

Early Intervention for Schizophrenia

Building Systems of Care for Knowledge Translation

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Abstract

Can regional *systems* of care be designed to disseminate best practices *and* drive necessary research? This is a question of generic interest across health-care conditions, and literature from allied fields will be brought to bear here on how this can be done for youth mental health, with the example of early intervention services for psychotic disorders.

This chapter argues that (i) *knowledge translation* should be the organizing goal of such a system; (ii) *population health* can serve as a conceptual basis for reform, which will be facilitated by a shared vocabulary of “*systems, networks, and pathways*”; (iii) measuring *value* can guide inevitable trade-offs in regional allocation of resources; (iv) services should be designed to embrace *complexity* and avoid simplistic approaches to *wicked* problems; and (v) *learning health systems* are an optimal framework within which to design systems for knowledge translation.

The heterogeneous group of primary, non-affective, and chronic psychotic disorders that fall under the umbrella term schizophrenia will be used as a stand-in for the chronic mental illnesses of adulthood that typically onset in youth. While this focus has limitations, it should enable vigorous critique of the proposed design of systems of care: both for relevance to psychotic disorders as well as across the wide range of disorders affecting youth.

Introduction

What follows is an argument for a particular kind of heuristic or “ideal type” to guide the design of systems that can best respond to the challenge raised by

this Forum. Can we design regionally relevant *systems* of care for youth with mental health needs that are fit to disseminate best practices and drive necessary research? As these systems have yet to be fully constructed or tested for mental illnesses, this remains in large part a pre-empirical proposal. Embedded in what follows is a critical interrogation of current “ideal types” that guide service design, both to consider their usefulness as well as the ways in which they limit progress.

Youth Mental Health: The Nature of the Challenge

There is an urgent need to develop systems of care that are focused specifically on the psychological health of emerging adults (12–25 years of age). Epidemiological studies provide actionable evidence on the needs of this age group, even as we continue to learn more about the neurobiological underpinnings of this important period in neural and social development (Jones 2013). Four populations are worth recognizing for purposes of service design:

1. *Those suffering from the common vicissitudes of adolescence:* These are exemplified by impulse control disorders and the adverse impacts of substance misuse. This broad, amorphous category of problems includes conditions that cause significant distress, disability, and even premature mortality (e.g., campus binge drinking, unplanned pregnancies, sexually transmitted diseases) while not usually resulting in mental illnesses that will persist into adulthood. Since these disturbances often surface during the transition to adulthood, their impact can reverberate well beyond this period if not addressed in an age-appropriate and timely manner. Examples of such derailments include entanglements with the legal system (which can permanently foreclose future employment opportunities) or, more commonly, setbacks in educational achievement, which can have a long-term impact in labor markets that disfavor those without a college degree or specialized vocational training. This is by far the largest subpopulation in terms of numbers, but not in terms of illness burden.
2. *Emerging serious and chronic mental illnesses:* This often neglected subgroup justifies the claim that “mental disorders are the chronic diseases of the young” (Insel and Fenton 2005). The epidemiological findings here are striking, as summarized by Kessler et al. (2007:359): “Roughly half of all lifetime mental disorders...start by the mid-teens and three-fourths by the mid-20s....Severe disorders are typically preceded by less severe disorders that seldom are brought to clinical attention.” The reality that youth and young adulthood are the highest risk period for the onset of mental illness and that treatment access is usually delayed for years after onset supports the formulation of the

12–25 yr age range as a critical focus for testing early interventions to protect long-term adult functioning. Mature models have been developed for early intervention in psychotic disorders (focused mostly on the period of 16–35 yr) and these have survived experimental tests around the world (Correll et al. 2018). These models are also ripe for adaptation to target other emerging serious and persistent mental illnesses including bipolar disorder, obsessive-compulsive disorder, and major depression.

3. *Children and youth with deprived or adverse developmental environments*: Deviations from healthy development can emerge during childhood in the absence of mental illness and are linked to a variety of deprivations (e.g., poverty, neglect, abuse) that can have serious and persistent effects. Those who enter adolescence with inadequate care for and planning around the psychological impact of these deprivations can fall further behind during this challenging phase of life, when poor decisions can have an outsized impact on long-term vocational and social trajectories.
4. *Disorders arising from the first phase of neurodevelopment* (i.e., in infancy): These disorders emerge from abnormal neonatal or early brain development and manifest in childhood, including autism spectrum disorders, attention deficit hyperactivity disorder, various learning disorders, and more severe cognitive impairments. The needs of this group, while ideally identified and treated prior to adulthood, require continued, careful, and specific attention during the transition to adulthood.

