Epidemiology and Psychiatric Sciences (2014), **23**, 11–16.
doi:10.1017/S2045796013000632

EDITORIAL

Mental health reform under policy mainstreaming: needed, but uncertain

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October 2013 marks the 50th anniversary of President John F. Kennedy's message to the US Congress on the need to reform mental healthcare. Much has changed in that time. In 2006, Frank and Glied summarized these changes and the forces behind them, finding that the well-being of people with mental illness was 'better but not well.' They also conclude that most improvements have been due to 'mainstreaming,' the inclusion of those with mental illness in broad reforms such as Medicare, Medicaid and Social Security. With the gradual assimilation of mental health concerns, leadership and resources into mainstream programmes and agencies, future improvements will require that these programmes are accessible and oriented to people with mental illness. The passage of broad health reform legislation in 2010 (the Affordable Care Act) reinforces this change; several of its provisions attempt to make healthcare more relevant to the population with mental illness. In this editorial, I discuss a set of challenges which remain for the population with mental illness in the healthcare system, and the prospects for change. These challenges include: (1) improving basic mental healthcare in primary care, (2) improving mental healthcare for children, (3) earlier detection and treatment of psychotic illness, (4) disability and unemployment and (5) the challenge of sustaining an adequate, speciality public mental healthcare system under conditions of mainstreaming. In general, I conclude that the prospects for successful reform are uncertain. Establishing mental healthcare specialization in mainstream systems has not been notably successful to date.

First published online 13 November 2013

Key words: Children, integration of care, mental health policy, reform.

Introduction

Fifty years have passed since President John F. Kennedy signed legislation to reform mental healthcare in the United States. It is timely to consider what has been accomplished over this period (as Lisa Dixon does in this issue) but also to consider what major challenges remain – considering both President Kennedy's vision and the issues that have emerged. In this paper, I will describe a short list of major challenges that are not yet resolved.

Clearly, problems persist; a commission appointed by President George W. Bush to review mental healthcare told the president that 'the United States mental health services delivery system is in shambles' (New Freedom Commission, 2002). However, there has also been progress. Frank & Glied (2006) reviewed changes in mental healthcare over the past 50 years. The title of their monograph (Better but not well) hints at the findings: the well-being of people with mental illness has improved, but progress has been uneven and incomplete. Frank and Glied found improvements not mainly due to the special attention to mental healthcare called for by President Kennedy ('exceptionalism') but to better access to broad societal benefits like healthcare and income supports ('mainstreaming'). Gronfein's (1985) analysis comparing the relative effect of Medicaid and community mental healthcare centres on patterns of mental healthcare provided an early hint that broad mainstream programmes would have a bigger effect.

Frank and Glied's review provides a new framework for analysing changes in mental healthcare. We must consider not just the challenges, but a new policy environment. A continued emphasis on the 'exceptionalist' strategies that have dominated mental health advocacy may no longer be as relevant, while ensuring that mainstream programmes do meet the needs of people with mental illness may be more important. These questions are particularly timely given legislation that further moves mental health into the mainstream. The 2007 *Mental Health Parity and Addictions Equity Act* (MHPAEA) required equitable coverage for mental illness care within health insurance. The 2010 *Patient Protection and Affordable Care Act* (ACA) does not have many provisions specific to mental health, but its effect on mental healthcare will be profound. Its expansion of health insurance builds on the MHPAEA, providing 'parity' coverage that will provide improved access to mental healthcare to millions of previously uninsured Americans. The ACA's provisions will indirectly stimulate attention to mental

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healthcare in contexts from primary care to hospital readmissions that might be due in part to poor mental health. Since the healthcare system is so dynamic and complex, there will be false starts and dead ends. However, any assessment of future prospects for mental healthcare must begin with a realization that reform has moved away from an approach that was separate and, perhaps inevitably, unequal.

In this summary of needed mental healthcare improvements, I will focus on selected policy challenges that have a significant effect on mental health well-being. For each of these challenges I will consider the prospects for change under mainstreaming. Any choice of policy targets is inherently idiosyncratic. The perspective of this editorial is policy and clinical challenges that are significant from a public health perspective and the healthcare system. I do not attempt to consider research needs – where the complexity of the brain and behaviour suggest that breakthroughs will not be quick or easy – or issues like the problematic intersection between the criminal justice system and mental illness.

