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Learning From History:
Deinstitutionalization of People with Mental Illness As Precursor to Long-Term Care Reform

Prepared by
Chris Koyanagi
Judge David L. Bazelon Center for Mental Health Law

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THE HENRY J. KAISER FAMILY FOUNDATION

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The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bi-partisan group of national leaders and experts in health care and public policy.

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Executive Summary

The provision of long-term services and support for people who are elderly or have significant disabilities is a major policy focus at federal and state levels. One and a half million individuals on Medicaid are in nursing homes and Medicaid pays almost half of all nursing home costs. Even though they were only seven percent of the Medicaid population, long-term care users accounted for over half of Medicaid spending in 2002 and three quarters of that spending was for their long-term care services.

As policymakers focus on changing the dominant locus of services from nursing homes to home and community, the experience of replacing state and local psychiatric institutions with community alternatives is instructive. While the deinstitutionalization of people with mental illness differs somewhat from reform of policy for long-term services, some parallels and lessons are relevant.

The History of Deinstitutionalization

The history of deinstitutionalization falls into several stages as policies and objectives have changed over time. The early focus was on moving individuals out of state public mental hospitals and from 1955 to 1980, the resident population in those facilities fell from 559,000 to 154,000. Only later was there a focus on improving and expanding the range of services and supports for those now in the community, in recognition that medical treatment was insufficient to ensure community tenure. In the 1990's whole institutions began to close in significant numbers and there was a greater emphasis on rights that secured community integration – such as access to housing and jobs.

In the initial stages, states funded small community pilot programs for individuals who responded well to antipsychotic medications that were then becoming available. The national deinstitutionalization movement was launched in 1965 through the community mental health centers program. The movement was further fueled by concerns over civil rights and the conditions in institutions. That led to the courts limiting involuntary institutionalization and setting minimum standards for care in institutions.

Federal policy significantly influenced states to shift between institutional sites of care. The CMHC program was expanded over the 1970's. Medicaid and Medicare covered a broad range of mental health services while SSI and SSDI provided income support. In response to the incentive provided by federal Medicaid reimbursement, community based general hospital psychiatric beds grew rapidly, and states moved individuals to nursing homes to capture Medicaid reimbursement that was not available to state mental hospitals.

However, overall progress was extremely slow and resources for community care were a major issue. Not until 1993 were more state-controlled mental health dollars allocated to community care than to the state institutions. In addition, while promising models of community care were

tried, they were rarely fully evaluated and even more rarely incorporated into standard practice. As new technologies came online they were often provided only through temporary pilot programs or in insufficient capacity; old approaches were not replaced but continued to eat up resources.

Assessing the Reform Represented by Deinstitutionalization

The history of deinstitutionalization began with high hopes and by 2000, our understanding of how to do it had solidified. But it was too late for many. Looking back it is possible to see the mistakes, and a primary problem was that mental health policymakers overlooked the difficulty of finding resources to meet the needs of a marginalized group of people living in scattered sites in the community. Multiple funding streams were uncoordinated. Even when needs were eventually recognized it was difficult to braid together a comprehensive service package.

Policy in large federal programs was not controlled by those responsible for mental health care, and often those programs were driven by other priorities. As a consequence, although housing, disability, education and employment programs are critical, they often fail to facilitate appropriate access by individuals with mental illness. Cost-neutrality has become the overriding rule. This way of thinking engenders a focus on minimal responses instead of a search for excellence.

What Might This Mean for Long-Term Care Policy?

Policy for long term services and supports may face similar issues to those that mental health policy makers have struggled with over the past fifty years.

Service Planning

Changing the locus of care is only the first step. There is now greater awareness in the field of long-term services than there was decades ago in mental health of the range of supports required for community membership. These include the right to choose and self-direct and ensuring that resource issues do not lead to de-emphasizing quality-of-life services, such as psychosocial services and community activities, including recreation.

National policy on long-term services and supports encompasses more than can be delegated to one or two programs, such as Medicare and Medicaid. It ideally reflects a government-wide objective that aligns various programs to provide high quality, coordinated care. This alignment could foster a concerted evaluation and quality-improvement initiative at the outset, guided by past experience and leading to more thoughtful implementation of long-term services policy from the start. As technology improves for meeting the needs of those who are harder to serve, providers must re-orient their practice and pilot approaches must come to scale.

Resource Issues

Resources need to be managed in a concerted manner across federal, state and local governments, and an appropriate role for the private sector should be integrated with those policies. The full implications of changes in financing also need to be assessed and unanticipated responses should be assessed promptly when they occur. A dearth of community resources will mean it may be necessary to retain institutional beds initially until community care is expanded. This means savings may not accrue immediately, until those beds and entire institutions can be closed.

Living Situations and the Role of Families

Many people with serious mental illness were moved from mental institutions to other institutional settings: nursing homes, single-room occupancy buildings, board-and-care homes. Others went to live with families who were ill-equipped and poorly supported to meet their needs. Focusing on where people will live and how to support them is an important part of long-term services policy. The burden on families—whether their relatives live with them or not—must not be overlooked. Training and support programs have proven very effective in mental health.