An important detail that emerged from these studies is that some of the disorders which first manifest in the period of emerging adulthood are *homotypic* (i.e., look the same at onset in childhood or adolescence as in later adulthood, e.g., antisocial disorders) while others are *heterotypic* (e.g., schizophrenia, which in its earliest phenotypic expression is often indistinguishable from mood and anxiety disorders, or of the normative social distress and dysfunction typical of late adolescence) (Jones 2013; McGorry et al. 2018c). This supports the need for specialized services, targeting the so-called transitional age (late adolescence through early adulthood), that develop the capacity (human and infrastructure) to expertly evaluate, engage, and treat these populations.

Emerging neurobiological understanding of the “second” phase (i.e., between 12–25 years of age) of neurodevelopment provides a rich, textured, and dynamic narrative (Kessler et al. 2007). Much has already been learned that has implications for service design and policy but much more needs to be learned about how these processes can go awry in illness. Such investigations can be supported by service systems that can engage, care for, and thereby recruit subjects with new onset illnesses. The emergence of the mature adult brain is a culmination of a process that begins before puberty and typically proceeds until the third decade of life. The particular sequence of this development suggests

why this is commonly a period of psychological turbulence, risk taking, and vulnerability for the emergence of mental illness, substance use disorders, and personality dysfunction. The present system of dividing care between adult and pediatric models of care presents a further challenge to individuals at one of their most vulnerable periods. These system transitions can impede clinical efforts to identify, follow-up, or treat individuals as well as research efforts to fill knowledge gaps about this important developmental period.

Addressing Service Gaps for Schizophrenia: Reform or Reengineer?

From a public health perspective, all four populations described above deserve sustained policy attention, with appropriately tailored solutions. For example, models to extend and carefully transition services and natural supports for those entering adolescence with an already diagnosed childhood-onset illness (population 4) or identified social deprivation (population 3) will not fully meet the needs of the largest population of emerging adults with more diffuse and temporary needs (population 1). Finally, for those with a serious and chronic mental illness that becomes apparent only during their transition from pediatric to adult life (population 2), no specific services may exist. While the choice to reform (an existing set of services) or reengineer (where none exist) services is often dependent on budgetary or regional exigencies, our focus here is on articulating a strategic response. We focus on population 2 and, within this, those with primary psychotic or schizophrenia spectrum disorders (henceforth, schizophrenia).

There are several reasons to use schizophrenia as the target population around which to construct a heuristic system for youth mental health care. First, early intervention service models are most mature in this area (McGorry et al. 2018c). This makes it feasible to consider dissemination and system design. Second, these disorders impact multiple sectors (e.g., health-care, legal, educational), raising the complexity but also the opportunity to consider how to enact shared societal responses. Third, these disorders exact a huge toll in terms of premature mortality, chronic disability, and caregiver burden, all measurable in terms of societal economic cost (Cloutier et al. 2016). Empirically based interventions that target several modifiable contributors are primed for dissemination. Finally, as an archetypal disorder of new onset in the young (population 2), schizophrenia illustrates the need to think beyond refinement and toward reengineering of care that is better attuned to the needs of emerging adults. This is an exercise that will likely provide lessons relevant for many mental illnesses.

While much about the etiology and pathophysiology of schizophrenia remains unclear and as yet of limited applicability to care, much is known about modifiable prognostic variables and effective treatments and services. We must

therefore imagine a way of “doing what we know” with best practices to help as many individuals as we can now, while also “learning what to do” (Glasziou et al. 2011), by building research capacity into the design of these services. The notion of *knowledge translation* is often invoked to hasten the application of research-derived knowledge into practice, but the connections between the bench, bedside, community, and policy are best viewed as bidirectional (Dougherty and Conway 2008). Indeed, the often implicit notion of completing research before implementation (Chambers and Norton 2016), or divorcing implementation from the need to ask and answer relevant research questions, is worth challenging. Especially for this heterogeneous group of disorders, with varying responses to available treatments, it is essential for services to not only be open to changing practices as evidence emerges, but to contribute proactively to knowledge generation across the continuum: from discovery-oriented biological research, to clinical trials, to implementation and services research and policy. Such services would be best positioned to refine interventions developed in research settings as well as to highlight knowledge gaps to inform research agendas.

