

**FROM IDEA TO PARADIGM**  
**THE INTEGRATED PRIMARY AND MENTAL HEALTH CARE MODEL IN NORTH**  
**CAROLINA**

By  
Rachel Weiner

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***Advisor***

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***Date***

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***Second Reader***

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***Date***

## ABSTRACT

The Affordable Care Act included funding for the piloting of the integration of mental health and physical health, a model that may help address poor outcomes and low quality of care for persons with mental illness. There is growing interest in this model and evidence for its effectiveness. This paper explores the development of the integration of physical and mental health care from an idea to a paradigm and explores how a model that has gained national attention can be implemented and spread at a local level. Using frameworks such as Kingdon's three streams model and the Advocacy Coalition Framework, as well as diffusion of innovation theory, in this study I look at the role that advocates, evidence, values, and policy played in the spread of the integrated health care model.

This research triangulates three methods: a careful review of the literature, a systematic review of government policy documents, and in-depth policy interviews with key stakeholders and other experts in the field. I used non-probability and convenience sampling to identify potential participants based on positions of leadership and expertise related to integrated health care in North Carolina. I coded interviews and analyzed them for common themes.

I interviewed six participants who represented elected government, bureaucratic government, academia, and advocacy. In the view of the participants, the spread of integrated care is driven by recognition of a problem, the view that integrated care is an attractive solution, and the excitement and collaboration of stakeholders. Participants also agreed that the integrated care model will be important in the future, becoming a permanent fixture in the way that primary care is practiced and the way persons with mental illness are treated. Their views, however, differed on the role of research, with half of the participants seeing research as not important in the spread of integrated care. Identified barriers to dissemination included payment models, cultural differences between providers, and a lack of clear definitions. Suggestions to overcome these barriers included creating a means for proponents to share lessons and clear definitions to facilitate communication.

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## INTRODUCTION

Mental illness causes an immense loss of quality and quantity of life. In 2006, the Institute of Medicine named mental and substance-abuse illnesses as the leading cause of death and disability for women of all ages and the second leading cause for men in the United States (Institute of Medicine 2006). One review reported a reduced life expectancy for persons with mental illness, by 6.3 years in persons with depression and 7.2 years for persons with schizophrenia (Druss and von Esenwein 2006), while other research found that the life span of persons with severe persistent mental illness (SPMI) is 25 years shorter than that of the general population (Colton and Manderscheid 2006). Although this is in part due to increased risk of suicide and injury, 60% of premature deaths are attributed to physical health conditions (Mauer and Druss 2007). Patients with mental illness are at increased risk for a number of chronic diseases including cardiovascular disease, high blood pressure, and diabetes (Croft and Parish 2013; Institute of Medicine 2006). Mental illness is in itself a risk factor for harmful health behaviors such as smoking, substance abuse, overeating, and a sedentary lifestyle (Barry and Huskamp 2011; Druss and von Esenwein 2006; Institute of Medicine 2006), and certain psychotropic medications are known to have adverse metabolic effects (Mauer and Druss 2007). An alternative perspective posits that just as mental illness is complicated by physical illness, medical conditions such as chronic pain or obesity also commonly involve psychosocial issues which can both exacerbate symptoms and undermine treatment.(Goodrich et al. 2013) Attempts to improve care of persons with mental illness and the health of the overall population will need to recognize this inextricable link between mental and physical health.

The burden of mental illness in the US is both caused and complicated by what the Institute of Medicine termed a “chasm” in the quality of mental health services.(Institute of Medicine 2006) Between the years 2001 and 2003, in all adults aged 18-54 who met the criteria for diagnosis of severe mental illness, only half received any treatment over a year long period

(Institute of Medicine 2006). The reasons for this “chasm” are likely manifold, but one common explanation is the fragmentation of care for mentally ill patients. There is a historical divide between general health care and mental health services,(Barry and Huskamp 2011; Druss and von Esenwein 2006) and mental health services are often provided by safety net systems and public insurance.(Croft and Parish 2013) This leads to patients with mental illness having to navigate multiple care providers and agencies.(Institute of Medicine 2006) As a result, even when treatment is received it is frequently marked by lack of continuity and coordination of care.(Goodrich et al. 2013; Mechanic 2012)

It is in this context that the Patient Protection and Affordable Care Act (ACA), passed by Congress in 2010, included explicit attention to mental illness. The ACA set out a number of provisions to help address the burden of suffering caused by mental illness and the gap in the quality of mental health and physical health services for persons with mental illness. These provisions, among other things, provide funding and support for a newer concept in the care of mental illness, that of integration of primary care and mental health services, which offers a means to better address both the physical and mental health needs of patients. The integrated care model, however, did not begin with the ACA, nor going forward does its inclusion in the ACA guarantee its spread and implementation at the state and local level. This paper explores the development of integrated care from an idea to a paradigm and explores how a model that has gained national attention can be implemented and spread at a local level.

## **BACKGROUND**

### **Development of the Integrated Care Model**

The integrated care model is supported in the Affordable Care Act both indirectly by payment reform and increased access to insurance and directly through grants for demonstration projects. Two particularly important provisions in the ACA include a grant for patient centered medical homes, which provide the opportunity to integrate mental health services into primary care, and co-location grants, which provide funding for demonstration projects that integrate primary care services into specialty mental health facilities (Croft and Parish 2013).

While the inclusion of integrated care in the ACA is a significant step, the integrated care model had been gaining ground for years before the ACA was passed. The model, which brings together physical and behavioral health, has roots in Engel's 1970's biopsychosocial model and Katon's Collaborative Care Model of the 1990's (Butler et al. 2008; Collins et al. 2010). It first developed in places like the Veterans Health Administration and HMO's such as Kaiser Permanente, but in the past two decades hundreds of other small pilots and projects were started throughout the country (Collins et al. 2010). Reflecting this growth of interest in integrated care, in an article published in 2012, Bevin Croft and Susan Parish note that the integration of primary and mental health care was a key priority in policy for the decade preceding the passage of the ACA, with the Institute of Medicine (IOM) and numerous federal agencies, including the Substance Abuse and Mental Health Services Agency (SAMHSA), and the Department of Health and Human Services (DHHS) publishing reports, holding meetings, and adopting initiatives to promote integration (Croft and Parish 2013). The ACA reflected and solidified the growing interest in this model of providing care.

## Defining Integrated Care

The exact delineation of what makes a model integrated is not always clear and there are a myriad of permutations of the integrated care model as it is adapted for the needs of various settings and populations. In the most basic sense, integrated care is defined as mental health and primary care providers communicating or collaborating to some degree with the goal of meeting both the physical and mental health needs of a patient (Butler et al. 2008). The model is often divided by whether it is occurring in a primary care or specialty behavioral health setting. The degree of collaboration is also used to describe different forms of the model. The degree of collaboration can range from occasional communication between providers in separate locations, to providers who are co-located and serve as consultants or resources for referral, all the way to providers who work as a part of the same team in a fully integrated system (Collins et al. 2010; Mauer and Druss 2007). Table 1 shows a list of terms to describe models, adapted from the lexicon on integrated care created by AHRQ to address the need for clear definitions (C.J. Peek 2013). The Four Quadrant Clinical Integration Model, illustrated in Figure 2 (Mauer 2003), provides a helpful framework for understanding what an integrated care delivery system might look like depending on the needs of the populations,

Table 1 and Figure 1 about here

Another layer of complexity is that, integration can also occur at different levels of the health care delivery system. Integrated care given by providers on a clinical level is supported and facilitated by policies influencing integration of financial and structural components at the level of practices, the larger health system, and health service payers (Butler et al. 2008; Mauer and Druss 2007). Integration as a concept can also be reflected in the understanding and beliefs of health care providers, policymakers, and the general public about whether mental health and physical health are separate or interrelated concepts.

## **Support for the Integrated Care Model**

In a systematic review of integrated care models, Butler, Kane, and Mcalpine, et al. describe five reasons in the research literature that support the integration of behavioral health into primary care. These reflect the findings above that people with mental illness suffer from high morbidity and mortality, often do not receive efficacious treatments, and that physical and mental illnesses are often comorbid. They also point out that persons with mental illness are as likely to be seen in the general health setting as in a mental health facility, they are more likely to be seen by a primary care provider every year, and there is evidence that effective mental health care can be delivered in a primary care setting. (Butler et al. 2008) At the same time, in support of the reverse co-location model, persons with SPMI often lack access to primary care and preventive services. (Butler et al. 2008) A 2008 publication by Funk and Ivbijaro enumerates a similar list, adding that integrating care has the potential to reduce stigma and discrimination (Collins et al. 2010).

There is also a growing body of research on integrated care. Over the past decade a number of systematic reviews have been published exploring the evidence for the efficacy of these integrated care models in improving both mental health and physical health outcomes. Overall, there appears to be positive evidence for the integrated care model in the treatment of patients with mental illness and comorbid mental and physical illnesses, with the greatest amount of evidence being available in a primary care setting for persons with depression. (Butler et al. 2008; Gilbody et al. 2003; Huang et al. 2013; Smolders et al. 2008)

However, there are also limitations to this research. A 2010 article identified research gaps, where either the research has not been done or the evidence is weak. Remaining questions include the efficacy of the model in a specialty behavioral health setting and for diagnoses other than depression, which components of the model are most effective, and

questions regarding implementation, such as what factors influence adoption and sustainability of the model (Carey et al. 2013). These last two questions are reflected in a quote from an article by Peek, Cohen, and deGruy, which points out that while there is evidence for the efficacy of the model in improving quality and patient experience, research has not yet shown "how to make the clinical, organizational, and professional changes necessary to accomplish and sustain integration --or which of these changes yield the greatest benefit" (C J Peek, Cohen, and deGruy 2014, 430).

### **Integrated Care in North Carolina**

Within this context of growing interest in and research on integrated care, North Carolina, on the state level, has also been fostering the growth of this new model. North Carolina's Medicaid system became nationally well known for its Medicaid care management program, Community Care of North Carolina (CCNC). CCNC is a collaboration between Medicaid, primary care physicians, and other care providers to provide care for patients with complex chronic illnesses in a way that addresses both quality of care and cost (Steiner and Denham 2008). The program created 14 community health networks across the state of North Carolina in which patients are assigned to medical homes which provide primary care as well as coordinate care from specialists and other health care professionals (Steiner and Denham 2008). CCNC, recognizing the frequency of comorbid mental and physical health problems, has been a proponent of the integrated care model. CCNC began a Behavioral Health Integration Initiative in 2010, which supports the integration of behavioral health professionals into CCNC primary care practices. The ultimate goal is for these co-located behavioral health specialists to provide mental health treatment within the primary care offices and serve as a liaison between the primary care provider and specialty mental health services, thus improving mental health and physical health outcomes for patients. (Community Care of North Carolina 2014a, 2014b)

The other leader in integrated care in North Carolina is the North Carolina Center of Excellence, which grew out of the ICARE (Integrated, Collaborative, Accessible, Respectful, Evidence-based) partnership, one of the first statewide organizations founded to support integrated care in the nation. ICARE began as a demonstration project from 2006 to 2009 to educate providers on the integrated care model by supporting the development of local pilot models, facilitating communication between primary care and behavioral health providers, and providing resources and technical assistance to integrated care practices. While the initial partnership has ended, the Center of Excellence continues to serve North Carolina as an educator on integrated care, a source for training and resources for providers who are initiating or implementing an integrated care model, and a facilitator for the collaboration of interested groups to develop best practices.(North Carolina Foundation for Advanced Health Programs 2014)

However, while there are strong proponents and advocates for improved mental health care in North Carolina, North Carolina also has a mixed history of providing quality mental health care particularly to Medicaid and uninsured patients and is no exception to the poor quality of care and lack of access described above for persons with mental illness in the United States.(Swartz and Morrissey 2012) Reform in North Carolina over the past two decades has attempted to address these shortcomings. In 2001, the public behavioral health system was reformed with the aim of shifting service from state psychiatrist hospitals to community based treatment. Local mental health agencies were converted to Local Management Entities, which, with state oversight, managed funding and private care providers, creating a newly privatized system of providers. (Rash 2012; Swartz and Morrissey 2012) However, this reform had the result of increasing the fragmentation of care, as private providers offered focused services and no one entity was charged with the coordination and overall care of patients, particularly those with high needs. (Swartz and Morrissey 2012) Further, the demand for state hospital beds did

not decrease and subsequently waiting lists for state beds were instituted.(Swartz and Morrissey 2012) Partly as a result of this, patients in crisis relied more on hospital emergency rooms, leading to long waits and increased mental health related ED visits.(Vicario 2012) This reform ultimately, was seen by many as “inadequate in building effective community-based services”. (Swartz and Morrissey 2012, 178) In 2011, further reform, which grew out of a struggling economy and concerns for the cost of Medicaid and was passed by a more fiscally conservative state legislator, consolidated the LME’s into the current system of 11 capitated managed care organizations (LME/MCO’s). (Rash 2012; Swartz and Morrissey 2012) There is some concern that this carve-out system could make it harder for behavioral services to be coordinated with the care management program under CCNC. (Swartz and Morrissey 2012)

Growing out of this history, the current situation in North Carolina provides a unique opportunity as well challenges for the integrated care model to become a standard part of the state’s policies and practices. The state government over the past year committed itself to reforming its Medicaid system. This has given proponents of the integrated care model a chance to advance the model once again. The North Carolina affiliate of the National Alliance for Mental Illness (NAMI NC) put integrated care at the top of its 2014 Public Policy Platform (NAMI-NC 2014). The Medicaid reform proposal that came out of the state advisory group in March included integration of mental health and physical health (North Carolina Department of Health and Human Services 2014) This proposal, however, has not passed in the General Assembly and a budget bill recently proposed in the state Senate chose not to build on the March proposal (General Assembly of North Carolina 2014). If integrated care is included in a bill that reforms Medicaid, this could create momentum on the state level for practice level and system wide integration of mental health and physical health.