Workforce Issues

Reductions in state hospital beds were bitterly opposed by unions and communities where the hospitals were often the dominant employer. This meant that institutions did not close and so the cost of running the hospitals did not fall very much. The process was best facilitated with retraining the workforce. Shifting workers with the aptitude from long-term care institutions into community alternatives could be a potentially useful approach.

The Political Landscape

There is growing recognition among policymakers of the building demographic pressure on long-term care services provision. However, political will to address current and potential issues needs to be sustained, even in the face of inevitable setbacks. Timing of initiatives is critical. Additionally, building in a significant consumer role in policymaking, monitoring and evaluation has proved valuable in mental health policy advocacy.

Conclusion

Complicated social problems such as the provision of long-term services require solutions with depth and breadth of understanding as well as changes in prevailing attitudes and systems. Unfortunately, deinstitutionalization and many other reforms are often too quickly followed by backsliding and public indifference, leading to a wide discrepancy between expectations and achievements. To ensure that this doesn't happen in the field of long-term services and supports, it is crucial that the lessons of the past be heeded.

Introduction

The provision of long-term services and supports for people who are elderly or have significant disabilities is a major policy focus at federal and state levels. One and a half million individuals on Medicaid are in nursing homes and Medicaid pays almost half of all nursing home costs.[1] Even though they were only seven percent of the Medicaid population, long-term care users accounted for over half of Medicaid spending in 2002 and three quarters of that spending was for their long-term care services.[2] Traditionally, the elderly have relied heavily on institutional care. While people under age 65 may also be institutionalized, they are more likely to use community-based services, although waiting lists for those services remain very long.

As policymakers focus on changing the dominant locus of services from nursing homes to home and community, the experience of replacing state and local psychiatric institutions with community alternatives may be instructive. The closing of state psychiatric hospitals and the development of a full range of community services to replace their functions has been the policy goal in mental health for 50 years. While deinstitutionalization of people with mental illness differs somewhat from reform of policy for long-term services, some parallels and lessons may be relevant. The purpose of this issue brief is to highlight these parallels and discuss their implications for those developing policy on long-term services and supports in the early 21st century.

The History of Deinstitutionalization

The history of deinstitutionalization is not linear; it falls into several stages as policies and objectives changed over time. The reduction in the number of people institutionalized began in 1956, when public hospitals housed 559,000 individuals. A substantial majority were on the back wards, usually for years—a parallel with nursing homes today. (Back wards of state hospitals were for those not expected to recover where custodial care, but no treatment, was provided. Over the next 25 years, the resident population dropped by nearly three-quarters, falling to 154,000 individuals in 1980. The 25 years after that saw the actual closing of institutions and significant changes in community services and supports.

The First Stage: Shifting the Locus of Care

Initially, states created small community programs and discharged individuals who responded well to the recently discovered antipsychotic medications. Governors and state legislatures were strongly motivated by cost concerns. State hospitals (despite appalling conditions) required a 300-percent increase in spending over a 10-year period, and were a substantial drain on state budgets.[3] Yet deinstitutionalization initially progressed very slowly (by 1962 the resident population in institutions had fallen only to 505,000). It only accelerated into a full-scale, nationwide policy in the late 1960s and 1970s, when the federal government became involved.

The national deinstitutionalization movement was launched through publication of a report by the Joint Commission on Mental Health, created by federal law to report to Congress. The Commission report, entitled *Action for Mental Health,* called for a national program and policies to treat people with mental illness in community-based clinics. The goal was for clinic care to furnish prevention and early intervention services in order to reduce mental disability in the future and to promote mental health. A further goal was to vastly improve hospitals for those disabled by mental illness.[4] To meet these goals, the Commission called for spending on mental health to double in five years, and triple in ten. It also called for increases in training to ensure availability of the necessary workforce to serve this population.

The federal response was swift, but did not fully follow the Joint Commission recommendations. In 1963, President John F. Kennedy sent a special message to Congress calling to replace institutions with comprehensive community programs to provide outpatient care, day treatment, rehabilitation, foster-home services and public education on mental health. Funding would flow to communities—to hospitals or nonprofit community agencies—and not to the states, which would remain responsible for long-term institutional services. Eventually, it was hoped, state hospitals would be replaced by the community programs.[5] As did the Joint Commission, Kennedy called for a tripling of funds to meet the goals he outlined.

The first federal program authorized in response to this call provided funds for the construction of facilities to serve as community mental health centers (CMHCs).[6] In 1965, a second federal law provided funds to staff the centers.[7] Eventually, the law was amended to extend the period of federal support to eight years and beyond. In addition, states funded similar community mental health programs.

The federal CMHCs were required, through regulation, to provide five essential services: inpatient, outpatient, emergency, partial hospitalization (day or night), and consultation and education on mental health. A second list of services was recommended, but not required: pre-admission screening, post-discharge services and rehabilitation for individuals with serious mental illnesses. Some of the centers provided these additional services; others did not.

