergency service (PES) admission contributed to the recycling of patients back for reassessment into the PES (Segal, Watson, & Akutsu, 1998). In sum, some mentally ill persons require hospitalization to meet their mental health needs and this service has to provided for as long as it is deemed appropriate.

Mueser et al. (1998) reviewed studies that have examined the reduction/withdrawal of PACT (or PACT like) services (Stein & Test, 1980; McRae, Higgins, Lycan, & Sherman, 1990; Audini, Marks, Lawrence, Connolly, & Watts, 1994; Salyers et al., 1998; Susser et al., 1997). This team suggests that the results of three (Audini et al., 1994; McRae et al., 1990; Stein & Test, 1980) of five studies indicate that the withdrawal of PACT services for high service users “was associated with erosion of treatment gains, especially time in hospital” (p. 60). Hence, it appears that reductions in hospital utilization outcomes persist as long as they are guaranteed by program effort; however, once eliminated, they leave the individual vulnerable to the same social situation, the same need for care or an adequate alternative. Again, when PACT program efforts are withdrawn, hospital outcomes approach those of pre-PACT status.

Fairweather and colleagues (1969) in their clinical trial on alternatives to hospitalization had results similar to those reported by Mueser et al. (1998). The Fairweather group found that the withdrawal of services at an alternative to hospitalization site led to a return to levels of hospital use among study participants that was similar to that experienced by the group prior to the introduction of the hospitalization alternative. These results are indicators of need: need for PACT type programs, need for other types of viable alternatives to hospitalization, need for better implemented and more diverse and more sensitive forms

of assisted, supervised and involuntary treatment. These types of programs must be expanded and State supported.

Objective 5: Local care is crucial but State responsibility and particularly fiscal responsibility for a full-continuum of care is required. One possibility for achieving this is to re-adopt or reinvigorate the principals established in the New York State Care Act of 1898 that guaranteed specialized state supported care to all the seriously mentally ill.

In California, the destruction of the Bureau of Social Work, a state-wide organization responsible to the total care of the seriously mental ill, was a key factor in the current failure to provide adequate community-based care. This was accomplished as part of a policy process that shifted responsibility for the mentally ill to the counties, and led to the abandonment of State responsibility for all but the seriously mentally ill offender population. The decentralization led to the creation of 58 separate county programs, the limitation of program expertise to within county borders, the implementation of “Greyhound therapy games,” and signaled the State’s abandonment of both medical and fiscal responsibility for the seriously mentally ill.

Serving the seriously mentally ill as part of the homeless services system, a transfer of care resulting in part from the State’s abandonment of the responsibility for residential provision, is unconscionable. It subjects people with serious mental illness to what has become a breeding ground for bio-psycho-social ills. It places them at risk of increased involvement with substance abuse, tuberculosis, AIDS and the criminal justice system (Segal, Silverman, & Gomory, 1998). It becomes an excuse for cheap accommodation and abandonment as is witnessed in the conversion of the Keener Building from a Manhattan State Hospital facility to a City of New York homeless shelter—one housing individuals with similar problems if not the same people.

We know a comprehensive, adequately funded, and integrated system of care works; when this kind of system exists, chronically and severely mentally ill persons experience both higher levels of functioning and quality of life (Lamb, 1998; Lamb & Bachrach, 2001; Smith, Hull, Hedayat-Harris, Ryder, & Berger, 1999). In an environment where fiscal resources for the treatment of persons with seriously mental disabilities are scarce, vigilance is needed to assure that systems of care are funded, not demonstration programs that may disappear.

Dorothea Dix would be appalled at the size of today's prison and jail populations with major mental illnesses. At mid-year 1998, The United States Department of Criminal Justice reported there were 283,000 mentally ill offenders in the nation's prisons and jails, representing 16% of state prison inmates, 7.5% of federal inmates and 16% in local jails (Ditton, 1999). This is more than one half the number in state mental hospitals in 1955 when these facilities reached their post-war population high. Over 150 years ago, Dorothea Dix fought the battle for State responsibility for the care of this population given full awareness of the difficulties involved in providing long-term protected care under the machinations of local financing schemes. While the state mental hospital is not the answer, long-term state managed care for those who require it in a full spectrum of housing environments is one big part of the solution.

POLICY AND PROGRAM CHANGES

The social context of care we have reviewed places the seriously mentally ill in grave danger of both physical and emotional harm and documents a pattern of neglect and exploitation. In view of what we now know about how to best care for this population, action is needed in the following areas:

We need to promote and enhance housing assistance. As we have noted, program efforts without adequate housing are likely to fail. Housing assistance can be promoted by: (a) having HUD issue subsidized mortgage loans for non-profit organizations seeking to open residential care facilities, and (b) expanding Section 8 certificate availability to the mentally ill with additional subsidies available when tied to professionally run patient support systems.

We need to enhance independent social functioning, personal empowerment, and treatment engagement so that people can maximally take responsibility for their own care. This can be achieved by providing funding for psycho-educational, vocational, and self-help programs. Managed care medical necessity criteria need to be expanded to include to maintenance of adequate levels of functioning and quality of life standards.

We need to make better use of the hospital, develop alternatives to hospitalization, and insure consistent long-term fiscal support in a stable policy environment. State responsibility for the long-term support of the mentally ill would help achieve these objectives.

While some (e.g., Torrey, 2002) have suggested that this might occur with the block granting of Federal funds currently expended on mental illness to the States, we believe that this action would simply perpetuate current failed policies. In fact, several states currently operating under managed care directives that cap Medicaid spending are managing their mental health system as one would manage a block grant based system. They pass fixed sums to county governments and delegated responsibility for care. These capped amounts are a de facto elimination of the entitlement aspect of Medicaid. The block grant solution is likely to result in simple pass through of such fixed amounts of money with significant loss of resources to alternative state objectives in a cash poor budget. Alternatives to hospitalization are not being supported now and without fiscal incentives to support them it is unlikely that states would invest in such residential resources. Further, a considerable part of the problem is embedded in SSI and Medicaid/Medicare financing policies that support unidentified mentally ill in the health and welfare system. Funds from those systems supporting such individuals would not be covered in a block grant approach focused solely on funds invested in the mentally ill.

Alternatively we suggest that state responsibility can be restored, the role of the psychiatric hospital reinvigorated, and the development of adequate alternatives to hospitalization promoted through federal funding and state management of the continuum of care for those with serious mental illness. This can be accomplished by extending Medicare/Medicaid coverage to all state psychiatric hospitals, crisis facilities, and other medically supervised halfway houses, residential group homes, and residential care programs. *The elimination of the Medicare/Medicaid IMD exclusion is the vehicle.* Such action would in all likelihood reduce the size of the mentally ill populations in inappropriate unsegregated care placements including nursing homes, homeless shelters, and criminal justice facilities. This would be achieved by eliminating the fiscal incentives imbedded in Medicare/Medicaid to house psychiatric patients in non-psychiatric facilities. It would provide support for care so as to avoid premature release from psychiatric hospitals and by expanding the availability of psychiatric hospital and hospital alternative beds. The latter is likely to enable police to get their charges into care before they end up in prisons and jails. With this policy change, we would create a real continuum of care and incentives to avoid cost overruns of the previous state hospital experience. This would be avoided by the encouragement, through legislation, of emphasis on adequate alternatives to hospitalization.

It is time for our nation to act to stop the abuse and neglect of the seriously mentally ill in our society. We can no longer afford to fail to address the current social context of our nation's public policy in meeting the needs of people with serious mental illnesses and a public sector system in need of basic reform.

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