Mental health needs in mainstream healthcare

Integrating basic mental healthcare into general healthcare – especially primary care – is an urgent and complicated challenge. Most Americans with mental health problems get no treatment for these problems. For those who receive some care, more get some treatment from their family physician or other primary care practitioner than from mental healthcare specialists (Kessler *et al.* 2005). The ACA's expansion of health coverage will increase help-seeking since more people will have coverage, reducing a barrier to receiving care. Owing to the stigma of seeking speciality care and the limited capacity of this sector, primary care will see more people needing and seeking help with common behavioural problems such as depression and anxiety.

Unfortunately, routine primary care for mental health problems seldom meets the effectiveness standards (Kessler *et al.* 2005). However, well-structured mental health treatment in primary care ('collaborative care') produces better outcomes (Katon *et al.* 1999), while not increasing – and perhaps even reducing – overall healthcare costs (Unutzer *et al.* 2008). Collaborative care has not been widely adopted. However, pressures and opportunities to integrate care will increase under mainstreaming. Mental illness is frequently comorbid with other medical problems, depressing outcomes and increasing costs (Simon, 2001). As cost pressures grow and the responsibility for healthcare is consolidated, more health systems will understand that treating comorbid mental health conditions among people with medical conditions addresses both cost and quality.

Collaborative or integrated care has now been tested in 79 clinical trials (Archer *et al.* 2012) and replicated in many real world clinics. Integrating care is not easy, but its elements are not complex: station a mental healthcare practitioner in the practice, screen for mental health problems, measure progress in treatment, allow billing for basic mental healthcare services and ensure a psychiatrist is available for consultation.

Although collaborative care is proven, barriers to integrated care must be addressed. The primary care setting must have the modest additional costs of providing integrated care covered. For example, Medicare still does not pay for some elements of collaborative care, despite the burden of depression for older Americans. National screening recommendations (U.S. Preventive Services Task Force, 2009) are also outdated, recommending screening only if ample treatment resources are available in the setting. Achieving primary care treatment of basic mental health problems is a first significant test for mental healthcare in a mainstreamed policy environment.

Children's mental healthcare

Mental health problems have been called the major chronic diseases of childhood, often emerging before adolescence, but average lag from first symptoms to treatment is 9 years (Wang *et al.* 2005). Only about a quarter of children with mental health problems see a mental health professional (Burns *et al.* 1995). Many mental health challenges for children emerge from environmental 'insults' such as exposure to trauma or other adverse experiences (Felitti *et al.* 1998) that create vulnerability and often progress to mental illnesses. In these early stages (post exposure but before 'illness' is diagnosable) targeted preventive interventions or family focused supports are often effective (O'Connell *et al.* 2009). However, the subtle nature of behavioural changes in the early stages of 'illness' coupled with the normal variance in child behaviour and the generally poor capacity to assess emerging behavioural health problems in mainstream settings (early education, even paediatric practices) mean that most problems are undetected. By the time behavioural problems have become diagnosable conditions they are harder to treat. Furthermore, speciality mental health services are often inaccessible.

There is now a robust literature summed up in the Institute of Medicine's report (O'Connell *et al.* 2009) showing effectiveness of early intervention for emotional/behavioural problems. However, these interventions are generally not available. Mainstream

https://doi.org/10.1017/S2045796013000632 Published online by Cambridge University Press

children's services (e.g. child care and early education) are not oriented or able to deliver these interventions. Prevention programmes that target 'high risk' children and have well established effectiveness (e.g. Nurse Family Partnership, Olds *et al.* 1988) are generally not covered by health insurance plans or provided by other mainstream systems (e.g. early education). Therefore, effective prevention and early intervention programmes are available to only a small fraction of children who need them. Preventive services that can be delivered most effectively when risks are high but no clinical diagnosis is (yet) present – services that might be thought of as the behavioural parallel of vaccination – are often not reimbursed under Medicaid or most private health insurance because no 'illness' is present. Policy makers express vocal concern about increased levels of psychiatric medication use among children (a speciality or exceptionalist problem). However, there is to date little interest in adapting mainstream programmes to expand preventive services for children with emergent problems or to provide counselling as an alternative to medication treatment.