Legal issues also accelerated deinstitutionalization, as concerns over individuals' civil rights and the conditions in institutions led courts to hand down rulings that both limited when individuals could be institutionalized against their will and set minimum requirements for their care and treatment when they were admitted. These judicial orders put constraints on the use of institutions and emphasized that care must be furnished in the least restrictive setting.[8]

These first steps in deinstitutionalization are instructive. A commission of experts from the field outlined a comprehensive approach, with a major focus on individuals who were at risk of institutionalization. By the time federal rules had been written, the emphasis had switched to treating all forms of mental disorder and to prevention, with little focus on the unique services needed by those who might be at risk of institutionalization. With experience, this loss of focus and lack of priority for community services might have been overcome, but there were no instruments in place to measure the changes and the effectiveness of community services.[9] Blunt

indicators, such as recidivism rates to hospital care, became the measure of impact—but this ignored other outcomes, including placement in other institutions.

The year 1965 also brought another important source of federal funding for community mental health services, although it was unrecognized at the time. Medicaid and Medicare were created with coverage for a range of services including components of the mental health continuum. These funding streams were to have unanticipated results.

Medicaid coverage of general hospital psychiatric services, coupled with an exclusion of coverage for individuals in "institutions for mental diseases" (such as state hospitals), led to the addition of a significant number of acute care beds in the community for psychiatric patients. General hospitals more than doubled their psychiatric patient-care episodes from 1955 to 1977, as state hospital use declined by 30 percent over the same time.[10] This was a very positive trend, as general hospital treatment was short-term and active and the hospitals were generally located closer to the individual's home and follow-up outpatient services.

Medicaid coverage of nursing homes had a less positive effect. It led many states to move state hospital patients into these settings. While in the 1970s, nursing homes were seen as more normalized and humane than state hospitals, as well as less costly for the state due to the federal match, the move has since been recognized as transinstitutionalization. By 1977, this shift cost Medicaid $2 billion, and by 1980, 750,000 people with serious mental illness lived in nursing homes, representing 44 percent of the nursing home population.[11]

In 1972, another major step supporting deinstitutionalization was taken with enactment of the Supplemental Security Income (SSI) disability benefits program, for which people with disabling mental illnesses are eligible. Both SSI and the Social Security Disability Insurance (SSDI) program underwrote living costs for many people discharged from state institutions.

Federal policy thus contributed significantly to the ability to shift the locus of care for people with serious mental illnesses. These policy changes were both intentional (but categorical and small), and serendipitous (large entitlements, such as Medicaid and SSI). Over the 1970s, there were no dramatic changes to this policy, although the CMHCs' role was expanded in response to perceived needs, particularly with respect to the services needed by those with more serious illnesses. For example, preadmission screening, follow-up and services to transition to community were finally added in 1975.[12]

If measured by reductions in state hospital placements, deinstitutionalization could be considered a significant success. By 1977, there were 650 community mental health centers covering 43 percent of the population and serving 1.9 million individuals a year. In 1955, three quarters of episodes had been inpatient (primarily in state hospitals), but by 1977 inpatient episodes represented only 7 percent of all episodes of care.[13] Not only had the resident population fallen; lengths of stay had dropped dramatically as the institutions focused more on short-term acute care (average lengths of stay in 1980 were 23 days compared with six months in 1954).[14]

Significant Problems Emerge

However, these data hid some major problems. Community mental health centers now suffered under more rules, as gaps in their services were identified and new mandates added as a result. They also received less money (inflation adjusted) as the federal government retrenched on domestic spending over the 1970s.[15] At one point, the Nixon Administration recommended that the program be phased out entirely.

Lack of critical review hurt the program. Promising models and new interventions in community care were tried, but were rarely fully evaluated and even more rarely incorporated into standard practice. In addition, too few centers were created—fewer than half of those initially planned. Later, as new technologies came online they were often provided only through pilot programs or at insufficient capacity, and old approaches were not replaced but continued to consume resources.

A Second Stage: Community Supports

There were also clear signs that many people who, in a previous era, would have been state hospital residents were not receiving adequate care. In recognition of this, the National Institute of Mental Health in 1975 created a small federal program—the Community Support Program (CSP)—to provide grants to state mental health authorities for planning a comprehensive range of mental health services and other supports to help adults with serious mental illnesses live successfully in the community. For the first time, policymakers recognized that changing the locus of care was a necessary but insufficient step in successful deinstitutionalization.

CSP stressed that, in addition to clinical treatment, a host of other issues had to be addressed for people transitioning to community living: housing, income support, medical care, employment, basic living supports (such as food stamps), employment, transportation and education. Funding for CSP was extremely modest—$6 million a year from 1980-1983 increasing to $19 million in 1988—but it had a major impact in changing state policies. CSP grants to states were able to re-orient state systems in a way the community mental health centers program had never done.

These issues led to plans for major change. President Carter established the President's Commission on Mental Health, which called for a new national priority for adults and children with serious mental disorders and recommended an orderly phase-down of state hospitals through performance contracts that would integrate federal and state funding. Congress responded by enacting the Mental Health Systems Act, with numerous changes to the federal CMHC program, including, importantly, a shift in emphasis to increase the priority of this population and to expand services beyond clinical care alone.