## **The Formation of a Paradigm**

As illustrated by the historical roots of and growing evidence for integrated care, the inclusion of the provisions in the ACA did not happen by coincidence nor was it an isolated phenomenon. This is also true for the inclusion of the integrated care model in proposals for Medicaid reform in North Carolina. Two policy models can provide a framework for understanding the context and variables that created these opportunities—Kingdon's three streams and the Advocacy Coalition Framework. The first, created by John Kingdon, is a model that sees policy change as a result of the convergence of three streams—the political stream, which includes politics and public opinion; the policy stream, which includes propositions for potential solutions to a problem; and the problem stream, which encompasses the attributes of a problem including how it is changing, key events, and the availability of solutions. The convergence of these streams creates a “window of opportunity”, which allows for the possibility of policy change. (Birkland 2005)

A criticism of the Kingdon model made by Paul Sabatier was that, while the three streams can create an opportunity, this model does not explain how policy change can actually occur once this window opens.(Birkland 2005) Sabatier pioneered the Advocacy Coalition Framework (ACF) as a model of policy change that helps explain the variables and systems that, given an open window of opportunity, can push through policy change. A large focus of the ACF model is on the organization of interest groups into coalitions around a shared value or belief (Birkland 2005) and how policy design can ultimately be a “translation” of these coalition beliefs (Rytina 2012). Another aspect of the ACF is that it allows for seeing policy making is an evolving process which takes place over a long period of time.

The two theories, Kingdon's model and the ACF, are not contradictory. They contain parallel themes, such as the recognition of the importance of individual and organizational

actors, an understanding that there are dynamic variables at play in policy change, and that policy change is a product of movements over time. The ACF can complement Kingdon's theory by providing insight into both how these systems, variables, and actors can move Kingdon's three streams, and also how coalitions can mobilize to change policy given a window of opportunity created by the meeting of these streams. Both models suggest the ways that public opinion, politics, the nature of the problem, available solutions, and consumers and advocates may have all been influential in the growth of integrated care models as a paradigm in the treatment of mental illness.

### **Diffusion of Innovation Theory**

Understanding the spread of the integrated care model, however, goes beyond just exploring how the idea can and did become a part of policy. Another theoretical framework to help understand this process is the theory of diffusion of innovation. In an article summarizing past research on the science of innovation and applying it to health care, Don Berwick identified clusters of variables that influence the spread of new ideas. The first is the perception of the innovation. This includes the perceived benefit, which is really "comparing the known status quo with the unknown future" (Berwick 2003, 1971) and the compatibility of the innovation with current belief systems and current needs. Another important cluster is contextual factors of the organization or social system in which the innovation is occurring. These factors can either support or hinder the spread of new innovations. One way they can support change is by fostering an exchange of information between those who have tried the change and those who have not. (Berwick 2003)

Two of Berwick's recommendations, based on these theories of dissemination, are to make the actions of the early adopters of change visible and also to "trust and enable reinvention" (Berwick 2003, 1974). This second recommendation reflects a theme that Berwick

discusses in his article—spreading change requires an ability to adapt an innovation to the needs and abilities of the local environment (Berwick 2003). For the dissemination of the integrated care model in North Carolina, the theory of diffusion can provide a framework to understand what has worked well in spreading this new idea and what may help with its continued spread going into the future.

## **Key Questions**

With these frameworks in mind, I seek to explore the role that advocates, evidence, values, and policy played in the spread of the integrated care model in order to gain insight into how innovative ideas gain traction, are disseminated, and may ultimately become permanent fixtures in policy and practice. This is particularly important at this time as the Affordable Care Act has supported a shift to trialing new models of care and created the opportunity to further spread innovative models such as integration of primary and mental health care.

However, improving the quality of mental health care will not be easy. Barriers include differing professional cultures among primary care and behavioral health providers and the financing of integrated care within current payment structures (Collins et al. 2010; Mauer and Druss 2007). The 2008 AHRQ report calls the sustainability of the model a “major concern” as integrated models from research and pilots are translated into varied clinical settings (Butler et al. 2008, 4). The leap from finding and trialing evidence-based practices to encouraging widespread use in varied geographic regions and practice systems is daunting.

I seek to answer four key questions in this paper: First, how does an idea become a widespread paradigm and subsequently how does that larger paradigm translate into policy and into implementation in actual patient care? Second, who are the key players and what are the key features that have allowed integration to become a widespread idea? Third, what role might advocates and values play in this process compared to the role of research and evidence?

Finally, going forward, what is it that helps an idea become a permanent fixture in policy and practice? I hypothesize that in the spread and implementation of the integrated care model, research evidence, rather than being central to the dissemination of a new idea, is only one piece in the puzzle and is definitely not sufficient for the spread or sustainability of a new model.

## **METHODS**

### **Study Design**

The aim of this study is to gain greater insight into how integrated models came to be widely used, the role of evidence, policy, and advocacy in the spread of the idea, and whether this new model will become a permanent fixture in the care of mental illness. In order to do this, I have triangulated three research methods: a careful review of the literature, a systematic review of primary government policy documents, and in-depth policy interviews with key stakeholders and other experts in the field.

### **Stakeholder Identification and Recruitment**

For the in-depth interviews, I decided to perform a within-case analysis focusing on key stakeholders in North Carolina. I chose to focus on North Carolina for two reasons. First, this more narrow focus allowed for more in-depth insight into how a new idea is spread and implemented locally. While the exact political, institutional, and historical contexts found in North Carolina is likely different in certain ways from those of other states, the insight into how innovation occurs and the role of local policy makers, researchers, and physicians may illustrate real lessons and challenges of implementing new models that have gained national attention, but must come to realization in a local setting. Second, North Carolina has a history of long standing and current support for the integrated care model through organizations such as ICARE and CCNC. The spread of integrated care in North Carolina is an interesting case study

of successes, challenges, and the complexity of the spread of innovative ideas in a local context.

I used non-probability and convenience sampling to identify potential participants based on positions of leadership and expertise related to integrated care. The goal was to balance participants such that I had at least one representing each of the four domains of elective government, government bureaucracy, advocacy, and academia, as well as professionals working at integrated models. The potential respondents were recruited via email using email addresses that were publicly available. I interviewed anyone who responded and was willing to be interviewed. I was able to complete interviews with five of the six initial persons. One state representative referred me to his colleague who works in the legislator as a consultant on mental health issues to interview in his place. I originally planned to identify further potential respondents; however, given the time restraints of this project and since the six respondents were broadly representative of the four domains and identified similar concepts and themes, I did not contact further participants.

### **Interview Protocol**

With the guidance of my faculty advisor, I designed a comprehensive structured interview protocol. To design the interview questions, I identified the four key questions that I wanted to answer with my research, came up with key constructs needed to answer those questions, and then created interview questions to operationalize those constructs. The constructs that I strove to operationalize in the interview questions were the process of how an idea becomes a paradigm, process of how paradigm becomes policy, key players, key features of the idea that allow for spread, the role of advocacy, research, policy, and the interaction of the three, and the predicted success or failure of the integrated care model.

I received training on interview skills from my faculty advisor. The interview was designed to be completed by telephone. Four were completed by telephone, one in person, and one via email response. I recorded and transcribed all interviews. Respondents were offered the opportunity to review the transcription for accuracy if they desired. Because I am interviewing policy experts only on their area of policy expertise, I requested consent to identify them, as this strengthens the credibility of the research, but also offered anonymity if desired. All participants agreed to be identified by name and title. The research study was approved by University of North Carolina at Chapel Hill Institutional Review Board.

### **Coding and Analysis**

I created a systematic coding procedure to allow for quantitative and qualitative analysis of themes and constructs found in the transcribed interview responses. I started with 12 constructs, based on the original constructs I wished to capture through interviewing, and as I coded interviews, if a new construct arose that was important I added it to the codebook and analyzed the other interviews for this same construct. For some of the concepts, I explicitly asked participants about their importance, thus giving them an opportunity to disagree. However, most questions were open ended, so for many concepts, participants either mentioned them spontaneously as important or did not refer to them at all. The constructs were coded as either 'agree', 'disagree', or 'did not refer to concept'. I ended with a total of 65 categories. Ideally, I would have had a second reader also code interviews. However given the time and resource constraints, it is an accepted limitation of this study that there was only a single coder. I then analyzed the coded responses for common themes and I noted direct quotes from interviews that were particularly good illustrations of each of these themes.

## FINDINGS

### The Mental Health System and Integrated Care Model in North Carolina

The participants' perspectives on the spread of the integrated care model in North Carolina, while giving insight into the drivers and barriers to spread, also told a vivid story of the history of this model in North Carolina and how that history has created what one of the respondents, Cathy Hudgins [Director of NC Center of Excellence for Integrated Care], called a "perfect storm" for the integrated care model to become solidified into North Carolina policy and practice. As described earlier, the two key players in this story are the North Carolina Center of Excellence and Community Care of North Carolina (CCNC). The brief history I gave did not, however, capture all the players, practices, and organizations that the people I interviewed saw as important in bringing the integrated care model to North Carolina. The history of integrated care in North Carolina is both rich and deep. Other key players named by respondents are listed in Table 3. The recognition that the current situation creates opportunity for change is reflected in a quote from the interview with Debra Dihoff [Executive Director of North Carolina's affiliate of the National Alliance on Mental Illness]: "So I think we're still in for a time of change and development. And we'll have to just see if it works— see if this method of integrating care is going to really be effective." If integrated care is included in a bill that reforms Medicaid, this could create unprecedented opportunity for practice level and system wide integration of mental health and physical health.

Table 3 About Here

## **Variables in the Spread of Integrated Care**

In speaking with participants about the integrated care model, I kept a large focus on the variables that have facilitated the spread of integrated care in North Carolina, making it an idea that now has potential to become part of policy on the state level. The variables that participants identified as important are shown in Table 4. The responses reflect a shared view of the importance of three main categories of variables in the spread of this model. The first is that there is a problem to be solved. The second is that the integrated care model is an attractive solution to that problem. The third is that there is sufficient energy, collaboration, and resolve in the state to move this new idea forward.

Insert Table 4 about here

### **A Problem**

Two variables capture participants' views on the importance of the nature of the problem as a driver of the spread of the integrated care model. These variables are the visibility and urgency of the problem and, second, providers' intense frustration with the current system. Of note, all six participants identified the urgency of the problem as a key driver of the spread of integrated care. The participants recognized different aspects of both the character of the needs of the population with mental illness, recognizing the current lack of access, comorbidity of behavioral health conditions and chronic conditions, and high mortality, as well as the flaws of the current system in which behavioral health needs are not well met in the primary care setting and physical health needs are not well met in the behavioral health setting. Further, 4 out of the 6 participants identified the resulting frustration of health care providers as another driver. Hospitals, emergency rooms, primary care providers, and behavioral health providers are unable to meet the needs of their patients with the resources available to them. Both of these are illustrated in a hypothetical example given by Cathy Hudgins.