Can children's mental healthcare be improved in an era of mainstreaming? The supply of speciality child mental healthcare providers (e.g. child psychiatrists) is inadequate and likely to change quickly. In addition, though speciality care remains necessary to help children with complex problems it does not help solve the problems of inadequate detection of emerging problems, and insufficient targeted prevention and early intervention programmes. Political commentator David Brooks (2012) laments the lack of focus on helping children at risk develop the capabilities for 'self-regulation' that are crucial for adult success. However, these concerns and the evidence that untreated children's behavioural health issues can lead to chronic and costly medical and mental health problems (Felitti *et al.* 1998) have a long-time horizon. Investments in child mental healthcare may prove unlikely for health payers focused on the short term.

An intriguing test case for child mental health in a reformed system is whether the healthcare system can treat maternal depression effectively. Unlike subtle developmental problems of children, depression is a reliably diagnosable, highly prevalent and treatable medical problem. Effective treatment is not only good for the mother, but also for her young child (Weissman *et al.* 2006). However, addressing maternal depression requires change in mainstream healthcare systems. Care must be staged in the mainstream health here (obstetrics and paediatrics) since depressed women – especially lower income women – are unlikely to seek out speciality care.

The benefits of improving treatment of maternal depression are clear and the means are available. Yet, success is scarcely guaranteed. This is an 'easier' target than addressing other child mental health problems, such as trauma exposure or poor self-regulation. Gawande's recent (2013) analysis of 'slow change' illuminates the problem. He suggests that healthcare changes that are visible and affect providers positively are more likely to be adopted quickly. Unfortunately, behavioural challenges for children and families do not fit this profile, and the dynamics of mainstreaming make the problem more complex. It is hard to see a path for widespread improvements in children's mental healthcare despite the urgency of need.

Effective early treatment of psychotic illness

Our approach to helping people with psychotic illnesses like schizophrenia is crude and ineffective. Usually, young people slip into psychotic illnesses for several years while they get no help. The subtle behavioural variations that can emerge well before a dramatic psychotic 'break' are usually not detected by parents, teachers or health professionals. The separation of general medical care and mental healthcare reinforces the problem: primary care lacks the capability to detect the 'prodromal' behavioural changes that precede psychotic illness, and the separate mental healthcare system does not respond until the problems are serious.

When young people have a 'first psychotic break,' they often are briefly hospitalized. Usually, medication treatment substantially reduces symptoms within a few days. When people feel better after discharge, they often stop taking them especially since the drugs have significant side effects. Relapse is likely, and then the revolving door begins. Often, after decades, people figure out how to manage their illness, but by then they are often on permanent disability status, unemployed and in terrible health. An acute/episodic care model is inadequate.

Teams delivering First Episode Psychosis (FEP) care are much more effective (Petersen *et al.* 2005). Effective intervention is early, person-centred, family driven, collaborative and recovery oriented. Staying in school or work is encouraged, rather than emphasizing disability. The two major challenges are finding ways to engage people immediately to reduce the disabling effects of prolonged untreated psychosis, and making teams available to deliver FEP care.

A mainstreamed policy environment creates both opportunities and challenges. The ACAs improved access to health insurance including mental health benefits can help. However, improved insurance coverage is only a first step. Mainstream healthcare systems must identify people needing care rapidly, and then assure access to FEP teams. It will be a daunting

https://doi.org/10.1017/S2045796013000632 Published online by Cambridge University Press

challenge to achieve specialized attention to this relatively low-incidence problem in a mainstream healthcare system that is stressed, undergoing dramatic change and focused on 'physical' illness. The question of whether FEP care is expanded – like the test case of treating maternal depression – will reveal whether a mainstreamed policy approach can be sufficiently customized to address serious mental illness (SMI).

Lifelong unemployment for people with mental illness is unnecessary

Policy changes have helped more people with mental illness obtain care, and provided subsistence supports allowing most to live outside institutions (Frank & Glied, 2006). However, the income support safety net (for most, subsistence level Social Security payments, and health/behavioural healthcare provided by Medicaid) has encouraged disability instead of employment. Disability and unemployment are the qualifying requirements to maintain healthcare. As a result, the employment rate among people with SMI is very low (Cook, 2006). The mainstream Vocational Rehabilitation (VR) system is focused on employment for people with disabilities, but it is both limited in scope and flawed in its approach to helping people with mental illness. Most people with SMI never get VR services, and among those who do, outcomes are poor (Cook, 2006). Therefore, participation in disability programmes is higher for people with mental illness than for people with other health conditions (Cook, 2006).