Knowledge Translation: Beginning with the End in Mind

With this goal of building systems of care that are primed for bidirectional knowledge translation (Figure 12.1), two broad categories of resistance must be recognized. First, practical tensions exist between the workflows of clinical care and research. In the face of limited time and resources, implicit allocations may favor one mission to the detriment of the other and reinforce a prevalent but nevertheless conceptually indefensible split between clinical care and research (Kass et al. 2013). An effective response to this inevitable tension

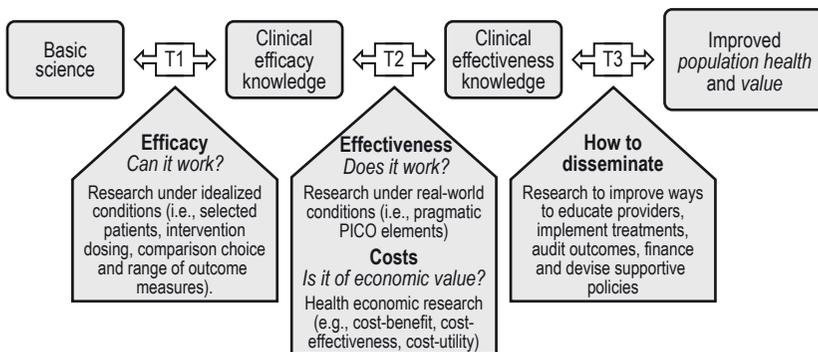


Figure 12.1 Knowledge translation as a goal for systems of care. PICO elements: problem/patient/population, intervention/indicator, comparison, and outcome of interest. Adapted from Dougherty and Conway (2008).

requires a design that can incentivize the agendas of research and care, within a culture that values both missions and enables this with robust informatics. This is detailed below in the description of learning health systems.

Second, it is important to expose an implicit allegiance to what we term a “pipeline model” of knowledge translation. This borrows from a compelling and useful metaphor for transmitting evidence-based information (Glasziou and Haynes 2005), but we use it here to label a misleading heuristic that all too often guides and derails service reform. This heuristic is best presented in mythologic form: pure and potent interventions are developed in research settings, distilled to their “active ingredients,” and then channeled to “real-world” settings. On arrival, however, these interventions are subject to local practice distortions (“leakage in potency”) that require various forms of policing to ensure application of the active ingredients with appropriate procedural “fidelity” to the original model of intervention. As with most myths, there are a few embedded truths (efficacious treatments or models of care are often misapplied or ignored in practice settings while, conversely, practices refuted by robust research persist), but this glosses over a key distinction between simple (e.g., three drops of polio vaccine) and complex (e.g., psychotherapy, service models) interventions, and leads to ineffective dissemination.

While the impact of a “simple” (but certainly not easy) intervention (e.g., the use of a vaccine or medication) can, in principle, be improved by monitoring for fidelity to research-derived dosing protocols, it is well understood, even here, that variability in pharmacokinetics (how each individual metabolizes a drug) and pharmacodynamics (how each individual is variably impacted by the same dose of the drug) should temper enthusiasm for such protocols. The pipeline model, however, uncritically extends this approach to psychosocial or service-level interventions. For example, efforts to disseminate empirically validated first-episode services (FES) (Srihari et al. 2012) will be misdirected by emphasizing process measures (e.g., delivery of a recommended set of component treatments, at some arbitrary “dose,” configuration of staffing, or elements of care) over population outcomes. Approaches to ensure such “fidelity” to research-derived procedures, while offering some reassurance that clinicians are “doing what they are tasked to do,” privilege activity over results and are ripe for reality testing. Unlike the delivery of vaccines (simple) or building bridges (complicated), most interventions in health care, as in education, are complex (Srihari et al. 2016). The latter involves iterative maneuvers that are personalized and responsive to patients and can thus vary in dose and nature in ways that do not correlate in any simple way with need or illness severity. While detailed blueprints executed carefully are vital to the construction of bridges, an equivalent fantasy for complex interventions requires disillusionment, not collusion. The practice of monitoring the “fidelity” of service interventions to ensure adherence to mostly process-based measures of research-derived models of care diverts limited resources and exacts excessive opportunity costs. A more realistic focus on the careful

measurement of valued outcomes can offer more reliable milestones toward the goal of reduced morbidity and mortality for the target population. We will return to this more concretely after a necessary detour into the population health perspective.

Population Health

The term *population health* has acquired varied uses (Kindig and Stoddart 2003). We prefer “the measurable improvement in the health of a defined population” using “the health outcomes of a group of individuals, including the distribution of such outcomes within the group” with the added qualifier that “geopolitical areas” (Jacobson and Teutsch 2012) be used to define target populations. This latter guidance was originally proposed to acknowledge that funding decisions are often based on political maps, but for our vision of population health for early psychosis, it allows a focus on a relevant network of regional stakeholders (see below). Population health (Figure 12.2) focuses critical attention on both the determinants and the desired outcomes of proposed interventions.