There's just a point of not being effective in talking to somebody when they keep coming back and back with the same issues medically or even behaviorally that have a comorbidity . . . that you weren't treating. So you knew that the choice, you know they're eating because of past trauma and you're helping them with their nutrition and you've given them this diet . . . But they just can't lose weight and, because there's trauma and no one's talked to them about this trauma. So they have grief and loss issues that are keeping them from being able to sleep and care for themselves and you know they have health issues because of that. And so you know, the things that are riding side by side and influencing each other's efficacy in terms of outcomes for the patient. And I think providers have always known that, they just didn't know what to do with it. And they didn't have time and they didn't have the person to do it.

Further, a common pattern in the interviews was to come back to the problem and need as a central driver for change. While this does reflect real and large gaps in the system of care, a quote from Beat Steiner [Associate Medical Director at Wakebrook Facility] also illustrates how this emphasis is also an important strategy in the spread of a new idea:

So in other words you need that burning platform to motivate change because there is such a strong desire to stay in the current system. I think that's another way to advocate, you go, this is so bad, you come up with lots of examples of why it is so bad so even if you don't have a perfect system to go to, you have this powerful example of how the status quo doesn't work.

In this case, proponents of this new model have likely both been moved and motivated by the needs of North Carolina's population and also know the importance of emphasizing the need for change. Tying this back into innovation theory, the perceived benefit of adopting this new model is high given the obvious problems in the current system and the poor outcomes for

patients. As Debra Dihoff put it, after referring to the suffering caused to families and communities when persons with mental illness die early, “It’s something that simply has to change.”

## **A Solution**

It is in this context, that the integrated care model offers a potential means to provide better care to patients. Another theme captured in Table 4 is that providers and others in health care do want to give this better care to their patients. Features of the model that participants identified as capturing the imagination of providers, advocates, and policymakers are shown in Table 5. Providing comprehensive and quality care that is also efficient, and doing this with the collaboration and support of other providers, is an attractive goal. This is reflected in two other variables identified as important drivers by almost all participants—the ideas of providing comprehensive care and having collaborative care. A quote from Beat Steiner illustrates this:

I give the patient an antidepressant, but what they really also need is counseling and I know that it is so difficult to navigate the system and it would be so much easier if I could just walk down the hallway. . . but I can’t walk down the hallway and get the counselor, psychologist, social worker to counsel.

The integrated care model is attractive as an opportunity to use collaboration to provide comprehensive care.

Interestingly, another variable that all of the participants saw as important is the face validity of the integrated care model. The model is viewed as an idea that makes sense. It is obvious that patients are not receiving quality care and collaborating with other providers to treat the full needs of the patient is a sensible goal. A quote from Courtney Cantrell [Acting Director of NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services]

uses an analogy to describe integrated care as an obvious and necessary addition to clinical practice:

I like to compare the emergence of the behavioral health consultant with a nurse...you can't always bill everything a BH consultant might do in primary care . . . but boy you wouldn't want to give up your nursing staff.

In the view of the participants, integrated care is an attractive and sensible solution to a pressing problem.

### **Converging Streams**

These last two categories of variables are illustrative of two of the three streams found in Kingdon's model. The problem stream encompasses the recognized flawed system and large need of primary care and behavioral health patients and the policy stream encompasses the integrated care model which is now on the table in North Carolina politics as one means to move towards more effective and efficient care of patients with behavioral health needs. The last stream, the politics stream, which includes politics and public opinion, was also addressed by participants, but with less overwhelming consensus.

One participant, Debra Dihoff, talked about the importance of changing public understanding and consumer empowerment.

I think people are becoming more empowered and realizing that health care needs to get better and be delivered . . . There's a greater understanding in the American public that our health care system is a problem.

The other five participants did not bring this concept up as important. This may be a reflection of Debra Dihoff's position with NAMI NC as representative of consumers with mental illness and an educator of the public on mental illness issues. A limitation of this study is that, since many

questions were open-ended it is not possible to assess whether other participants see this as less important or simply did not think to mention it.

The role of policy actually brought up a divergence in opinions. While four of six participants saw policy as playing an important role, there was disagreement over whether that role was to help or hinder the spread of the integrated care model. An example that illustrates this view is that the policy behind health care payment models was described by Beat Steiner as an impediment currently, but if reformed a potential support, for the integrated care model. Relating back to diffusion of innovation theory, these policies can be seen as the contextual factors in the system of North Carolina health care that can either support or hinder the spread of innovation.

### **Pushing the Idea through the Window**

Kingdon's three streams are reflected in the participants' responses. However, as described earlier, these streams are not sufficient to create policy change nor are they moving themselves. This is where the Advocacy Coalition Framework offers complementary insight into the role that advocates, coalitions, and brokers between groups play both in moving the streams forward and taking advantage of a window of opportunity. Further, within the Advocacy Coalition Framework, coalitions form and organize around a shared value or belief (Birkland 2005) and policy design can be a "translation" of these coalition beliefs (Rytina 2012). In the spread of integrated care models in North Carolina, ICARE has, in a sense, played that role by being an organization that brings people together. Cathy Hudgins, in talking about ICARE, of which she is the director, said:

One of the things that's unique for North Carolina is what we've been allowed to do is to be that convener of folks to try to determine a more comprehensive way to talk about it, something more unified.

ICARE has been an organization that has helped move the integrated care model forward in North Carolina.

Reflecting the importance of coalitions in bringing together interested groups, three participants saw the ability of diverse groups of providers, policymakers, advocates, and academics to come together and work together as a vital piece in the spread and current inclusion of integrated care into Medicaid reform proposals. As Cathy Hudgins put it, the relationships in North Carolina are “deep and broad”. Further, participants recognize the importance of involving players in decisions. Patricia Porter states that “. . . in North Carolina we have gradually become sensitive to the fact that we make changes and develop policy in this state best when the stakeholders involved are at the table early on.” This coalition of interested parties has played an important role in promoting the integrated care model and is working to take advantage of the current window of opportunity to further the position of the model in North Carolina.

### **The Role of Research**

Berwick in his article on the dissemination of innovation in medicine talks about the challenges of going from generating good ideas for change to actually using those ideas and disseminating that change. Something he does not talk about, though, is the complex reality of both generating ideas, testing them, and disseminating them all at the same time. Courtney Cantrell reflected the difficulty of this, saying, “Research on the BH Consultant model had to come as we’ve refined what works in primary care...building the plane while we were flying it.” The responses about the role of research in dissemination by the participants reflect a nuanced view of research (Table 6). Since I asked specifically about the role of research, there are respondents who disagreed that research played an important role. For most statements in the table, there is a split between those who agree and disagree. Further, there were a few

responses that I could not categorize as either agreeing or disagreeing, reflecting an individual's perspective that the role that research can play in policy and dissemination is often nuanced.

Out of the six respondents, half actually did not believe that research and evidence played an important role in the spread of the integrated care model. Cathy Hudgins stated that, "I'm not so sure that research really influenced anything. I just think that it started in primary care and the need was there more apparently." This again reflects the sentiment also seen in the interview with Courtney Cantrell that providers and practices were responding to their desire to better address the needs of their patients rather than evidence that the integrated care model was effective. On the other hand, Beat Steiner saw research as perhaps not sufficient, but still necessary:

It really seems that when there is no evidence that's a dangerous place, but often times even good evidence is not enough, so I think sort of what you need is you need the good evidence to be able to refer to, but then develop other strategies, the personal anecdotes, the powerful stories, but I think that is where the evidence helps, because there [are] some people who will pay attention.

The contrasting views expressed on the importance of evidence raise an important question. If, as with the integrated care model, the need is great and the solution makes sense, how important is the role of evidence?

Another reason that likely influences the view that research and evidence were not key in the spread of integrated care is that there are limitations to research. One limitation that came up in the interviews is that research can often be slow. Courtney Cantrell said, "Rather than waiting for research on best practices of integration, I think people just started doing what they believed would work." Another limitation is that the research of care delivery models such

as integrated care can be especially difficult. This is illustrated by another quote from Courtney Cantrell,

Being so broad and population-based, it is hard to do controlled studies of interventions...imagine doing a controlled study of what a primary care physician does in everyday practice...or what a nurse does.

Research, even when sought after, may be limited in its ability to influence implementation.

Further, there is a tension between the importance of creating a model that is replicable and can be easily described and researched and the importance of a flexible model that can meet the needs and goals of a unique practice in a local setting. A quote from an article by Don Berwick touches on the importance of being able to meet local needs—"local adaptation, which often involves simplification, is nearly a universal property of successful dissemination"(Berwick 2003, 1971). Reflecting an understanding of the importance of this, four of the participants saw the implementation of the model in real world setting, figuring out the logistics and details of how to integrate care in a way that is not overly complicated, as a potential barrier to spread. Also, two of the participants, Cathy Hudgins and Courtney Cantrell, suggested that one key piece in ensuring the continued spread and future success of integrated care was to allow the model to be flexible. A quote from Cathy Hudgins reflects both how evidence can serve as a foundation, while the model is still adaptable as it is implemented:

And they're all talking about integrated care, but they're terrified. It just doesn't sound doable for them. And I was so grateful for her to say that, because that gave me the opportunity to say you know, it's, you get to do it your own, this is yours. Now it has to be from an evidence-base. There's a foundation of understanding and theory behind and there are some best practices and they can be adjusted, if they just have to be applied.

The participants' views on research reflect the sometimes conflicting goals of creating an evidence-based, well-researched model and creating a model that is attractive and flexible enough to meet the needs of a diverse populations and practices.

### **The Future of the Integrated Care Model**

Another question that all the participants agreed on was that the integrated care model will continue to be important in the future. Their responses were confident and enthusiastic about its ability to spread and to improve outcomes, as well as become a permanent fixture in the way that primary care is practiced and the way persons with mental illness are treated. The quotes shown in Table 8 reflect the reasons for this confidence – again the need is great, the model is sensible, and, further, it can improve quality and save money.

### **Barriers and Suggestions**

There are also barriers that will need to be addressed so that the integrated care model can truly thrive. Barriers identified by participants are shown in Table 7. Two important themes that came up in talking with participants about barriers are the importance of communication and bridge building, as well as the influence of payment models as either a help or hindrance.

The one variable that all the participants brought up as a barrier was the divide between mental health care and physical health care systems and providers. Two explanations for this are training and the resultant culture of practice. This is illustrated in a quote from Cathy Hudgins:

Then you kind of are working like from the, you know parts of the elephant. Ok, here's your tail and this is a leg and you know. Um, behavioral health issues have always kind of looked at it from the psychosocial, so when, and here's the medical doing the bio. If you put those altogether it makes sense, but we've not been trained to really to do that.

Given this barrier it is not surprising that two suggestions to improve the probability that the model will be successful (Table 7) are to share lessons between people who are implementing the model and to have clear definitions and communication about the integrated care model.

Another way the mental health care system and physical health care system are divided in North Carolina is in the way that the state pays for care. As a separate variable, payment models were recognized as a key barrier by five participants. The current system and potential problems is summed by this quote from Patricia Porter:

It has been difficult because we have a physical health model that is based on fee-for-service and we have a mental health system of services that is based in capitated at risk managed care. And so we have a very, very closely managed mental health system now in which the LME/MCO is given an actuarially sound amount of money every year and they must function within that amount of money. And then we have a relatively non-managed fee for service system in physical health in which the physician can and does provide whatever services they see fit. And they bill whatever they can in order to draw down the amount of money to support their work. Now, neither of those systems are inherently bad, but it's very difficult to integrate the two, those systems.

This demonstrates how integrating mental and physical health solely at the practice level is not sufficient.

In the United States, Medicaid is the largest payer of services for people with mental illness. (Swartz and Morrissey 2012) In NC, 52% of adults needing mental health services are treated by the state's public system of care. (Duda and Rash 2012) Thus, state-level Medicaid policies and reform are a necessary to improve provision of mental health services. For the integrated care model to spread further and for practices to be able to bill for services and

sustain themselves, it will take the decision to support the idea of integrated care at the level of policy.

## **Limitations**

The six participants in this study offered rich perspectives on what drove the spread of the integrated care model in North Carolina and barriers and suggestions as to what they see as important going into the future. However, the small number of interviews limits the ability to generalize their perspectives to the perspectives of all proponents of the integrated care model in North Carolina. Many other people have played an important role in this state and could offer further insight. However, the six participants did cover all the domains of elected government, bureaucracy, advocacy, and academia. By the sixth interview, few new themes were coming up. This offers reassurance that although limited, these six interviews do still offer breadth and fairly comprehensive insight into this topic. This study is also not designed to be generalizable to other states' experiences. It is rather an in-depth exploration of the North Carolina case. It can however offer insight into North Carolina's experience with variables that might support or block the spread of the integrated care model.