In addition to the Commission report, the Department of Health, Education and Welfare produced a blueprint for further policy change in the most significant federal human services

programs (Medicaid, Medicare and SSI) to better support individuals with mental illness in the community.[16] With the CSP program reorienting state planning, and plans to make changes to the major federal programs to reinforce those efforts, deinstitutionalization policy entered a new stage, focused on successful integration of people with mental illnesses into their communities.

Once again the experts had spoken, but again their recommendations were derailed. In 1981, shifts in political thinking toward a smaller role for government changed the focus of mental health policy still further, and moved lead responsibility firmly back on the states. The Mental Health Systems Act was repealed and funds for community mental health shifted into a block grant to states. Federal funding was also cut by 25 percent.

A further crisis was caused in the early 1980s by the Reagan Administration's policies to reduce other federal human service program costs. A policy of accelerated reviews of individuals on the federal disability rolls left hundreds of thousands of people with mental illnesses without income as it exposed the inappropriateness of federal rules for assessing disability for this population.

The Administration also slashed federal support of public housing. As low-income housing became less available, and income support evaporated almost overnight, a significant number of people with serious mental illnesses were left on the streets, representing at least a quarter of homeless individuals. With no money, nowhere to live and an underfunded mental health service system, many were in dire straits.

Ultimately, with intervention by Congress and the Supreme Court, the SSI/SSDI rules were substantially revised, enabling many individuals to regain these benefits. This crisis also alerted states to the importance of SSI in supporting people with serious mental illnesses in the community, and many began programs to help their clients apply for benefits.

Although deinstitutionalization policy had been blown about by the political winds, state and federal governments made important strides in the 1980s. First, there were significant improvements in understanding the service needs of people with serious mental illnesses and adjusting state policy to meet those needs. In the mid-1980s, states discovered that, through the Rehabilitation Service category of Medicaid, reimbursement could be claimed for a range of services that improved the functioning of people with serious mental illnesses.

At the federal level, important recommendations in the National Plan began to take effect through changes to Medicaid and Medicare that were buried in omnibus budget reconciliation bills. A new Medicaid service of targeted case management specifically allowed states to target individuals with a "chronic mental illness." Medicare was amended to equalize the co-payment for medication management services. And amendments to SSI bridged a serious gap by continuing benefits for people who were temporarily hospitalized and creating a pre-release program enabling others to apply for reinstatement prior to discharge.[17]

During the 1990s, the first objective of deinstitutionalization policy was finally realized as state hospitals began to close. The number of such hospitals, which had remained more or less

constant for 35 years (at roughly 300), dropped by over 40 in the 1990s.[18] This decade also saw accelerated advances in the scientific knowledge base on treatment and services. By 1999, the Surgeon General was able to issue a Report on Mental Health stating that the efficacy of mental health treatment is well-documented, with a range of treatments from which people may choose.[19]

In addition to improved service responses, the legal rights of people with mental illnesses now living in the community were expanded by enactment of the Americans with Disabilities Act in 1990 and, in 1988, amendments to the Fair Housing Act extended its protections to people with disabilities.[20] Medicaid also brought with it an additional set of rights to benefits.

Third Stage: Rights and Recovery

By 1993, states reached a significant milestone. Finally, 40 years after deinstitutionalization began, more state-controlled mental health dollars were allocated to community care than to the institutions.[21] The federal government also contributed significantly to community care, but not through a mental health funding stream. Instead, Medicaid became the single most significant source of support for public mental health systems.[22]

A further shift in thinking also occurred as individuals with serious mental illness began to organize and more effectively speak for themselves. A new philosophy of recovery arose, defined not as total remission of symptoms or cure, but rather as living a normal life despite having a serious mental illness. With such goals, the aspirations of consumers of mental health services fully aligned with those of people with other disabilities. Recovery challenges mental health systems to reform still further, as articulated by the President's New Freedom Commission on Mental Health, which has called for transformation to a recovery-oriented system.

History of Deinstitutionalization

1961	Joint Commission report *Action for Mental Health*
1963	John F. Kennedy's Message to Congress
1963	Mental Retardation Facilities and Community Mental Health Center Construction Act enacted
1965	Community Mental Health Centers Construction Amendments authorizing staffing funds for CMHCs
1965	Medicaid and Medicare enacted
1971	Wyatt v. Stickney case decided regarding obligations for treatment of those involuntarily hospitalized
1972	Supplemental Security Income program enacted
1977	Commission on Mental Health established by President Jimmy Carter
1975	Community Support Program established by the National Institute for Mental Health
1980	Mental Health Systems Act enacted
1980	Publication of National Plan for the Chronically Mentally Ill by HHS
1981	Mental Health Systems Act repealed and community mental health centers program replaced by block grant
	Supreme Court rules SSI/SSDI benefit rules must be revised
1988	Fair Housing Act amended to include persons with disabilities
1990	Americans with Disabilities Act enacted
1999	Surgeon General's Report on Mental Health
2003	President's New Freedom Commission on Mental Health Report