This dismal picture reflects the deficits of mainstreaming and exceptionalism. Under a more successful mainstreaming approach, VR services would be more widely available, and disability programmes would incentivize work. Under an effective exceptionalism strategy, mental healthcare systems would implement effective supported employment approaches (Drake *et al.* 2012). However, supported employment is generally not available.

This problem has been made more complex as states turned to Medicaid to finance community mental healthcare (Frank *et al.* 2003), since Medicaid will not effectively pay for employment services. The move towards Medicaid payment – a mainstreaming strategy – allowed states to shift part of the cost of care to the federal government. However, it made providing employment services more complex.

The ACA provides a mechanism to address this problem by making available certain *Medicaid Home and Community Based Services* (HCBS) waivers that have been available to support intensive and individualized community services for individuals with Developmental Disabilities (DD) and other disabling conditions – but not for individuals with SMI. The ACA includes a new provision – Section 1915(i) – that allows states to provide HCBS services without demonstrating that they will save costs for Medicaid. The state's 1915(i) plan may target particular populations (individuals with SMI are specifically mentioned as a possible eligible group). HCBS services are quite flexible, and may include traditional Medicaid services (e.g. clinic, medication and inpatient services) as well as services not traditionally covered under Medicaid (e.g. Supported Employment).

The 1915(i) alternative is a good example of an approach that adjusts mainstream provisions to meet the needs of the population with SMI. Whether states take up this alternative will provide another test of whether a mainstreaming approach can be customized sufficiently to help people with SMI effectively.

Protecting the safety net

Although health reform creates mainstream opportunities to improve mental healthcare, the major 'exceptionalist' approach to care – the public mental health system – is stressed. Recession-driven budget pressures have led to more than $4B in state budget cuts between 2009 and 2012 (Glover *et al.* 2012). The public mental healthcare system evolved from state asylums and mental health centres to a diverse array of state-directed community based treatment, rehabilitation and support services. Its financing depends on Medicaid and state general funds, with a role for counties in some states.

While long-term budget pressures have been damaging, in many states the mental healthcare safety net is better focused than it was a generation ago, when President Reagan's budget effectively ended the Community Mental Health Center programme in favour of a small mental health 'block grant.' Community mental healthcare providers and state officials have learned what works. Examples include supported housing and people in recovery from mental illness/addiction working as 'peer specialists.' The public mental healthcare system is better focused than in the past, while also stretched thin.

There are threats to this exceptionalist system in an era of mainstreaming. Budget cuts are visible, but the less visible erosion of informed leadership for the public mental healthcare system is a threat to the focus and quality of care. Within states, as Medicaid has become the dominant payer for mental healthcare services, the mantle of leadership is swinging away from mental health (and addiction) agencies towards Medicaid and general health agencies. A similar trend is occurring at

https://doi.org/10.1017/S2045796013000632 Published online by Cambridge University Press

the level where healthcare is managed; a reliance on 'carved out' or speciality managed care is trending towards placing mental healthcare benefits in mainstream managed care contracts. It is uncertain whether these mainstream policy and management arrangements will have sufficient mental healthcare expertise to effectively lead. Since care for those with the most SMI is largely a state responsibility, national standards for care for people with SMI do not exist. This makes the transition away from expert leadership risky.

Conclusion

A generation of policy mainstreaming has resulted in some improvements in the well-being of the population with mental illness. In healthcare, the trend towards mainstream approaches is accelerating. I have discussed several clinical and policy challenges where mainstream approaches must be tailored if mental healthcare needs are to be met. The prospects for specialized approaches within mainstream settings and programmes are uncertain. One major challenge is the limited mental healthcare expertise in mainstream systems. Mental healthcare experts (whether clinicians or policy leaders) are still largely focused on the speciality care system, and many mainstream leaders (e.g. in healthcare) are not aware of the scope of the problem or of the available solutions. Whether mental healthcare leadership and knowledge can be 'installed' in mainstream programmes will go a long way towards determining if society's approach to mental healthcare will improve.

Conflicts of Interest

Commissioner of Mental Health, State of New York until October 30, 2012. Consultations/engagements since include: American Psychiatric Association, New York University Department of Child Psychiatry, Magellan Health Services, Wayne-Holmes Mental Health and Recovery Board (Ohio), Education Development Corporation, Oklahoma Department of Mental Health and Substance Abuse Services, University of Rochester Department of Psychiatry, WESTAT, Center for Social Innovation, Sunovion Pharmaceuticals and Federation of Mental Health Centers, The Joint Commission. No known conflicts of interest.

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