Two ways this research could be furthered would be to interview a larger number of people within North Carolina. This in particular could offer further insight into the role of variables where there was not consensus, such as the role of policy and research. Another research design would be to interview people in similar positions in other states that have implemented integrated care models. This could offer insight into whether the experience in North Carolina and the drivers and barriers identified in this study are unique to North Carolina or shared by other states. I suspect that while the history of integrated care and key players in North Carolina may be unique, many of the same drivers, such as a recognition of a problem, frustration of providers, and the attractiveness of the solutions, and the same barriers, such as payment and cultural divide, would be important in other states.

## **GOING FROM IDEA TO PARADIGM: SUSTAINING THIS NEW MODEL OF CARE**

The dissemination of a new idea is always challenging. As identified in this study, there are multiple barriers to acceptance, not the least of which is resistance to change, especially in a model such as integrated care which requires a significant investment of time and energy as well as a shift in paradigms of patient care. However, this study also suggests that a few characteristics can help a new model spread, and they can be emphasized by proponents to assist in that spread. Foremost is whether the new model appears to be, in the view of those who would be implementing and promoting it, a good idea. On one level that can mean it is based in evidence and has research proving its efficacy, however this study suggests that perhaps more important is whether the idea is sensible and if there is a perceived need for change. As Berwick put it when talking about diffusion of innovation, what matters is if the innovation is “compatible with the values, beliefs, past history, and current needs of individuals”.(Berwick 2003, p. 1971) In this study, this is reflected in the emphasis on both the face validity of the model and the importance of the need for action. For other states that would like to foster the spread of the integrated care model or for any new model, it is important to focus on why there is a need for change, why the new model makes sense as a way to address that need, and how it is coherent with perceptions of what is good patient care.

What appears less sure in this study is what role evidence does and should play in the dissemination of new models of care. Research and evidence are important and likely necessary for the spread of a new idea, but it is unlikely that evidence alone is sufficient. This study also raises the question of what role research should play in the case of the integrated care model, where there is obvious need and high face validity. The traditional randomized control trial (RCT) is important as a foundation to show the efficacy of a new model in order to allow it to be scaled up, but it is also limited. RCTs may create interventions that are unsustainable in local practice and exclude participants with comorbidities.(C J Peek, Cohen, and deGruy 2014). This allows the RCT to answer whether a complex intervention works for a

certain set of patients. Yet, it is questions such as what component of that intervention is most helpful, what pieces are essential and which are not, that are often more relevant to those who must implement changes in real world practices.

As a number of respondents pointed out, researching new practice models and balancing the importance of a flexible, adaptable model that can fit local needs with a researchable intervention are challenging. Given this, there is a need for more creativity in adapting research methods to answer questions relevant to local practices, as well as provide the information needed by clinicians, payers, and policymakers seeking to spread, support, or implement new models. Implementation research, which emphasizes creating generalizable knowledge to facilitate implementation at a local level, offers an alternative to traditional research (Damschroder, Peikes, and Petersen 2013).

This is explored in an article by Peek, Cohen, and deGruy. For them, research on the integrated care model must go beyond just the question of *what* works to *how* to move clinical, operational, and financial pieces to make a model work (C J Peek, Cohen, and deGruy 2014). One way to do this is through pragmatic clinical trials in which randomization occurs at a practice level and the intervention is designed for a real world setting, emphasizing effectiveness over efficacy and external over internal validity. These trials combine qualitative and quantitative methods to understand both the outcomes and the process of implementation for complex interventions, such as the integration of primary care and behavioral health.(C J Peek, Cohen, and deGruy 2014) Implementation research can also include quality improvement research.(C J Peek, Cohen, and deGruy 2014) However, Peek, Cohen, and deGruy point out that it is important for practices to utilize data from quality improvement to create generalizable knowledge.(C J Peek, Cohen, and deGruy 2014) This caveat goes back to the suggestions given by participants in this study to create a learning network in order to share lessons between practices.

Research that goes beyond the question of whether a specific model works, to explore how to make that model work better, will help overcome the challenge of spreading a new model and facilitate the closing of the gap between what is known in research and what is actually practiced in clinics. Ultimately, if researchers design studies that are generalizable and relevant to real practices and if clinical practices share lessons learned in the process of implementing new models, the integrated care model will be more sustainable.

The integration of mental health and physical health appears to be an idea that has taken root and continues to spread in North Carolina. Whether this will be supported by new policy is yet to be seen and state policymakers in their current debate over Medicaid funding have the potential to either support or create greater barriers for the integrated care model. Proponents, however, are confident that despite barriers this is a model that will continue to be important and shape the way primary care is practiced and the way mental illness and behavioral health needs are treated into the future. Allowing flexibility, designing research that is relevant to clinics implementing the model in a local setting, and sharing lessons learned will make it possible for the integrated care model to go from a well-like but still uncommon idea to a regular part of practice.

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**TABLE 1: Models of Integrated Care**

<b>Model (other names)</b>	<b>Description</b>
Integrated Primary Care (Primary Care Behavioral Health)	<ul style="list-style-type: none"><li>• Integrates specialty behavioral health care into a primary care setting.</li><li>• Typically to provide care for persons with mild to moderate mental illness.</li><li>• Can also address behavioral health needs of persons with physical illnesses or any other problem.</li></ul>
Co-Located Care	<ul style="list-style-type: none"><li>• Primary care provider and mental health provider working in the same practice.</li><li>• Implies proximity in space, but not necessarily collaboration</li></ul>
Reverse Co-Location (Bi-directional Model)	<ul style="list-style-type: none"><li>• Integrates physical health services into a behavioral health setting</li><li>• Addresses the physical needs of persons with severe mental illness.</li></ul>

Adapted From: Peek CJ, Ph D, National T, Academy I. *Lexicon for Behavioral Health and Primary Care Integration*.

**TABLE 2: Interview Participant Characteristics**

<b>Name</b>	<b>Title</b>	<b>Organization</b>	<b>Reason for Inclusion in Study</b>
Beat Steiner	Associate Medical Director, Professor of Family Medicine	UNC Wakebrook Facility	<ul style="list-style-type: none"> <li>Family medicine trained academic physician who is helping lead an initiative to integrate primary care services into a mental health hospital.</li> </ul>
Verla Insko	State Representative	North Carolina House of Representatives	<ul style="list-style-type: none"> <li>Long standing proponent for mental health care in North Carolina.</li> </ul>
Debra Dihoff	Executive Director	National Alliance on Mental Illness (NAMI), North Carolina affiliate	<ul style="list-style-type: none"> <li>NAMI is nationally well-known advocate for mental illness.</li> <li>NAMI NC testified for NC Medicaid Reform Advisory Group on mental health reform and integrated care.</li> </ul>
Patricia Porter	Senior Advisor and Policy Consultant to the General Assembly	North Carolina General Assembly	<ul style="list-style-type: none"> <li>Recommended by State Representative Nelson Dollar.</li> <li>Works closely with Representative Nelson Dollar on issues related to health and human services.</li> </ul>
Cathy Hudgins	Director	North Carolina Center of Excellence for Integrated Care	<ul style="list-style-type: none"> <li>NC Center of Excellence (previously ICARE) supports North Carolina practices implementing integrated care and promotes the integrated care model.</li> </ul>
Courtney Cantrell*	Acting Director, Policy Advisor for Integrated Care	NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services	<ul style="list-style-type: none"> <li>Testified at Medicaid Reform Advisory group hearing on integrated care</li> </ul>

\*Interview with Courtney Cantrell was completed via written email response. All others were spoken interviews.

**TABLE 3: Key Players in the Spread of the Integrated Care Model**

<b>Key Players</b>	<b>Responses Included in this Category</b>	<b># who mentioned this group as a key player*</b>
Elected Government	Governor's office, elected officials	3
Bureaucratic Government	DHHS, Office of Rural Health, Division of Medical Assistance	4
Advocates, Consumers, and Families	Patients, families, and advocacy groups	4
Academia	Universities, NCIOM, ICARE	3
Health Care Providers and Professional Organizations	CCNC, MAHEC, BH professional groups, PC professional groups, providers, hospitals	6
Other	Foundations	1

\*Out of 6 total participants.

**TABLE 4: Drivers in the Spread of the Integrated Care Model in North Carolina**

Variable	# who mentioned this variable as:*			Illustrative Quotes
	Important	Not Important	Did not refer to it	
Problem that needs to be solved	6	0	0	"So I think it comes from, I think Berwick used it . . . the idea if you are in the middle of the ocean and you are on an oil rig and it's burning, right, everything is caught on fire, you have to do something." (BS)
Frustration of Providers	4	0	2	"I think also it's, there's just a point of not being effective in talking to somebody when they keep coming back and back with the same issues medically or even behaviorally that have a comorbidity . . . that you weren't treating. . . And I think providers have always known that they just didn't know what to do with it." (CH)
Face Validity of Model	6	0	0	"Well I think that it is just so full of common sense. Why would you only treat part of the person, why aren't people working together for whole health outcomes." (DD)
Importance of Comprehensive Care	5	0	1	"And we have to have a integrated system that responds to the changing needs of these individuals and the fact that many of those needs are not uh managed by licensed health care professionals. And they are just as important to the quality of life of that person as the, as the acute health needs, often." (PP)
Idea of Whole-Person Care	1	2	3	"Yeah I suspect it's partly holistic care, but I think it's partly the frustration of just having such a dysfunctional system. . . ." (BS)
Collaborative/ Team Care	5	0	1	"I think it's becoming increasing clear through data, through studies that you have to care for both the brain and the body. And you have to care for it together." (DD)
PCP's Want Full Scope Primary Care	3	0	3	"Some primary care doctors want to provide all the basic services for their patients. I believe they would say that is a quality of care issue." (VI)
Patient Access to/ Comfort with Certain Provider	4	0	2	"I think a lot of people with mental illness like just going to primary care docs, because they aren't labelled by going to see a psychiatrist in the same way." (DD)  "This is the model that really ensures that individuals with SPMI and SA have access to primary care that really understands their issues. (CC)
Coalition of Interested Groups	3	0	3	". . . the thing about North Carolina too, and maybe it's just my sense of it, is relationships are deep and broad." (CH)
Right People/ Right Time	2	0	4	"...we're right now in a perfect storm to make this happen." (CH)

Excitement/ Energy/ Resolve	5	0	1	“ . . . the interest and the excitement is there and the support. . .I’ve never been in a place, especially when we have a lot of meeting all the time, where people get mad if you don’t invite them.” (CH)
Change in Public’s Attitude	1	0	5	“There’s a greater understanding in the American public that our health care system is a problem. And then particularly for people with severe mental illnesses.” (DD)
Cost/Finances	3	0	3	“I think finances really end up being a much driver than any of us think...” (DD)
Policy	4	0	2	“So I guess anyone that’s you know designing policies for payment or against payment reform or for payment reform is either impeding or helping that.” (BS)
Affordable Care Act	2	3	1	“The inclusion of the, of integration in the ACA has, as is true of any federal initiative, does have an impact on the state. . . But, um again, I would like to think that part of our commitment to integration and mental health and physical health care comes from our understanding and our knowledge of the gaps that we’ve seen in actual patient care.” (PP)
Needs of Rural Areas	1	0	5	“but I think North Carolina has some risk factors that are more unique. . . the rural areas are so desperate for providers, on both the primary care and the mental health side.” (CH)

\*Out of 6 total participants.