Assessing the Reform Represented by Deinstitutionalization

The history of deinstitutionalization began with high hopes that modern medications and modern treatments could assure people with serious mental illness a successful life in the community. By 2000, our understanding of how to do that had solidified, but it was too late for many. Times had changed. Resources had not flowed as expected. The array of programs that support people with mental illness in the community were not controlled by policymakers who fully understood mental health. Even the programs funding treatment and rehabilitation, Medicaid and Medicare, did not reflect a scientific understanding of what was needed. Housing, disability, education and employment programs were now perceived as critical, but they often were inadequately accessed by individuals with mental illness. As communities became less tolerant of the use of alcohol and drugs, people with serious mental illness who had co-occurring substance abuse issues were arrested in ever-increasing numbers.

Shakespeare tells us there is a tide in the affairs of men which, taken at the flood, leads on to fortune. Unfortunately, deinstitutionalization missed the flood. By the time the necessary knowledge existed, political will had faded. The optimism of the 1960s regarding government's

ability to solve major social woes was gone. The memory of the snake-pit institutions had faded. The policy picture had become more complex than expected. Even as the great majority of people with serious mental illness succeeded in living successful, if not rich, lives in the community, a highly visible small percentage of them continued to struggle. Many more were in other institutions, such as nursing homes, jails and prisons.

What could have been done differently? And what does this experience tell us about movements to shift policy from long-term care institutions to alternative community settings?

Mistakes in Deinstitutionalization Policy

No policy exists in a vacuum, and various actors responded at different times to the opportunities they saw in deinstitutionalization policy. These changes were generally not anticipated, and did not always accrue to the benefit of individuals with mental illness. Many remain unresolved today.

- Living situations: instead of living in institutions, people with serious mental illness were moved to nursing homes, single-room occupancy buildings, board-and-care homes or with families who were ill-equipped and poorly supported to meet their needs.

- Essential services: the array of supports that people with serious mental illness need to live independent and successful lives in the community were not appreciated and therefore not provided.

- There was insufficient connection between state policy for institutions and federal policy for community care. At the outset, CMHCs were not even required to provide preadmission screening and follow-up care. Many people fell through the cracks.

- Mental health systems continued to cling to blunt measures of success, such as bed days, instead of quality of life in the community.

- Resources were never sufficient for the need:

    - State funds that would have been spent on state institutions were not reinvested in community programs. (State spending on mental health, adjusted for inflation and population growth, was 30 percent less in 1997 than in 1955.)[23]

    - Federal funds for the community mental health centers program did not come close to approaching the early promises or projections of need.

    - Third-party health insurance policies and public programs, such as Medicare, provided limited coverage for the treatment of mental illness,

with arbitrary limits and/or high co-payments that did not meet the needs of people with serious mental disorders.

- Multiple funding streams were uncoordinated. Even when needs were eventually recognized it was difficult to braid together a comprehensive service package.

- Reductions in state hospital beds were strongly opposed by unions representing state hospital workers and by communities where the hospitals were a large and often dominant employer.

- While beds were reduced, institutions did not close and so the costs of running the hospitals did not fall very much.

- Discrimination in housing—the not in my backyard (NIMBY) syndrome—in employment, and in the community at-large worked against the goals of community mental health.

Moreover, the funding streams for support services, such as SSI and public housing, are means-tested programs that provide minimal support. People with serious mental illness remained extremely poor, which created further obstacles to meeting their needs and also left them living in economically depressed and crime-riddled areas. Individuals with serious mental illnesses who had never been institutionalized presented a new and disturbing problem. Many became involved with drugs and alcohol, leading to arrest and difficulty in providing successful treatment.

According to federal policy experts, these problems led to a grievous muddle of cause and effect and abandonment of responsibility on all sides.[24] Deinstitutionalization was more complex and more costly to implement than its proponents had claimed, and certainly more complex and costly than states or the federal government ever anticipated. In 1988, a former state mental health commissioner called the system "fragmented, uncoordinated and disorganized" and reported that a great deal of federal, state and local money was spent poorly and often in the wrong places.[25]

In one sense, the first stage of deinstitutionalization is now a complete success: very few people live in mental institutions. Yet today's mental health system is a picture of broken promises and partially fulfilled dreams. State and local policymakers have grand plans that, if implemented, might radically alter the experiences of people with serious mental illness. But instead we see too little funding, an overburdened workforce, overwhelmed families, very poor, often marginalized consumers, and a system under siege.

The Impact of Deinstitutionalization

Deinstitutionalization policy had an impact on many of the same players who will be affected by a shift in policy for long-term services and supports to emphasize community care: the affected individuals, their families and providers, and society at large.

Clearly, deinstitutionalization policy has been a success for most people who might in other times be in a public psychiatric hospital. But for many it has fallen short of providing the services necessary to move toward recovery and have a desirable quality of life. For a small minority (about 1% of those with serious mental illness, or 136,000 people in 2000)[26] now incarcerated in jail and prison, the situation is particularly bad and a great many individuals with serious mental illness who are still in nursing homes could be in the community.