First, we are reminded that medical care is only one of several contributors (*determinants*) to improved health. While psychiatric services might be ahead of general medicine in including behavioral factors and basic needs into standard care models for severe mental illnesses, there remains a clear need to pay more attention to social determinants of health and, relatedly, to include a wider set of stakeholders (beyond traditional health-care agencies) in mounting responses. Second, the rubric to measure success (*population health outcomes*), within the domains of mortality and morbidity, requires assessment and action on disparities across subgroups (e.g., race, class, gender). Social justice aspirations for equitable distribution of the benefits of care provide the

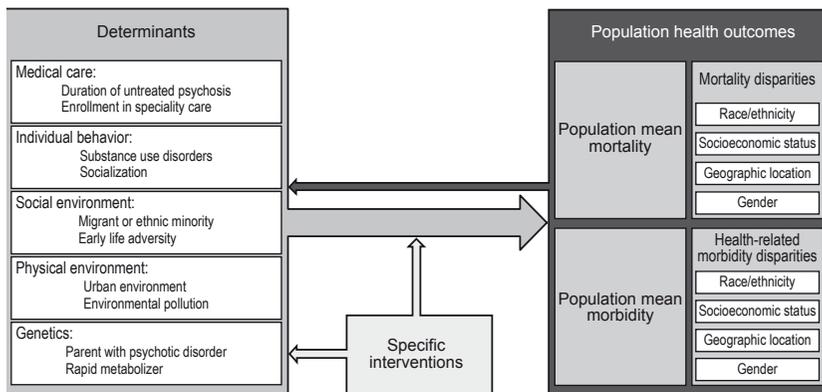


Figure 12.2 Population health for early intervention services for schizophrenia. Adapted from Kindig et al. (2008).

imperative to assess and intervene on the causes of these disparities. These are not an afterthought; they are integral to this model of population health.

How can such a population health framework organize care for recent onset schizophrenia? For those of us working in health-care agencies, this requires both a broader consideration of our role, with respect to the populations we treat, and a reconsideration of some of the terms we use.

Systems, Networks, Pathways: A Vocabulary for Enacting Population Health

A system of care for complex health conditions is a set of activities with a common set of objectives. A network is a set of organizations and individuals that deliver the system of care. Pathways are the routes that patients follow through the network. —Srihari et al. (2016)

A *system* of care is thus differentiated from its colloquial use, as in some notional aggregation of health-care agencies. After all, health-care agencies represent only a few of the several stakeholders in any region and have a limited, albeit important, impact on overall health outcomes (Schroeder 2007). Added to these agencies are the teachers, friends, family members, clergy, police, and many others who (in ways often unknown to each other) by their responses to psychotic illnesses create the de facto *network* that determines the nature of the *pathways* experienced by young people and their families as they access and engage with the formal health-care sector and community supports.

Designing a population health-based early intervention system for new onset psychosis requires the identification of a target geopolitical region for a defined population (e.g., first-episode psychosis). The various actors in the region can be recognized not simply as facilitators or barriers but rather as active *filters* (O’Sullivan et al. 2007; Srihari et al. 2014) who act to facilitate or delay effective access to care, depending on the characteristics of the patient or situation. For example, agitated male patients might be ferried rapidly to emergency rooms by the same police officers who might underestimate the need for care in those socially isolated by deficit symptoms. With targeted outreach and education, these police officers (stakeholders) can be mobilized and integrated into a functional *network*. Established or nascent FESs might see their role in hosting such a network toward the goal of population health-based care. By way of illustration, Figure 12.3 shows a network of stakeholder groups that a particular FES (Specialized Treatment in Early Psychosis, or STEP) has intentionally sought to integrate across a 10-town region in southern Connecticut (population ~ 400,000) (Srihari et al. 2014). Such a network would, if functioning to purpose, ensure that *every* individual with new onset psychosis in the region experienced a pathway to the local best practice service (STEP), and in a matter that reflects the work of an organized and humane *system of care*, as illustrated in the following case:

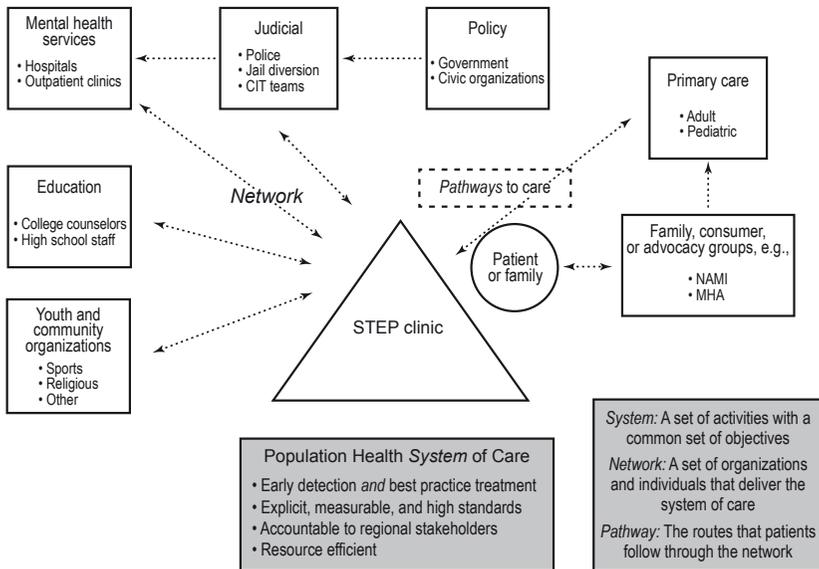


Figure 12.3 Early intervention services as integrators of regional access to care for psychosis: crisis intervention teams (CIT), National Alliance on Mental Illness (NAMI), Mental Health America (MHA).