**TABLE 5: Features of the Model that Capture the Imagination**

Concept	# who mentioned this concept as important*	Illustrative Quotes
Comprehensive/ Whole Person Care	5	"I was once at the NC council annual meeting, they are a trade association for LME/MCOs, and they put on a skit. . . And the psychiatrist, it was just sort of a parody of our system and how it works right now. He completely ignored all of those other physical health symptoms and said, well I guess things are going well with your meds and I'll see you again in four months, or whatever he said. But, its common sense that you need to look at the whole person, in looking at health care. This compartmentalization makes no sense." (DD)
Collaboration/ Coordination	5	"Right so I give the patient an antidepressant, but what they really also need is counseling and I know that it is so difficult to navigate the system and it would be so much easier if I could just walk down the hallway and [?] but I can't walk down the hallway and get the counselor, psychologist, social worker to counsel." (BS)
Efficient use of Resources	3	"Health care costs have been increasing a lot faster than inflation. Medicaid takes a bigger and bigger % of our state budget and is crowding out other programs. It is not sustainable. We must be more efficient - without compromising good care." (VI)
Quality of Care	4	"And again because it's so hard to get the psychiatrist on the phone quickly and all of a sudden you really feel like gosh I'm not providing good care."(BS)
Providing Basic Health Care	1	". . . let's get basic health care to people with severe mental illnesses. And it should be routine, it should be a matter of policy, it shouldn't be hard for them to go out and get that care." (DD)

**TABLE 6: Perspectives on the Role of Research**

<b>Statement</b>	<b># who:*</b>			
	<b>Agree</b>	<b>Disagree</b>	<b>Mixed</b>	<b>Did Not Refer to It</b>
Research played important role in the spread of model.	2	3	1	0
Research is important, but it is lacking.	3	0	0	3
Politicians use evidence when making policy.	3	1	1	1
Evidence drives the implementation of new models.	0	5	1	0
Hard to research integrated care model.	1	0	0	5
Research is too slow.	2	0	0	4
Evidence is not sufficient for spread of new idea.	1	0	0	5

\*Out of 6 total participants

**TABLE 7: The Future of the Integrated Care Model**

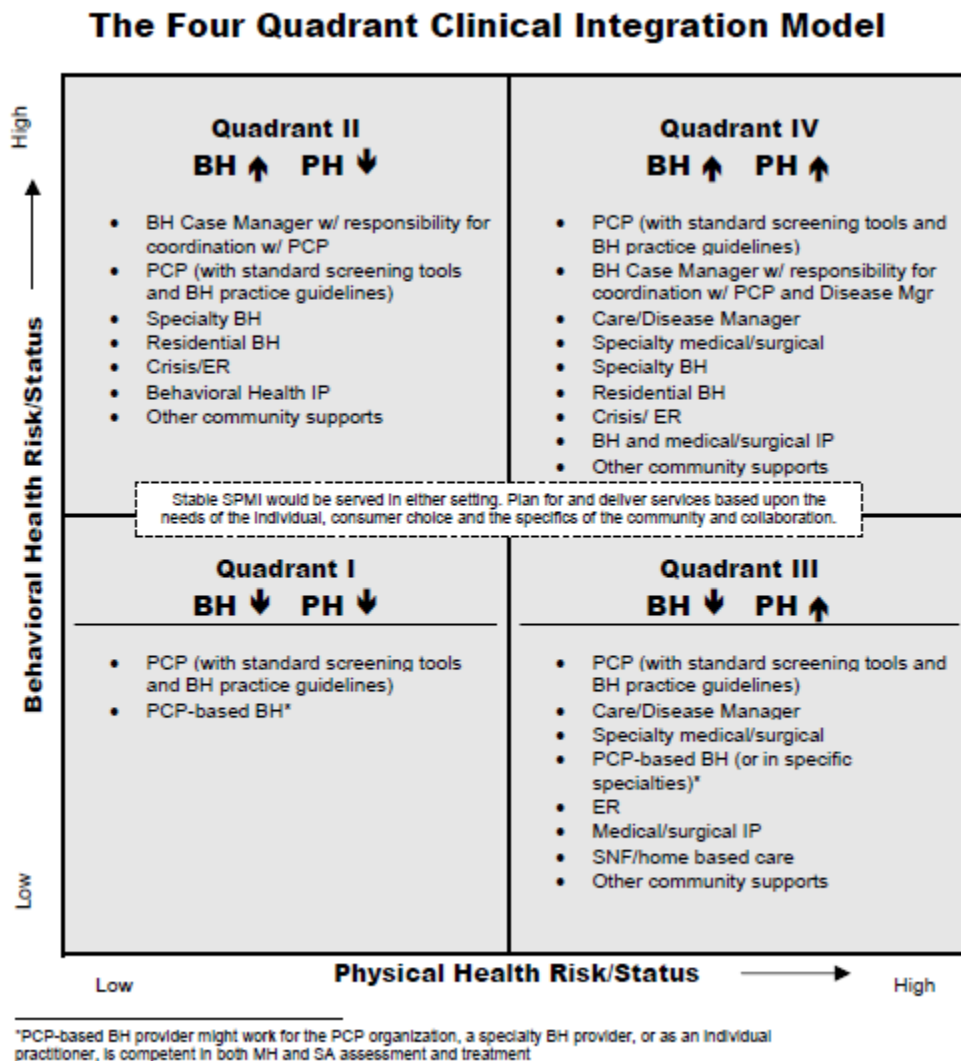
<b>Concept</b>	<b># who mentioned this concept as important*</b>
<b>Features that will allow it to continue to be important:</b>	
High satisfaction	1
Team based approach	3
Better care	2
Model that is responsive to local setting's needs	2
Broad support	3
<b>Barriers to success:</b>	
Divide between mental and physical health systems	6
Payment models	5
Resistance to change	4
Limited resources	2
Real world implementation	4
Lack of clear definitions	2
<b>Suggestions for the model to be successful:</b>	
Sharing Lessons/ Creating a learning network	3
Flexible model	2
Clear definitions, communication, and expectations	4
Full integration	1
Bridging the divide between mental and physical health	2
Patience	3

\*Out of 6 total respondents. All other respondents did not refer to the concept.

**TABLE 8: Will the Integrated Care Model Remain Important?**

Participant	Quote
Patricia Porter	"I think it will have growing importance because I think we can no longer fragment services for people, we just can't afford to do that. And I think consumers of health and mental health services are becoming more knowledgeable consumers and I don't think they are going to stand for the kind of fragmentation that we've had in the past. So I think it's very very important for the state to pay a great deal of attention to this and again begin with what's in the best interest of that particular individual and that patient."
Debra Dihoff	"O, I just think it's one of those ideas, there's no going back from. It's so sensible. The data is so clear that we spend too much, we don't achieve good outcomes, people die early, the practitioners themselves feel inadequate on both sides. Yeah, I think it's going to stick with us. I absolutely do."
Cathy Hudgins	"We have this speaker at the policy summit in Colorado at our last CFHA meeting, she says you know after you buy a suitcase with wheels you'll never buy another one without. And it just such, if people will open it up and let it happen and policies start catching up to the practice, I can't see how anyone would go back the other way."
Courtney Cantrell	"It is just GOOD CARE. Not special care. It addresses needs for people that help prevent them from needing specialty care, it helps people who would never followup with a specialty referral, it fosters communication, it allows for population-based screening and interventions for BH and behavioral issues. When PCPs have a good integrated team going, the BH Consultant becomes about as important a part of the team as a nurse. Research does show us that addressing those BH issues, as payment models move to pay for performance and subcapitation, will improve quality and save money."

Figure 1: Four Quadrant Clinical Integration Model



Source: Mauer BJ. *Background Paper: Behavioral Health/Primary Care Integration Models, Competencies and Infrastructure*. Rockville, MD; 2003.

## **Integration of Primary Care and Mental Health Care: The Formation of a Paradigm**

### **INTRODUCTION**

Disparities in the treatment and outcomes of persons with mental illness in the United States are well documented and pose high monetary and disability costs to society. (Institute of Medicine 2006; U.S. Department of Health and Human Services 1999; World Health Organization 2008) The Patient Protection and Affordable Care Act (ACA), signed into law in 2010 by President Obama, sets out a number of provisions to help address these disparities. These provisions provide funding and support for a newer concept in the care of mental illness, that of integration of primary care and mental health services. This integration is supported both indirectly by payment reform and increased access to insurance and directly through grants for demonstration projects. Two particularly important provisions in the ACA include a grant for patient centered medical homes, which provide the opportunity to integrate mental health services into primary care, and co-location grants, which provide funding for demonstration projects that integrate primary care services into specialty mental health facilities.

Over the past decade a number of systematic reviews have been published exploring the evidence for the efficacy of these integrated care models in improving both mental health and physical health outcomes.(Butler et al. 2008; Gilbody et al. 2003; Huang et al. 2013; Smolders et al. 2008) The most comprehensive of these reviews, published in 2008 by Mary Butler, Robert Kane, et al, was commissioned and funded by the Agency for Healthcare Research and Quality.(Butler et al. 2008) It is a comprehensive review which looks at randomized controlled trials and high quality quasi-experimental trials to assess the evidence for whether models of integration lead to better outcomes and how those outcomes vary based on

study population. This systematic review divides integrated care into two divisions—the integration of mental health into a primary care setting and the integration of primary care into a mental health setting.

For the first model, that of mental health care integrated into primary care, the authors conclude that, overall, there is positive evidence that integrated care improves mental health outcomes for persons with mental illness compared to usual care. Evidence is strongest and most abundant for the care of depression, but there is growing evidence for anxiety disorders and sparse evidence for other mental illnesses such as ADHD. There is also more limited and less consistent positive evidence for improvement in quality of life and physical outcomes such as arthritis pain with the integrated model for patients with depression. The authors also did an analysis to see if the level of integration, which they scored for each study, correlated with outcomes. While overall integrated care was linked to better outcomes, there was no correlation between outcomes and level of integration. For the second model, primary care integrated into a mental health setting, the authors only identified three eligible studies. These studies provided positive, although limited, evidence for improvement in quality of care and patient outcomes with the integrated model compared to usual care.

Overall, the authors conclude that current evidence suggests potential benefit to patients with the integrated model of care; however, they also recognize limitations in the evidence. In particular, they note a need for further research on what subgroups might most benefit from integrated care, how integrated care affects outcomes in mental illnesses other than depression, and what elements of the model are essential to improved outcomes. Ultimately, they conclude that while there is reasonable evidence to encourage the integrated care model as a means to improve outcomes, particularly in depression, they also warn against “premature orthodoxy” in regards to a particular model for integrated care given the lack of a “clearly superior model”. (Butler et al. 2008, vi)

The positive outcomes found in the Butler review have been replicated in other reviews, including another 2008 systematic review comparing various primary care interventions for anxiety. This review concluded that the best evidence for improved outcomes in anxiety was for collaborative care interventions which included communication between a primary care provider and mental health specialist.(Smolders et al. 2008) A 2003 systematic review also found that improved outcomes in primary depression care was seen in complex interventions such as increased integration of primary and specialty providers.(Gilbody et al. 2003) A more recent systematic review and meta-analysis published in 2013 which focused on patients with comorbid depression and diabetes, found that primary care based integrated care compared to usual care led to improved depression outcomes and medication adherence, but the meta-analysis did not show greater improvement in A1C.(Huang et al. 2013) Overall, there appears to be positive albeit limited evidence for the integrated care model for the treatment of patients with mental illness and comorbid mental and physical illnesses, with the greatest amount of evidence being available in a primary care setting for persons with depression.

Given that these reviews already comprehensively assessed the evidence for the integrated model, my focused systematic review will incorporate grey literature from the federal government and important academic sources. In an article published in 2012, Bevin Croft and Susan Parish note that the integration of primary and mental health care had been a key priority in policy for the decade preceding the passage of the ACA, with the Institute of Medicine (IOM) and numerous federal agencies, including the Substance Abuse and Mental Health Services Agency (SAMHSA), and the Department of Health and Human Services (DHHS) publishing reports, holding meetings, and adopting initiatives to promote integration.(Croft and Parish 2013) While evidence likely plays a role in the dissemination of this new model of care, in this paper, I look beyond research evidence to better understand the way that a new idea was framed by academicians and politicians and how the themes and beliefs found in research and

politics helped motivate the growth of integration into a paradigm that ultimately was codified into law and history through the ACA. To do this, I explore themes revolving around evidence, values, and historical roots discussed in a few key government agency and IOM reports published in the decade preceding the Affordable Care Act. In particular, I am interested into the importance of evidence compared to values in talking about the idea of mental health, mental illness, and reform.

## **METHODS**

In order to answer these questions, I identified key reports from federal government agencies that addressed mental health broadly or integration of primary care and mental health more specifically and that were published in the decade before the passage of the Affordable Care Act. These reports were identified through three methods. I searched PubMed on June 1, 2014 using the following search algorithm, “delivery of health care, integrated” AND “mental health services” AND “primary care” AND United States, and limiting the search to the decade before the passage of the ACA. This returned 66 English language results. I included articles that were published in the United States, focused on mental health services at a national level, were published by or with the support of federal agencies or the IOM or commentary on such, and that self-identified or were identified by other articles as key or important reports in the study of mental health. After excluding articles that did not meet these criteria, this search returned one article. I also searched the Institute of Medicine report database under the section “Quality Health Care” using the search term “mental health”, limiting the search to reports published in the decade before passage of the ACA. This returned 17 results. Using the same exclusion criteria as above, I found two articles that met the criteria. Last, I searched the references of identified articles, which led to the inclusion of two more articles meeting the criteria. In total, I identified five reports.