Families immediately felt the impact of deinstitutionalization policy as they became the first line of defense for people with serious mental illness in the community. Two-thirds of people discharged from institutions returned home.[27] Even those who did not live with their families depended on them for other needs and social contact. Specific services to help families understand the needs of their loved ones and how to meet them have now emerged and family psychoeducation is now recognized as an evidence-based practice in community mental health. However, no such service existed in the 1970s and 1980s.

The establishment of CMHCs led to shifts in workforce and in the roles of various professionals. The expanded need for professionals, with too few psychiatrists to staff the centers, led to increased demand for clinical psychologists and social workers, and later for para-professional workers as well. Care increasingly shifted to non-medical providers. Turf wars emerged that were not helpful to the field. Caseloads also became extraordinarily high and providers found it easier to treat patients with mild or moderate mental disorders who were more amenable to treatment.

Providers outside mental health also benefited from deinstitutionalization, particularly general hospitals and nursing homes. These institutions initially took advantage of the opportunity to provide alternative services. However, this shifted decision-making to institutions with a broader health mission and away from mental health policymakers. Acting again out of self-interest, today many general hospitals are disinvesting in psychiatric beds as they respond to changes in reimbursement policies, causing ripples across community mental health systems.

Policymakers had intended deinstitutionalization to benefit taxpayers by reducing costs. There is no doubt that closing institutions has saved significant resources (although merely closing down beds has not). But while the issue of whether community care is less expensive than institutional care has been researched many times, results are mixed. Some studies find savings, others find approximately equal costs, depending upon the services used. Moving people into the community can also shift costs to other budgets (including corrections), but may not always benefit taxpayers overall.

Fifty years ago, isolating people in large institutions hidden from public view marginalized them and facilitated turning a blind eye to their needs. Now, society at-large faces some of the consequences of deinstitutionalization's failures as people with mental illness have become visible on the streets. Yet, more positively, integration of people with mental illnesses into society has lessened stigma and increased understanding.

What Might This Mean for Long-Term Care Policy?

Deinstitutionalization as a policy goal can clearly be seen today as correct. It was inconceivable to continue the status quo in the 1960s, both morally and economically. But could things have been different; could the unhappy outcomes for those who have not been well served by this policy have been either anticipated or dealt with more quickly? What does this tell us for policy on long-term services and supports today?

There is widespread recognition that policy on long-term services and supports must accelerate its focus on community alternatives to institutions. As in the early days of deinstitutionalization, there is momentum for policies to make community care more the norm. For younger people with disabilities, much has already been done to improve the technologies of community-based care and address these individuals' wide range of needs. However, those with more complicated disabilities, including co-occurring problems, often remain in institutions. In addition, there is a serious shortage of community services.

Service Planning

Deinstitutionalization began with innovative pilot programs run by states concerned with the escalating costs of institutional care, encouraged by the promise of new treatments and compelled by the vision that community care was more humane. Then, concerned that moving slowly would mean not really moving at all, reformers pushed for dramatic change on a national scale. Policymakers believed that the forces supporting institutional care were powerful and entrenched, and that only by moving swiftly and fully would it be possible to change the dynamics.[28]

Similarly, many forces favor the status quo in long-term services policy today and can delay or derail a meaningful shift to community alternatives. Comprehensive, nationwide policy may be needed to overcome this inertia.

Federal and state governments face rising costs as the population ages and the need for institutional care increases. Today's reimbursement policies generally encourage institutional care and community alternatives, while highly promising, remain too few and far between. Further, many older individuals in need of supports have longstanding community connections and will have high expectations of care, which may make community services for this group a more challenging and expensive option.

Several major mental health policy reports made recommendations for comprehensive approaches, but these have not always been followed. Piecemeal implementation has been, at best, flawed. There have been several reports on long-term services policy over the years that also suggest comprehensive, thoughtful approaches from experts in the field. Such reports can inform future policy changes.

It may be necessary initially to retain institutional beds while expanding community care. Individuals cannot be moved until the necessary services can be furnished. Not until there is a critical mass of community services, permitting the significant downsizing or closure of entire institutions, will there be substantial savings.

Changing the locus of care is only the first step. Initial planning for community mental health care failed to ensure that, as deinstitutionalization severed care and treatment, CMHCs provided the critical services focused on the difficult issues of transition and continuity of care. Full understanding of a meaningful quality of life for people with mental illnesses (i.e., recovery) did not emerge for 40 years, and recognition that services must be relevant to the individual also lagged. While there is greater awareness of the array of supports needed for those now in long-term care institutions and of their right to choose and self-direct, resource issues may well lead to de-emphasizing quality-of-life services, particularly psychosocial services and recreation.

As community care expands, new issues may emerge. Pre-planning of critical evaluations and adjustments is key. A concerted evaluation and quality-improvement initiative at the outset could lead to more thoughtful implementation of long-term services policy from the start, in part because experience has shown us the potentials and the barriers.