Anton is a 17-year-old African-American resident from a nearby town, who was noted to be increasingly suspicious and disheveled over a period of several months. School security staff was called one afternoon to intervene when he was seen brandishing a stick in a busy corridor, and shouting “I hear you” to no one in sight. The staff summoned one of his teachers, who was able to convince him to travel with her in a squad car to the local emergency room. There, rapid assessment determined the presence of a psychotic illness, and during the ensuing hospital admission, Anton was introduced to an outreach worker from a local FES. Upon discharge and with his permission, Anton’s teacher and family were included in the initial assessment and provided valuable collateral information on the pace and development of Anton’s symptoms. In addition, the school security guard requested and was provided information on the signs and symptoms of psychotic illnesses, and expressed relief that he had not been instructed to take Anton to jail. He asked the FES manager to give a presentation on the topic to his colleagues at a local recreational club. One month later, Anton was able to return to school and, with the assistance of a vocational counselor, advocated for specific accommodations which enabled him to complete graduation requirements despite the need for frequent medical appointments and one additional hospitalization over the next six months.

All too often, pathways to best practice care for youth with new onset mental illnesses do not reflect the coordinated activities of a *system* such as the one

above. Instead, they are marked by long delays, multiple help-seeking attempts or, worse, inappropriate diversions into the criminal justice system (Wasser et al. 2017). Individuals outside mental health-care systems are often thrust into the role of “first responder” to socially disruptive behaviors that ensue from psychiatric illnesses. If not adequately educated and integrated, these observers can feel powerless to reduce the shame and social isolation for patients and their families, and frustration for other onlookers. This represents an opportunity—a network in waiting—wherein activities in response to psychotic distress or disorganization can be coordinated into what can more rightfully be called a system of care.

Such systems can be further organized around a clear goal, or *overall aim*, and include concrete *objectives*, *measures*, and *standards*. Such a “system specification,” exemplified by STEP’s population health-based system for early psychosis (Table 12.1), should be continuously refined with input from patients, caregivers, and other stakeholders who constitute the regional network. The specification provides a template for dashboards to assess

Table 12.1 System specification in STEP: a population health-based early intervention strategy used in southern Connecticut set up to transform outcomes of all within the first three years of psychosis onset within a catchment zone of 10 surrounding towns.

Objective	Measure	Standard	
		Achievable	Aspirational
<i>Access</i>			
1. Rapidity	DUP 1 < 3 mo	30%	75%
	DUP 2 < 12 mo	50%	75%
2. Equity	Proportion of females	20%	30%
	Ratio of ethnic groups		matches census %
	Ratio of towns of residence		matches % of 10 towns
3. Coverage	Proportion aged < 18	15%	80%
	Number annually offered STEP care/ expected annual incidence in zone	15%	80%
4. Pathways to care	Proportion of patients admitted to STEP after psychiatric hospitalization	60%	30%
<i>Engagement</i>			
1. Overall	FES contact at 12 mo post admission	70%	90%
2. Exposure to family education/ support	Family participation in at least 1 qualifying event in first month	75%	90%
3. Exposure to specialized, empirically based psychotherapy	Engagement in qualifying event in first month	75%	90%

continuously the performance of the system, and annual reports to hold the system accountable to the community. Some implications that can be drawn from this approach to implementing early intervention services for psychotic disorders in a public health framework are summarized below:

- Individualized care is attentive to social determinants of access, quality, and outcomes.
- Care processes are responsive to population outcomes measured across domains of access, disease-related morbidity, and broader determinants of social and vocational functioning.
- Fidelity of the service to recommended care processes is treated as one of several potential mediators of population outcomes and is thereby subject to empirical scrutiny, but is not an end in itself.
- Ownership: regional stakeholders set expectations for the system (i.e., objectives and standards).
- Local control allows for creative resourcing of, and even disinvestment from, standard components of care: if a particular outcome (e.g., employment) exceeds benchmarks, then resources can be allocated away

Table 12.1 (continued). Abbreviations: BMI, body mass index; FES, first-episode service; NEET, not in education, employment, or training; PANSS, positive and negative syndrome scale; GF, global functioning; DUP 1, duration of untreated psychosis (time between psychosis onset and first antipsychotic medication trial; DUP 2, duration of untreated psychosis (time between psychosis onset and enrollment in STEP). Adapted from Srihari et al. (2016).