The first of the five reports, *Mental Health*, published in 1999 was initiated by U.S. Surgeon General David Satcher as a collaboration between the Substance Abuse and Mental Health Services Administration and the National Institute of Health. It was the first Surgeon General's report to focus on mental health. In the report's foreword, the authoring agencies identified the document as a "landmark report", growing out of other 1999 federal initiatives such as the White House Conference on Mental Health and Secretarial Initiative on Mental Health, and designed to both recognize progress in mental health care as well as serve as a call to action to continue progress.(U.S. Department of Health and Human Services 1999) The second report, titled *Crossing the quality chasm: A new health system for the 21st century*, was published in 2001 by the Institute of Medicine.(Institute of Medicine Committee on Quality of Health Care in America 2001) While focused on the health care system more broadly and not specifically on mental health, it is both influential and reflective of the attitudes and ideas captivating leaders in health care at the time. The third report is the *New Freedom Commission Report* published in 2003.(The President's New Freedom Commission on Mental Health 2003) This was a presidential commission announced by George W. Bush. Michael Hogan, the chairman of the commission, saw it as a response to growing attention to mental health exemplified by the Surgeon General report mentioned above and the growing pressure from a more "mature" mental health advocacy community. To Hogan, it was an opportunity to "galvanize change".(Hogan F. 2003)

The fourth report, titled *Improving the Quality of Health Care for Mental and Substance-Use Conditions*, was published by the Institute of Medicine in 2006 as part of the quality chasm series started by the 2001 IOM publication.(Institute of Medicine 2006) The fifth report published by the Agency for Health Care Quality and Research within the U.S. Department of Health and Human Services, titled *Integration of Mental Health/Substance Abuse and Primary Care*, was published in 2008 and is the only report uncovered by my search that focuses specifically on

integration of mental health and primary care.(Butler et al. 2008) These five reports are not a comprehensive list, but do capture attitudes towards mental health within the federal government and mental health policy priorities in the decade leading up to the passage of the Affordable Care Act.

I then identified themes discussed by each report and determined if and how the report talked about the history of mental health care and the role of evidence and research. I organized these themes into eight common categories that I found in some or all of the reports. This paper is not intended to be an evaluation of the evidence for integrated care nor an account of the history of mental health care, a description of health systems, nor disparities faced by persons with mental illness, but rather an exploration of the identified themes in order to capture the attitudes and belief systems that may have motivated the development of integration as a common idea in mental health care leading to its inclusion in the ACA.

## **RESULTS: INTEGRATION POLICY THEMES**

The eight themes identified in the reports include: the burden of mental illness, the historic and contemporary separation of mental health from physical health, the call to end this separation, the emphasis on collaborative care, a systems based approach, the important role of advocates, the contributions and gaps of research, and the need for societal resolve. Overall, the themes identified in these reports seem to reflect a similar purpose and approach. They reflect the desire to create a platform for change by showing the burden of illness and exploring the roots of the issue in fragmented systems of care; they suggest that it is both necessary and possible to improve care; and they provide an agenda and call to do so. Table 1 shows which themes were identified in each of the five reports. A more detailed description of how each of these ideas was described can be found in Sub-Appendix A. I explore each of these themes and how they are discussed below.

Table 1 about Here

## **The Burden of Mental Illness**

The first overarching theme in the reports is recognition of mental illness as a societal problem with high costs and broad and serious consequences for the United States. This concept was often used as an introduction and a justification for the reports. The New Freedom Commission reported mental illness as “common” and “universal”, words seconded by the 2006 IOM report.(Institute of Medicine 2006, 37; The President’s New Freedom Commission on Mental Health 2003, 1) The Surgeon General’s report, the New Freedom Commission, and the Institute of Medicine all highlighted mental illness as a significant cause of disability and mortality.(Institute of Medicine 2006; The President’s New Freedom Commission on Mental Health 2003; U.S. Department of Health and Human Services 1999) The Global Burden of Disease study conducted by the World Health Organization in 1990, which reported the disease burden of mental illness as secondary only to cardiovascular disease in established market economies such as the US, was cited commonly by these reports.(U.S. Department of Health and Human Services 1999)

The cost of mental illness was also laid out in financial terms. For example, the New Freedom commission reported the annual cost to the United States of treating mental illness as 71 billion dollars.(The President’s New Freedom Commission on Mental Health 2003) The 2006 IOM report estimated the direct cost of medical care for mental and substance abuse disorders in 2001 to be \$104 billion.(Institute of Medicine 2006) Both reports also mentioned the substantial indirect costs of mental illness, such as loss of productivity or costs to welfare or criminal justice systems. These reports posit the view that, as stated in the Surgeon General’s report, focusing on mental health is essential to “achieving prosperity”.(U.S. Department of Health and Human Services 1999, iii)

## **The Separation of Mental from Physical Health**

The next theme was the importance of the historical separation of mental health from the rest of the field of medicine and how that historical separation continues to play out in the current mental health system. This was explored in most detail by the Surgeon General's report, which traced the history of our current system from the belief of 17<sup>th</sup> century philosopher Rene Descartes that while the body is the concern of physicians, the mind is the concern of religion, through the 19<sup>th</sup> century use of asylums as a way to handle mental illness in the context of urbanization.(U.S. Department of Health and Human Services 1999) The 2006 IOM report recognized the separation as arising from a historical lack of understanding of the biology of mental illness, leading it to be seen as a social rather than medical problem.(Institute of Medicine 2006)

Further, the reports note that this historical separation continues to play out in the mental health care system today, in what the AHRQ report labelled as the “parallel health systems” of mental health and physical health services.(Butler et al. 2008, 10) Per the Surgeon General report, "these historical influences exert an often immediate influence on perceptions and behaviors in the modern world".(U.S. Department of Health and Human Services 1999, 23) Linguistically, “physical” is still used to distinguish general medicine from “mental” health (U.S. Department of Health and Human Services 1999, 23) and the reports point to a current system that is a “patchwork relic” offering services that are “fragmented, disconnected, and often inadequate” (The President’s New Freedom Commission on Mental Health 2003, 1) with multiple organizations and funding sources involved in the care of patients, lack of parity in payment, and the practice of “carving out” mental health insurance from general health insurance. (Institute of Medicine 2006; U.S. Department of Health and Human Services 1999)

Another important theme that comes up as a result of the historical separation of mind from body is the stigma that continues to be associated with mental illness. The surgeon general's report notes that "illnesses of the mind remain shrouded in fear and misunderstanding". (U.S. Department of Health and Human Services 1999, 3) The reports view this historical separation and stigma as continuing to cause profound harm and contribute to disparities in outcomes and barriers to quality care for persons with mental illness. (The President's New Freedom Commission on Mental Health 2003; U.S. Department of Health and Human Services 1999)

### **The Inseparability of Mental and Physical Health**

After beginning the report by laying out both the burden of disease and historical roots of our mental health system, another common theme was for the authors to then counter the historical separation with a strong assertion that mental health is inseparable from and as important as physical health. A number of quotes from the reports illustrate this emphasis. The Surgeon General's report states that "mental illnesses are just as real as other illnesses" and "mental health is fundamental health". (U.S. Department of Health and Human Services 1999, 3) The reports justify this claim with two assertions. The first is an assertion of the view that, as stated by the Surgeon General, "mental health and our physical health and well-being" have an "inextricably intertwined relationship". (U.S. Department of Health and Human Services 1999, 4) President Bush in his call for the New Freedom Commission echoed this, saying that "mental disability is not a scandal—it is an illness". (The President's New Freedom Commission on Mental Health 2003, 2) The AHRQ report, which focused specifically on the relationship between mental health and physical health as a reason to justify integrated care, and the 2006 IOM report also emphasized the link between physical health and mental health, noting that mental illness often exacerbates physical illness and, conversely, physical illness is common in persons with serious mental illnesses. (Butler et al. 2008; Institute of Medicine 2006)

The second assertion lies in looking back to more recent history, particularly the 1990s, and recognizing the advances in the understanding of the brain through neuroscience and the advances in the treatment of mental illness. Neuroscience helped to “[mend] the mind-body split” (U.S. Department of Health and Human Services 1999, 28) by allowing scientists to “observe the brain in action” (Institute of Medicine 2006, ix) and providing evidence that mental functions are “physical” and that changes in the brain are linked to changes in the body (U.S. Department of Health and Human Services 1999). These advances have both helped make mental illness into a more tangible and embodied disease and offered hope that, like many physical illnesses, it is treatable if not curable.

This theme can be summarized by the first recommendation made by the 2006 IOM report: “Health care for general, mental, and substance-use problems and illnesses must be delivered with an understanding of the inherent interactions between the mind/brain and the rest of the body.” (Institute of Medicine 2006, 11) These reports both assert and reflect a new view to counter the historical understanding of mental health as separate from physical health.

### **Collaborative Care as a Solution to Disparities**

Building on the view that the historical separation of mind and body is not only inaccurate, but harmful, the reports also sought to offer solutions that addressed both disparities in outcomes and the fragmented systems and disorganized care that contribute to those disparities. This is where the concept of integrated care came in, directly in the two reports from the IOM and AHRQ, and indirectly through emphasis on coordination and collaboration in the earlier Surgeon General’s and the New Freedom Commission’s reports. This is summed up well by two recommendations made by 2006 IOM report on mental health. The first recommendation is “To make collaboration and coordination of patients’ [mental and substance abuse] health care the norm” through routine sharing of information among providers. The

second recommendation builds on this: “To facilitate the delivery of coordinated care by primary care, mental health . . .” by formal agreements, case management, collocation of providers, and clinically integrated practices. (Institute of Medicine 2006, 16) This emphasis on collaboration, as well as recognition of the important role of primary care, is also found in the other reports.

### **A Systems Based Approach to Mental Health Care**

Looking beyond just the care of persons with mental illness, the reports also state the need to take a populations and systems approach to health. A quote from the IOM’s 2001 report on quality sums up this attitude:

"The committee is confident that Americans can have a health care system of the quality they need, want, and deserve. But we are also confident that this higher level of quality cannot be achieved by further stressing current systems of care. The current care systems cannot do the job. Trying harder will not work. Changing systems of care will." (Institute of Medicine Committee on Quality of Health Care in America 2001, 5)

This focus on systems reform is found in all of the reports and appears as an important theme in the recommendations made by the reports.

### **The Role of Advocates in Mental Health Care Reform**

Another theme that arose is the key role that consumers, families, and advocacy groups have played historically and currently in mental health care and policy. The Surgeon General’s report traces the strength of the contemporary advocacy groups from the consumer movement of 1970’s as well as a strong history family advocacy in mental illness. (U.S. Department of Health and Human Services 1999) This recognition of the contribution of consumers and families is also paralleled by an emphasis on patient and family centered care. The 2006 IOM

report even states that mental health care, with its strong history of consumer and family advocacy as well as a longstanding use of peer support and self-help programs, led the way for the contemporary concept of patient centered care. (Institute of Medicine 2006)

### **The Role of Research**

The next common theme is that of research and evidence based care. Scientific research as discussed previously is credited with making the advances that helped stimulate a new understanding of the brain and mental illness and with offering new and effective treatments for mental illness.(The President's New Freedom Commission on Mental Health 2003; U.S. Department of Health and Human Services 1999) The structure of the reports themselves, which draw to varying degrees on research, also reflect this emphasis. However, despite recognition of advances, all of the reports also emphasize the gaps in knowledge and the need for further research. For the reports, the biggest gap is often stated not as a gap in basic science, but rather in the knowledge of how to go from evidence to evidence-based care and how to make sure that known efficacious treatments actually reach people with mental illness. The New Freedom Commission calls for demonstration projects to find a "more effective system to identify, disseminate, and apply proven treatments to mental health care delivery" (The President's New Freedom Commission on Mental Health 2003, 24) and the IOM calls for "translational research" that will allow existing knowledge to be applied in the usual setting of care (Institute of Medicine 2006, xii). Research has allowed a better understanding of the mind as a part of the physical body, but has not yet overcome the barriers that keep people with mental illness from reaching recovery.