On the one hand, unlike the disenfranchised mental health population, a substantial proportion of people in need of long-term services reflect the social "mainstream." However, within this population are many who have significant living problems, as well as individuals who are extremely poor and have no family, or families who, for whatever reason, are unable to play a significant role in supporting them in the community. In other words, there may be a population requiring more intensive assistance, different policies and more generous support who will otherwise struggle in the community. This is similar to the issue that arose during deinstitutionalization for individuals with the most serious mental illness. Programming to meet their needs should not be delayed again for a decade or longer.

As technology improves for meeting the needs of those who are harder to serve, providers must re-orient their practice and pilot approaches must come to scale. Both of these changes have been difficult in mental health, as old approaches continue far beyond their usefulness. In addition, some providers avoid consumers with more complex problems, particularly in a world of finite resources and great demand.

Financing Strategies

Policymakers in mental health overlooked the difficulty of finding resources to meet the needs of a marginalized group of people living in scattered sites in the community. People with serious mental illness were transferred from inadequate institutions to inadequate community systems. Even after this population was given priority, necessary resources did not flow to them. It will be important for community long-term services to be funded comprehensively and adequately over a sustained period of time.

Both mental institutions and long-term care facilities have built strong support among state legislatures and state executives, investing considerable resources in the process. Diffused community services have not generated the same level of support. It may not be easy to obtain the appropriate level of funding for a range of community supports, and particularly to shift quickly to a situation with fewer institutions.

Mental health policymakers at all levels assumed that community care would be cheaper. As the full range of needs of people living in the community became better understood, it was clear this was not always the case. However, mental health policy has become mired in arguments over whether every new community innovation is not only better, but less expensive than hospital care. Cost-neutrality has been made the rule. This way of thinking engenders a focus on minimal responses instead of a search for excellence. It also uses a standard of dubious meaning, since services have long ago shifted from that institutional hub.

Resources need to be managed in a concerted manner across federal, state and local governments, and an appropriate role for the private sector should be integrated with those policies. Early planners avoided linking CMHCs to state systems because this might slow the development of community-based care. This may initially have been correct, given the states' track record. But at some point before 1980, it might have been helpful to bring the states more closely into alignment with the federal program in order to focus on shifting resources from the institutional budget to the community. By 1980, much of those resources had gone elsewhere—into roads and other community services. Capturing the long-term services resources now spent on institutional care by all levels of government might provide sufficient resources for community services.

Policymakers must consider the full implications of changes in financing. It is important to anticipate, to the degree possible, the fiscal incentives being created and to plan around them. Unanticipated responses should also be assessed promptly when they occur. The early mental health planners did not anticipate transinstitutionalization into nursing homes or the expansion of general hospital psychiatric beds. What perverse incentives might be created in funding community long-term services and supports a certain way?

The recognition in the 1980s that social welfare policies were critical to the success of community placements should have led to changes to make those systems more conducive to meeting the needs of people with mental illnesses. SSI, SDDI and Medicaid and Medicare are

critical underpinnings for this population in the community. The agencies running these programs, however, do not have the specialized expertise that mental health agencies do and at times federal policy in these programs has worked against successful community living for people with mental illness. Further, it took decades before mental health policymakers in states and communities even appreciated how to access these programs (flawed as they are) to fund the array of services and supports people need.

National policy on long-term services and supports should not be limited to one or two programs, such as Medicare and Medicaid, but would be better approached as a government-wide objective. Many federal programs will be critical to community tenure for the population needing long-term services: disability programs, food stamps, housing, transportation and socialization programs, as well as Medicaid and Medicare. Rules in these various programs need to work in concert to support people in their community-living situations (for example, income and resource levels for benefits are not the same in all programs, leading to piecemeal support for needy individuals). It might be advisable to evaluate these various programs to assess their effectiveness in supporting individuals in the community and to then make the necessary changes to them (for example, rules regarding where services can be delivered and reimbursed, such as in the client's home).

Many other funding streams—federal, state and local—may also prove helpful. Braiding these funds into a single plan of care for an individual requires careful interagency planning. In mental health, this has been achieved more successfully for children's services than adults. In children's systems of care, the service team can be free from funding considerations and allow need to drive the plan of care. At the administrative level, services are then matched with funding sources and the necessary billing and accounting occurs.

Living Situations and the Role of Families

Focusing on where people will live and how to support them is an important part of long-term services policy. Those who have not been institutionalized may require a range of services to maintain their current situations. Those being moved out of institutions should be placed in as normal a setting as possible. Replacing nursing homes with other, albeit smaller, institutions (such as group homes) would be a repetition of policies that have proven misguided in mental health.

The assumption that families could pick up the slack in terms of housing and social supports for people with serious mental illness, and do so with little help, was a major mistake. Moving into the vacuum, a new industry sprang up of board-and-care homes, adult foster homes and halfway houses. It was not until several decades later that the mental health field adopted the concept that a person with a mental illness should live in a normal setting, such as an independent apartment. By the time this occurred, group homes, board-and-care and other placements had built strong support among policymakers. It will be a slow process to replace them.