Objective	Measure	Standard	
		Achievable	Aspirational
<i>Outcomes</i>			
1. Hospitalization	Psychiatric admission in months 1–6 and 7–12	<25% <25%	<10% <10%
2. Suicide prevention	Patients attempt, first yr of admission	<10%	<1%
3. Remission	PANSS positive sub-core <3 at 6 mo	70%	85%
	PANSS positive sub-core <3 at 1 yr	80%	90%
4. Recovery	GF: Role scale level ≥ 8	70%	85%
	GF: Social scale level ≥ 8	70%	85%
5. Vocational engagement	NEET nor full-time caregiver	<10%	<5%
6. Cardiovascular risk			
Smoking	New smokers at 6 mo	<20%	<10%
	Smoking rate at 6 mo	<60%	<30%
Overweight or obese	BMI < 25 at 12 mo	30%	75%
	Normal BMIs retained at 12 mo	60%	75%
7. Disposition	Successfully transitioned to main-stream health-care services ≤ 2 yr	70%	80%

from specific care processes (e.g., supported employment models) to other areas of need (e.g., support for transportation).

- **Accountability:** annual report focused on outcomes of value to local stakeholders.

Value

[I]n health care we've allowed "quality" to be defined as compliance with evidence-based practice guidelines rather than as improvement in outcomes... Billing data...don't capture suffering due to the delays, chaos, confusion, and complications that often characterize health care. —Porter (2010:504, 505)

The health economist, Michael Porter, has championed a particular approach to monetizing the impact of health-care interventions represented by the equation: value = health outcomes achieved per dollar spent, over a meaningful period of care (Porter 2010). This perspective highlights the remarkable lack of reliable health outcome data for much of what is ordinarily reported by health-care agencies. For example, less than 2% of measures listed in the U.S. National Quality Measures Clearinghouse are related to outcomes that can be directly tied to patient health (Porter et al. 2016). The relatively large proportion of process measures will not surprise anyone working in health-care agencies, where the notion of valuing what is most easily measured, rather than measuring what should be valued, sadly dominates administrative practice. This often devolves to a focus on worker productivity and related documentation of service utilization. Quite apart from the limited inferences that can be made from such measures to the health of the populations served, they can exert a corrosive effect on cultures of practice. Measurement becomes associated with irrelevant, tedious "paperwork" that has often migrated into (and even been amplified by) regressive electronic systems, thus becoming a contributor to clinician burnout (Shanafelt et al. 2016). This also degrades the quality of any data collected.

A useful sociological commentary recommended a principle of "negotiated accountability" to counter a growing "cult of efficiency" that is overly focused on narrow measures of productivity and health-care utilization (Stein 2002). In a similar spirit, recent principles published by the International Consortium for Health Outcomes Measurement are worth considering for their relevance to the design of population health-based systems of care (Porter et al. 2016):

- Commit to measuring a minimal set of patient-related outcomes.
- Measure outcomes across a "full care delivery chain" or meaningful cycle of care.
- Use explicit, replicable ways to measure outcomes.
- Consider explicit ways to risk-adjust these outcome measures.

- Standardize sets of outcomes for equivalent services, nationally and globally.
- Maximize value = health outcomes achieved per dollar spent.

Value can be a potentially powerful way to prioritize health-care spending (Gray 2012; Lee 2010). While within the general framework of cost effectiveness, the measures used depart from traditional approaches to economic analyses that privilege omnibus measures, such as quality-adjusted life years (QALYs). While QALYs can be pegged in a standardized way to societal preferences and can inform allocations across health-care conditions, they suffer long-recognized limitations in appropriateness and sensitivity to change for mental illnesses (Brazier 2010; McCrone 2011). More to the point, for our argument here, QALYs are not intuitively accessible and are difficult to use in allocative decisions by stakeholders at a regional level. Funding decisions are often made by particular agencies in particular regions with idiosyncratic prioritizations of outcomes. To illustrate, we asked the question: What is the value derived from the incremental investment necessary to mount a FES in a U.S. public sector setting, in terms of patient-centered outcomes (psychiatric hospitalization), over a meaningful duration (1 year) of care? This was one of many outcomes measured in a randomized trial and assessed with traditional cost-benefit analysis (Murphy et al. 2018). While it would cost about 978 USD for one psychiatric inpatient day, an investment of <\$100 in the tested FES per patient would help avoid one psychiatric inpatient day over a year of care. Similarly, \$152 was the cost of one jail day, whereas \$6.6 was the per-patient investment in FES care to prevent one jail day over a year. These were the outcome domains of particular decisional salience to funders of this FES. Sensitivity analyses accommodated expected variability in such costs articulated by this stakeholder. The value approach can thus make clearer, in a more modular way, what the FES could deliver to the local system in terms of improvement in specific outcomes of interest, for the dollars spent. Our estimates were idiosyncratic to the additional cost of mounting the FES within our community mental health center, thus limiting the generalizability of the results, but they made transparent the “return on investment” on an outcome that local decision makers happen to value (see Table 12.1, Hospitalization). While a full presentation of the use of such value-based analyses is beyond the scope of this chapter, it helps make the point that population health-based systems of care for youth mental health can be coherently tied to economic analyses and payment models (Porter and Kaplan 2015) for the transparent consideration of a variety of regional stakeholders. Of course, while the above example focuses on one stakeholder (public sector funder), the population health approach proposed here envisions vigorous input from all relevant stakeholders (Figure 12.3) in specifying the overall system (Table 12.1).