### **The Need for Societal Resolve**

The reports however also recognize that more research and the dissemination of evidence are not sufficient to change the system. The last theme is that of a need for a societal

valuing of mental illness. The Surgeon General's report states that, "promoting mental health for all Americans will require scientific know-how but, even more importantly, a societal resolve that we will make the needed investment". (U.S. Department of Health and Human Services 1999, 4) This concept is also seen indirectly in the strong assertions, which can be seen as value statements, of the importance of mental health. In the reports, mental health is a "cornerstone" (U.S. Department of Health and Human Services 1999, 467), "essential" (The President's New Freedom Commission on Mental Health 2003, 12), and "crucial" (Institute of Medicine 2006, xi) to the health of individuals and populations and the "prosperity" of the nation (U.S. Department of Health and Human Services 1999, iii).

## **DISCUSSION**

The eight themes described above -- the burden of mental illness, the historic and contemporary separation of mental health from physical health, the call to end this separation, the emphasis on collaborative care, a systems based approach, the important role of advocates, the contributions and gaps of research, and the need for societal resolve -- reflect an overarching story for mental health care in the United States and give a logical context for the adoption of the idea of integrated care a paradigm. The turn of the century and the decade leading up to the signing of the Affordable Care Act reflect the greater shift in the view of mental health from being separate and less than physical health to being a part of and essential to the health of a whole person.

These reports reflect the value being placed on mental health and assert a perspective counter to historical views. The reports identified two potential contributors to this shift. The strength of consumer and family advocacy play out in the recognition of the importance to society of the harm caused by mental illness and an emphasis on patient-centered care. The scientific advancements in the understanding of the observable functions of the brain in health

in illness also influenced the recognition of the link between mental health and health. All of this occurred in the context of a growing recognition of health care as a system.

## **CONCLUSION**

Exploring these themes gives insight into why certain ideas can be so enticing at a given point in time. For the idea of integrated care, it was the intersection of the scientific research, the consumer advocacy, and the shifting values in health care that set the climate for its adoption as a paradigm in mental health care. The story is not over, and how this idea is sustained as the ACA continues to be implemented and demonstration projects funded and researched is yet to be seen, but this example suggests that ideas have a greater chance of becoming set as policy when there is a meeting of evidence and values.

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## TABLES

**Table 1: Reports and Identified Themes**

Name or Author of Report	Agency or Institution	Year	Themes Identified in Report
<i>Mental Health: A Report of the Surgeon General</i>	US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Health, National Institute of Mental Health	1999	<ul style="list-style-type: none"> <li>• Burden of mental illness</li> <li>• Separation of mental health from physical health</li> <li>• Call to end separation</li> <li>• Collaborative care</li> <li>• Systems based approach</li> <li>• Role of advocates</li> <li>• Contributions and gaps of research</li> <li>• Need for societal resolve</li> </ul>
<i>Crossing the quality chasm: A new health system for the 21st century</i>	Institute of Medicine	2001	<ul style="list-style-type: none"> <li>• Burden of mental illness</li> <li>• Call to end separation</li> <li>• Collaborative care</li> <li>• Systems based approach</li> <li>• Contributions and gaps of research</li> </ul>
The Presidents New Freedom Commission on Mental Health	Commissioned by President George Bush	2003	<ul style="list-style-type: none"> <li>• Burden of mental illness</li> <li>• Separation of mental health from physical health</li> <li>• Call to end separation</li> <li>• Collaborative care</li> <li>• Systems based approach</li> <li>• Contributions and gaps of research</li> <li>• Need for societal resolve</li> </ul>
<i>Improving the Quality of Health Care for Mental and Substance-Use Conditions</i>	Institute of Medicine	2005	<ul style="list-style-type: none"> <li>• Burden of mental illness</li> <li>• Separation of mental health from physical health</li> <li>• Call to end separation</li> <li>• Collaborative care</li> <li>• Systems based approach</li> <li>• Role of advocates</li> <li>• Contributions and gaps of research</li> <li>• Need for societal resolve</li> </ul>
Butler	Prepared for Agency for Healthcare Research and Quality	2008	<ul style="list-style-type: none"> <li>• Burden of mental illness</li> <li>• Separation of mental health from physical health</li> <li>• Call to end separation</li> <li>• Collaborative care</li> <li>• Systems based approach</li> <li>• Contributions and gaps of research</li> </ul>

## SUB-APPENDIX A: Evidence Table for Systematic Review

Author/Title, Year	Agency or Institution	Themes in Report
<i>Mental Health: A Report of the Surgeon General</i> , 1999	US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Health, National Institute of Mental Health	<p><b>Burden of mental illness:</b></p> <ul style="list-style-type: none"> <li>- P.20: report grows out of growing awareness of "centrality" of mental health and "immense burden" of disability associated with mental illness</li> <li>- P.21: mental health disorders are disabling</li> <li>- P.22: Mental health is "ingredients of each individual's successful contribution to community and society"</li> </ul> <p><b>Separation of mental health from physical health/ History:</b></p> <ul style="list-style-type: none"> <li>- p. 22: Rene Descartes: mind as completely separate from body; mind was concern of religion, body concern of physicians; thus today "mental" and "physical" health, despite 20th century science showing interrelationship</li> <li>- p. 23: use of language, "physical" to distinguish from "mental"</li> <li>- p. 23: 19<sup>th</sup> century separation of mental health treatment system from physical health</li> <li>- p. 23: "By the late 19th century, mental illness was thought to grow "out of a violation of those physical, mental and moral laws which, properly understood and obeyed, result not only in the highest development of the race, but the highest type of civilization" (cited in Grob, 1983)."</li> <li>- p. 23: "These historical influences exert an often immediate influence on perceptions and behaviors in modern world"</li> <li>- p. 24: public attitudes from 1950-1990 <ul style="list-style-type: none"> <li>o 1950s - mental illness as stigmatized condition with fear of "unpredictable and violent behavior"</li> <li>o 1996-increased scientific knowledge, but still social stigma (more freq. perception of violent behavior <ul style="list-style-type: none"> <li>▪ Why? <ul style="list-style-type: none"> <li>• Selective media reporting</li> <li>• Deinstitutionalization - can't distance oneself</li> </ul> </li> </ul> </li> </ul> </li> <li>- p. 26: As cause/ treatment discovered, diseases removed from mental health field <ul style="list-style-type: none"> <li>o Ex. Syphilis, hormone related disorders</li> <li>o Mental health field "repository for mental disorders whose etiology was unknown"</li> <li>o May reinforce stigma for those diseases left in mental health field</li> </ul> </li> <li>- p. 438: Parity: 1996 Mental Health Parity Act <ul style="list-style-type: none"> <li>o Focused only on "catastrophic" benefits</li> <li>o Prohibited different lifetime and annual limits on coverage for mental and somatic illness</li> <li>o Only for companies with &gt;50 employees</li> </ul> </li> <li>- p. 3: "mental health is often an afterthought and illnesses of the mind remain shrouded in fear and misunderstanding"</li> <li>- p. 4: Contrast this with advances in "illnesses of the body, once shrouded in fear"</li> <li>- p. 5: Past century of "extraordinary progress" in public health and medical science; But, mental health "relegated to the rear of our national consciousness"; "whispers and shame"</li> <li>- p.25: Stigma and separation of treatment systems, access to care, public reluctance to pay for mental health treatment <ul style="list-style-type: none"> <li>o "public generally ranks insurance coverage for mental disorders below that for somatic disorders"</li> </ul> </li> <li>- P.37: "The U.S. mental health service system is complex and connects many sectors (public-private, specialty-general health, health-social welfare, housing, criminal justice, and education). As a result, care may become organizationally fragmented, creating barriers to access. The system is also financed from many funding streams, adding to the complexity, given</li> </ul>