Consideration also should be given to where else people who need long-term services and supports might end up. Will there be an increase in homelessness? Incarceration? Use of emergency rooms and hospital care? Will there be expanded need for day care centers? Will those centers have the best array of services? What role can assisted living facilities play in the new community-based policies?

The burden on families—whether their relatives live with them or not—must not be overlooked. Caring for frail elderly people with physical impairments or younger people with significant disabilities is a significant task. When the individual also has a mental impairment (dementia, depression, etc.) it becomes even harder. Policies might be needed to support families as caregivers. Some policies might take advantage of whatever level of support a family is able to give—for example, allowing families to provide financial support to their loved ones (which would require changing the SSI rules to permit such gifts).

Still unaddressed are problems of poverty. SSI condemns recipients to live with incomes at about 75 percent of the federal poverty level. As a result, in 2004, they would have needed 110 percent of their entire monthly income to rent a modest one-bedroom unit.[29] Many individuals now in nursing homes have depleted their resources and will be left with SSI or similarly low incomes. Many elderly individuals living in the community will be in similar situations. Addressing the problems of abject poverty will take a comprehensive effort.

Workforce Issues

If a significant shift is made from long-term care institutions to community care, institutional workers will be at risk of losing jobs. After many contentious years, unions representing workers in state psychiatric institutions won recognition that workers needed retraining in order to move into community programs. There will be a need for a well-trained workforce for community long-term services. Shifting workers with the aptitude from long-term care institutions into community alternatives should not be overlooked as a potentially useful approach to meeting workforce needs for home- and community-based care and minimizing opposition to this significant policy shift.

In mental health, the expanded scientific knowledge base that has emerged over the last decade or two has not been effectively used. Services as furnished are too often not evidence-based or best practice. Networks of entrenched public-sector providers have not sufficiently changed their mode of care. Often, as a new evidence-based service is tested and brought online, it is layered upon, and exists side-by-side with, older services. Competition for funding results and new modes of intervention are very hard to bring to scale. While the Surgeon General's report pointed out that we know what to do, we rarely do it.

All areas of human services can improve as our understanding expands. Maintaining flexibility to adjust to new knowledge is critical. However, entrenched interests and providers trained and comfortable with the old way of doing business can undermine progress. This will be a challenge for long-term services policies in the future as technologies continue to evolve rapidly.

The Political Landscape: Issues for Advocates of Change

Policymakers respond to crises and to concepts that seem inherently correct. Currently, there is recognition of the coming pressure from demographics on policy for long-term services and supports and their cost. This impending crisis may create the necessary political will to begin the shift towards community care. But can that political will be sustained, particularly if there are some highly visible failures? Mental health advocates soon learned that it is also more difficult to generate political support for a diverse array of community services than for institutions. Those seeking changes must also expect some unanticipated consequences from the policies that are put in place. Political will also needs to be sustained, even in the face of inevitable setbacks.

This suggests a need for a concerted and substantial public and policymaker education effort. The public will need ongoing information on the purpose and goals of any new initiative. Many policy experiences, including deinstitutionalization, demonstrate that there are often too many opportunities for original intent to be misunderstood, lost sight of or disregarded.

Timing is critical. In mental health, for example, repeal of the Mental Health Systems Act in 1981 was probably the biggest policy mistake of all. By then, the flaws of the early policy were well understood. The Systems Act would have provided the resources behind many of the themes of the very successful (but tiny) CSP program that would have yielded significant changes to services in the states. But the Systems Act arrived at the wrong moment in history. There is more opportunity for dramatic change early on, while the new vision is fresher and more acceptable and seen as a high priority.

Administrations come and go at all levels of government and priorities can change within administrations as well. This makes it hard to ensure sustained commitment. Changing gears, reducing funding or simple neglect could undermine policy for long-term services and supports in the future. Public support is perhaps the best hedge against these swings in policy, but to inform the public and policymakers, continued evaluations, research and policy advocacy will be essential.

Building in a significant consumer role in policymaking, monitoring and evaluation has proved valuable in mental health. Consumers are very effective advocates. Long-term care policy should also be informed by those most affected by it, both recipients of services and their families.

Conclusion

Forty years ago, the mental health field did not have the tools for successful community care. There was an evident need for more effective mental health treatment, improvements in the social welfare system and provision of community support.[30] But those in the field were quite unaware of this. It would not be surprising if the field of long-term care still has much to learn.

It is not the purpose of this paper to lay out a suggested policy for long-term services and supports, but it is important for policymakers to learn from the experience in mental health. Complicated social problems such as these require solutions with depth and breadth of understanding as well as changes in prevailing attitudes and systems. Unfortunately, deinstitutionalization and many other reforms are often too quickly followed by backsliding and public indifference, leading to a wide discrepancy between expectations and achievements.

As in the case of deinstitutionalization, long-term care policy change will be complex, unpredictable and, at times, not science-based. One of the most important goals of such policies should be to ensure that, unlike those in the vanguard of deinstitutionalization, users of long-term services and supports do not move from unsatisfactory placements in institutions to empty, idle lives in the community because the range of services and supports they need are not available.

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