Embracing Complexity

How can services be designed to deliver population health-based care that delivers measurable value to stakeholders? Traditional approaches for dissemination of evidence-based practices for severe mental illnesses have emphasized fidelity to procedures developed at research sites (Addington et al. 2007; Bond et al. 2000). Historically, these have had a variable and, at best, modest impact in moving research into practice, most notably evident in persistently reported gaps in schizophrenia care (Dixon et al. 2010). Fidelity-based approaches, however, do not address well-known barriers to knowledge translation (Jensen 2008; Lane and Flagg 2010): the diverse and evolving needs of implementation sites for leadership, clinical ownership of the problems addressed, and the overall culture of practice (Torrey et al. 2001). Indeed, these barriers to “doing what we know works” (Glasziou et al. 2011) have long been recognized as pervasive across health-care settings and conditions (Institute of Medicine’s Quality of Health Care in America 2001).

Another way to describe this problem is that extant models of dissemination are fundamentally ill-suited to *complex* interventions and to the complex adaptive systems into which they must be integrated (Hawe et al. 2004; Mackenzie et al. 2010). The implicit presumption of a research to practice “pipeline” (Glasziou and Haynes 2005), which aspires to deliver identifiable “active ingredients” with high fidelity, may apply for conceptually simple (albeit, not easy) interventions (e.g., polio vaccines) but can reduce the potency of complex interventions. The latter include several interacting components, require variable integration of these in response to the needs of patients, and thus require a great deal of flexibility and variability in their conceptualization, even if this is sadly ignored in simple-minded, fidelity-driven efforts at dissemination.

Additionally, variations across implementation sites in patient samples, clinical and rehabilitative resources, and desired outcomes make straightforward applications of research-based service models inappropriate (Plsek and Greenhalgh 2001). The logistical challenges of delivering team-based, multicomponent care in environments with myriad regulatory demands, inefficient medical record systems, and limited reimbursement for psychosocial services means that standards based on some notion of “minimal dosing” of treatment components cannot be persistently met. More usually, cultural norms determine trade-offs that should be made in the service of patient/population outcomes rather than bureaucratic allegiance to procedures. In addition to the treatment packages or services, the context in which they are to be implemented is often also complex (Plsek and Greenhalgh 2001:625):

A complex adaptive system is a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that the action of one part changes the context for other agents.

Table 12.2 Comparing simple, complicated, and complex problems. Adapted from Glouberman and Zimmerman (2002).

Simple: Following a Recipe	Complicated: Sending a Rocket to the Moon	Complex: Raising a Child
The recipe is essential	Formulae are critical and necessary	Formulae have a limited application
Recipes are tested to assure easy replication	Sending one rocket increases assurance that the next will be OK	Raising one child provides experience but no assurance of success with the next
No particular expertise is required. But cooking expertise increases success rate	High levels of expertise in a variety of fields are necessary for success	Expertise can contribute but is neither necessary nor sufficient to assure success
Recipes produce standardized products	Rockets are similar in critical ways	Every child is unique and must be understood as an individual
The best recipes give good results every time	There is a high degree of certainty of outcome	Uncertainty of outcome remains
Optimistic approach to problem possible	Optimistic approach to problem possible	Optimistic approach to problem possible

Accepting such complexity includes embracing inherent nonlinear change, tension, creativity, and emergent phenomena (Shiell et al. 2008). Glouberman and Zimmerman (2002) outline some differences between approaching complex problems (versus simple or complicated problems) by evoking the metaphor of raising a child (Table 12.2).

For a related perspective, let us consider elements of problems which Rittel and Webber (1973) term as “wicked”:

- Problem framing, not problem solving is often the main task.
- No stopping rule: limits are resources aimed at “good enough” responses.
- (Re)solutions are not true/false but good/bad.
- There are no “permissible” limits on what is worth trying.
- Every wicked problem is unique: real but limited transfer of processes across cases.
- A problem may not be solved (in a generalizable manner) but rather “resolved” within a community of stakeholders and may need to be revisited as conditions or priorities change.

These elements are easy to invoke when considering this typical case presenting to a FES:

Jack is a 21-year-old high school student who was recently asked to leave his college dormitory after repeatedly threatening his roommate who he accused of

“spying on his thoughts” by “using radio waves.” He refused to inform his parents and thus had to live in a homeless shelter, which he described as very stressful. He arrived at the FES refusing to accept treatment but demanded assistance in finding better housing and a “doctor’s letter” which he said was necessary for him to return to college. He displayed an obvious thought disorder, and at times it was very difficult for the assessor to follow his line of thinking. He demonstrated no insight into any of his psychotic symptoms and denied need for any kind of clinical treatment.

Which problem should be addressed first? Would insistence on antipsychotic medication treatment reduce his symptomatic burden enough to allow him to participate in informed decision making? Would this instead alienate him and lead him to drop out from the service? Would a return to college simply expose him to more public ridicule and negative academic consequences, or would it improve the FES’s alliance with him and thereby facilitate his acceptance of treatment?

These questions are but a small subset of those presented in ordinary practice and cannot be resolved with reference to a standard set of procedures. Rather, an iterative set of options may be pursued, failure may lead to retraction or refinement even as the target problem is changed or specified more clearly as the patient’s preferences (the utility he attaches to different component of the service), the disease process (severity of symptoms), or environmental constraints (college’s requirements for his return) evolve over time, and in response to interventions. Complex (rather than merely complicated) problems are thus commonplace in the implementation of multicomponent services like FES. This reality has implications for how best practices might be disseminated effectively, while also enabling continued research focused on addressing persistent challenges, whether amenable to simple, complicated, or complex interventions.

Complex problems in complex systems require continual observation of the systems on multiple levels, problem-framing rather than problem-solving, fostering conditions for change by exerting “influence” rather than futile “command and control” (Rouse 2008). At the level of mental health services, this would mean influencing cultures of practice toward achieving patient-centered outcomes rather than overly specifying processes of care (Pollard et al. 2016).

Learning Health Systems for Knowledge Translation

A learning health system occurs when “science, informatics, incentives, and culture are aligned for continuous improvement and innovation...and new knowledge is captured as an integral by-product of the care experience. —Institute of Medicine (2013)

How can such population health-oriented services be enabled to participate in a multisite system for knowledge translation? The notion of a learning health

system offered by the Institute of Medicine (2013) provides a useful framework. These systems must be designed to attend simultaneously to

- *science*, through the collection of valid and reliable measures, innovative statistical and translational research methodologies, and the identification, generation, and free exchange of knowledge and expertise between researchers and clinicians,
- *informatics*, robust, user-friendly and collaboratively designed software that allows for a range of data collection methods, integrating with existing databases/health records and interfacing with all stakeholders,
- *incentives*, by facilitating accountability to key stakeholders, fostering creativity, growth and optimism, and empowering members with support, tools and resources, and
- *culture*, via the formation of nonjudgmental, diverse communities of agencies which embrace both local ownership of care and a shared core mission of measuring and learning from patient outcomes.

For early intervention models for schizophrenia, we have specified many details of a system that would meet these design principles. Existing FESs could serve as catalytic nodes within regional networks that share a commitment to a core set of outcomes within a shared system specification, as exemplified in Table 12.1 and detailed in Srihari et al. (2016), and which share lessons across sites to support cultures that are consistent with these principles. Member services of such a network would commit to measuring and reporting a minimum core set of benchmarked, patient-centered outcomes (rather than simply process or fidelity measures) to guide continuous quality improvement. Customized informatics and communication infrastructures can provide user-friendly functionality, such as modular practice management functionality, centralized structured assessments (as needed by under-resourced clinics), as well as integrated and passive data collection from extant electronic medical record systems. Multi-stakeholder groups within local communities would be periodically engaged to validate the objectives or range of outcome domains and review overall system performance. This relevant and rigorous data from the sites within this system would also be available to researchers to better understand and deliver new approaches to persistent challenges. This alignment of practice-relevant research and informatics within a culture that supports measurement and provides the necessary supports and incentives would model a learning health system for early psychosis.

There is a dual reality for schizophrenia care today. On one hand is the considerable public health impact that can be derived by implementing existing interventions. On the other, there is too much that remains mysterious about the causes and physiologic bases of these illnesses. Services that are designed for knowledge translation, as we have argued here, will be in a good position to contribute to these two tasks. The success of pediatric oncology in wedding the

two missions of best practice delivery and quality improvement (“doing what we know”) with research (“learning what to do”) offers a useful precedent (Unguru 2011). The development of learning health-care systems for new onset psychotic disorders is a good place to start and may provide a compelling prototype for other mental illnesses.