		<p>sometimes competing incentives between funding sources."</p> <p><b>Call to end this separation:</b></p> <ul style="list-style-type: none"> <li>- p. 3: "mental illnesses are just as real as other illnesses"</li> <li>- p. 3: "mental health is fundamental health"</li> <li>- p.4: "This report recognizes the inextricably intertwined relationship between our mental health and our physical health and well-being."</li> <li>- p.5: "mental health flow in the mainstream of health"</li> <li>- p.5: Advances in neuroscience <ul style="list-style-type: none"> <li>o Brain as "integrator of thought emotion, behavior, and health"</li> <li>o "one of the foremost contributions of contemporary mental health research is the extent to which it has mended the destructive split between "mental" and "physical health"</li> </ul> </li> <li>- p.4: These thing set "optimistic tone for progress that will be realized in the years ahead"</li> <li>- p.22: "Mind and body are inseparable" <ul style="list-style-type: none"> <li>o "mental functions" are "physical"</li> <li>o Neuroscience - illness seen in physical brain changes</li> <li>o Physical change in brain causes physical change in body (ex. Racing heart, dry mouth)</li> <li>o Suggests use of "mental" and "somatic" - where soma means body</li> <li>o Mental - mental functions paramount (brain disease, ie stroke, could be mental or somatic depending on function effected)</li> </ul> </li> <li>- p.26: "When people understand that mental disorders are not the result of moral failings or limited will power, but are legitimate illnesses that are responsive to specific treatments, much of the negative stereotyping may dissipate.</li> <li>- p.28: Neuroscience- "mending the mind-body split"</li> <li>- p.32: mind as physical: "In the process of transforming human experience into physical events, the brain undergoes changes in its cellular structure and function."</li> <li>- P.467: Conclusion of report: <ul style="list-style-type: none"> <li>o "The journey ahead must firmly establish mental health as a cornerstone of health: place mental illness treatment in the mainstream of health care services; and ensure consumers of mental health services access to respectful, evidenced-based, and reimbursable care."</li> </ul> </li> </ul> <p><b>Collaborative care:</b></p> <ul style="list-style-type: none"> <li>- P.417: increased reliance on primary care</li> <li>- P.419: discoordination of multiple organizations involved in care, multiple streams of funding</li> <li>- P.31: "Although the hybrid system that exists today serves diverse functions well for many people, individuals with the most complex need? and the fewest financial resources often find the system fragmented and difficult to use. A challenge for the Nation in the near term future is to speed the transfer of new evidence based treatments and prevention interventions into diverse service delivery settings and systems, while ensuring greater coordination among these settings and systems."</li> <li>- P.39: Ensure supply of mental health services and providers <ul style="list-style-type: none"> <li>o "fundamental components of effective service delivery": <ul style="list-style-type: none"> <li>▪ Integrated community-based services</li> <li>▪ Continuity of providers</li> </ul> </li> <li>o Primary care as source of care for less severe mental illness <ul style="list-style-type: none"> <li>▪ Facilitate entry into treatment</li> </ul> </li> </ul> </li> </ul> <p><b>Systems based approach:</b></p> <ul style="list-style-type: none"> <li>- P.20-21: Public health model for mental illness <ul style="list-style-type: none"> <li>o Concern for health of population</li> <li>o Recognition of links between health and environment</li> <li>o Focus from just severe mental illness to health promotion and disease prevention</li> </ul> </li> </ul>
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		<ul style="list-style-type: none"> <li>- P.33: Persons and illness or health must be understood in context of social environment</li> <li>- P.36: "In the United States in the late 20th century, research based capabilities to identify, treat, and, in some instances, prevent mental disorders is outpacing the capacities of the service system the Nation has in place to deliver mental health care to all who would benefit from it."</li> </ul> <p><b>Role of advocates:</b></p> <ul style="list-style-type: none"> <li>- P.31-32: "Consumerism/ consumer movement" <ul style="list-style-type: none"> <li>o Consumer/family organizations key in stimulating research and service delivery design</li> <li>o "powerful agents for changes"</li> <li>o Shared goals <ul style="list-style-type: none"> <li>▪ Overcome stigma</li> <li>▪ Focus on recovery</li> <li>▪ Draw attention to specific needs of particular populations</li> </ul> </li> </ul> </li> <li>- P. 107: Consumer movement <ul style="list-style-type: none"> <li>o 1970's- protests by former mental hospital patients, "liberation movements"</li> <li>o 1978 - President's Commission on mental health recognized formation of groups all over US</li> </ul> </li> <li>- P.109: self help groups</li> <li>- P.111: "empowerment" <ul style="list-style-type: none"> <li>o Consumers influence on mental health policy, tailoring of services to needs and involvement in planning, delivering, evaluating, services</li> </ul> </li> <li>- P.111: family advocacy <ul style="list-style-type: none"> <li>o Impetus for formation <ul style="list-style-type: none"> <li>▪ Fragmentation and lack of services</li> <li>▪ Deinstitutionalization <ul style="list-style-type: none"> <li>• Families left to care</li> </ul> </li> <li>▪ History of blaming families for mental illness</li> </ul> </li> <li>o P.111: large organizations: <ul style="list-style-type: none"> <li>▪ NAMI: Principal goal is advocacy for improved services for severely mentally ill <ul style="list-style-type: none"> <li>• "accomplishments are formidable" <ul style="list-style-type: none"> <li>o Expansion of community services</li> <li>o "prime force" behind legislation for parity</li> <li>o Lobbying for increased federal research funding and set up private research foundations</li> </ul> </li> </ul> </li> <li>▪ Federation of families for children's mental health (FFCMH), national mental health association(NMHA)</li> </ul> </li> </ul> </li> </ul> <p><b>Contributions and gaps of research:</b></p> <ul style="list-style-type: none"> <li>- p.3: Research -&gt; understanding mechanism of disease (brain based) and "lead to better treatments and improved services"</li> <li>- p.26: science base for report</li> <li>- p.27: "level of evidence"</li> <li>- p.35: Recognition of gap between research and implementation and/or access; "Care and treatment in the real world of practice do not conform to what research determines is best. For many reasons, at times care is inadequate, but there are models for improving treatment."</li> </ul> <p><b>Need for societal resolve:</b></p> <ul style="list-style-type: none"> <li>- p.4: "a challenge to the nation . . . To take action"; To "generate needed knowledge" and to "translate that . . . To the service systems"</li> <li>- p.4: "Promoting mental health for all Americans will require scientific know-how but, even more</li> <li>- importantly, a societal resolve that we will make the needed investment."</li> <li>- p.4: "The investment does not call for massive budgets; rather, it calls for the willingness of each of us to educate ourselves and others about mental health and mental illness, and thus to confront the attitudes, fear, and</li> </ul>
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		misunderstanding that remain as barriers before us. It is my intent that this report will usher in a healthy era of mind and body for the Nation."
<i>Crossing the quality chasm: A new health system for the 21st century, 2001</i>	Institute of Medicine	<p><b>Burden of mental illness:</b></p> <ul style="list-style-type: none"> <li>- p.10: depression, anxiety in top 15 priority conditions</li> </ul> <p><b>Separation of mental health from physical health:</b></p> <p><b>Call to end this separation:</b></p> <ul style="list-style-type: none"> <li>- p.14: eliminate practices that fragment care systems</li> </ul> <p><b>Collaborative care:</b></p> <ul style="list-style-type: none"> <li>- <b>p.9: principles in redesigning care:</b> <ul style="list-style-type: none"> <li>o "Care based on continuous healing relationships"</li> <li>o "Cooperation among clinicians" <ul style="list-style-type: none"> <li>▪ Collaboration and communication to ensure coordination of care</li> </ul> </li> </ul> </li> <li>- <b>P.11: challenges that organizations will need to navigate:</b> <ul style="list-style-type: none"> <li>o Serve chronically ill with "coordinated, seamless care across settings and clinicians and time"</li> <li>o Coordination of care across conditions, services, and settings</li> <li>o Team practice</li> </ul> </li> </ul> <p><b>Systems based approach:</b></p> <ul style="list-style-type: none"> <li>- Quality as system property</li> <li>- P.5: "The committee is confident that Americans can have a health care system of the quality they need, want, and deserve. But we are also confident that this higher level of quality cannot be achieved by further stressing current systems of care. The current care systems cannot do the job. Trying harder will not work. Changing systems of care will."</li> <li>- P.8: "improved performance will depend on new system designs."</li> <li>- P.21: final vision- "The committee envisions a system that uses the best knowledge, that is focused intensely on patients, and that works across health care providers and settings."</li> </ul> <p><b>Role of advocates:</b></p> <p><b>Contributions and gaps of research:</b></p> <ul style="list-style-type: none"> <li>- P.10: Evidence based care practices</li> <li>- P.13: Applying research to practice- currently slow (17 years)</li> <li>- P.13: Create infrastructure to ID best practices for care processes; enhance dissemination</li> </ul> <p><b>Need for societal resolve:</b></p>
The Presidents New Freedom Commission on Mental Health, 2003	Commissioned by President George Bush	<p><b>Burden of mental illness:</b></p> <ul style="list-style-type: none"> <li>- p.1: mental illness is common and universal</li> <li>- p.8: mental illness as cause of disability, suicide</li> <li>- p.8: high financial cost <ul style="list-style-type: none"> <li>o Annual economic indirect cost estimated at 79 billion in U.S.</li> <li>o 71 billion spent on treating mental illness</li> </ul> </li> </ul> <p><b>Separation of mental health from physical health:</b></p> <ul style="list-style-type: none"> <li>- p.1: Recovery is real possibility; But services support "fragmented, disconnected, and often inadequate, frustrating the opportunity for recovery"</li> <li>- p.1: Mental health care system is "patchwork relic" "result of disjointed reforms and policies"</li> <li>- p.1: "system presents barriers that all too often add to the burden of mental illnesses"</li> </ul> <p><b>Call to end this separation:</b></p> <ul style="list-style-type: none"> <li>- P.6: Bush- ""The time has long passed for yet another piecemeal approach to mental health reform. Instead, the Commission recommends a fundamental</li> </ul>

		<p>transformation of the Nation's approach to mental health care."</p> <ul style="list-style-type: none"> <li>- P.15: "Address mental health with the same urgency as physical health."</li> </ul> <p><b>Collaborative care:</b></p> <ul style="list-style-type: none"> <li>- P.9: consumer/family in partnership with provider; personalized care</li> <li>- P.11: "seamless and convenient" system</li> <li>- P.14: "Improving services for individuals with mental illnesses will require paying close attention to how mental health care and general medical care systems work together. While mental health and physical health are clearly connected, the transformed system will provide collaborative care to bridge the gap that now exists."</li> <li>- P.10: role of primary care providers <ul style="list-style-type: none"> <li>o P.17: early screening/intervention in "readily accessible, low-stigma settings" such as primary care office</li> </ul> </li> </ul> <p><b>Systems based approach:</b></p> <ul style="list-style-type: none"> <li>- P.9: "The Commission does not attribute the shortcomings and failings of the contemporary system to a lack of professionalism or compassion of mental health care workers. Rather, problems derive principally from the manner in which the Nation's community-based mental health system has evolved over the past four to five decades. In short, the Nation must replace unnecessary institutional care with efficient, effective community services that people can count on. It needs to integrate programs that are fragmented across levels of government and among many agencies."</li> <li>- P.9: traditional reform not enough, need for fundamental transformation</li> <li>- P.16: "The burden of coordinating care will rest on the system, not on the families or consumers who are already struggling because of a serious illness."</li> <li>- P.21: Use of IT to "foster continuous, caring relationships"</li> </ul> <p><b>Role of advocates:</b></p> <p><b>Contributions and gaps of research:</b></p> <ul style="list-style-type: none"> <li>- P.7: Science has broadened knowledge; But many americans not benefiting from these advances <ul style="list-style-type: none"> <li>o Treatments based on clinical research "languish" for years</li> </ul> </li> <li>- P.24: Need for circulation and availability of researchat community level; "more effective system to identify, disseminate, and apply proven treatments to mental health care delivery" <ul style="list-style-type: none"> <li>o Demonstration projects</li> </ul> </li> </ul> <p><b>Need for societal resolve:</b></p> <ul style="list-style-type: none"> <li>- P.12: goal- "Americans understand that mental health is essential to overall health"</li> </ul>
<p><i>Improving the Quality of Health Care for Mental and Substance-Use Conditions, 2005</i></p>	<p>Institute of Medicine</p>	<p><b>Burden of mental illness:</b></p> <ul style="list-style-type: none"> <li>- P.3: societal burden of mental illness</li> <li>- Mental illness is common</li> <li>- P.35: Poor care hinders recovery for many</li> <li>- P.38: Serious societal consequences for not providing care <ul style="list-style-type: none"> <li>o Leading cause of disability and death</li> <li>o Decreased productivity in workplace</li> <li>o High cost to nation</li> </ul> </li> </ul> <p><b>Separation of mental health from physical health:</b></p> <ul style="list-style-type: none"> <li>- P.59: Historical in origin: <ul style="list-style-type: none"> <li>o Poor understanding of "biologic aspects" led diseases to be viewed as social rather than medical problem</li> <li>o Specific therapies rareley mentioned in medical lit. before 1800</li> </ul> </li> <li>- P.60: Separation persists despite better understanding of biology <ul style="list-style-type: none"> <li>o Continued reliance on public-sector delivery systems and funding</li> <li>o Carved-out health plans</li> </ul> </li> <li>- P.60: "separation of those with M/SU problems and illnesses from the</li> </ul>

		<p>mainstream population might nurture the residual stigma and discrimination faced by some of these individuals"</p> <ul style="list-style-type: none"> <li>- P.218: "The President's New Freedom Commission reported that consumers often feel overwhelmed and bewildered when they must access and integrate mental health care and related services across multiple, disconnected providers in the public and private sectors."</li> <li>- P.219: separation of care systems</li> <li>- P.116: A previous Institute of Medicine (IOM) report found that carved-out M/SU services "do not necessarily lead to poor coordination of care.... However the separation of primary care and behavioral health care systems brings risks to coordination and integration..."</li> </ul> <p><b>Call to end this separation:</b></p> <ul style="list-style-type: none"> <li>- P.ix-x: "Link between mental and substance-use problems and illnesses and general health and health care is very strong."</li> <li>- P.x: "Mental and substance-use problems and illnesses should not be viewed as separate from and unrelated to overall health and general health care", "integrated concept" <ul style="list-style-type: none"> <li>o It is this that will allow for improved quality of care</li> </ul> </li> <li>- P.xii: High quality mental care is "crucial to overall good health"</li> <li>- P.11: Recommendation: "Health care for general, mental, and substance-use problems and illnesses must be delivered with an understanding of the inherent interactions between the mind/brain and the rest of the body."</li> </ul> <p><b>Collaborative care:</b></p> <ul style="list-style-type: none"> <li>- P.210: coordination of multiple providers</li> <li>- P.215: co-occurrence with "general health" conditions</li> <li>- P.16: "Recommendation 5-1. To make collaboration and coordination of patients' M/SU health care services the norm, providers of the services should establish clinically effective linkages within their own organizations and between providers of mental health and substance-use treatment. The necessary communications and interactions should take place with the patient's knowledge and consent and be fostered by..."</li> <li>- P.16: "Recommendation 5-2. To facilitate the delivery of coordinated care by primary care, mental health, and substance-use treatment providers. . ."</li> </ul> <p><b>Systems based approach:</b></p> <ul style="list-style-type: none"> <li>- P.x: "Dealing equally with health care for mental, substance-use, and general health conditions requires a fundamental change in how we as a society and health care system think about and respond to these problems and illnesses."</li> </ul> <p><b>Role of advocates:</b></p> <ul style="list-style-type: none"> <li>- P.xii: Mental health care led way for patient-centered care <ul style="list-style-type: none"> <li>o Strong voice of consumers, families, and consumer advocacy organizations</li> <li>o Long standing use of peer support programs (esp is substance-use illnesses)</li> </ul> </li> </ul> <p><b>Contributions and gaps of research:</b></p> <ul style="list-style-type: none"> <li>- P.ix: Report "represents the intersection of two key developments now taking place in health care" <ol style="list-style-type: none"> <li>1. increased attention to improving quality of care by paying attention patient preferences and values and scientific findings</li> <li>2. scientific research that gives better understanding of mental illness</li> </ol> </li> <li>- P.ix: Technology - neuroimaging, genomics <ul style="list-style-type: none"> <li>o "Observe the brain in action"</li> </ul> </li> <li>- P.xii: Gaps in knowledge <ul style="list-style-type: none"> <li>o Strong evidence for therapies and medications</li> <li>o One remaining need is how to meet needs of individuals with "complex and co-occurring mental, substance-use, and general</li> </ul> </li> </ul>
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		<p>health illnesses"</p> <ul style="list-style-type: none"> <li>○ Translational research: <ul style="list-style-type: none"> <li>▪ Apply existing knowledge to usual setting of care</li> </ul> </li> <li>- P.16: Use of "evidence-based coordination models"</li> </ul> <p><b>Need for societal resolve:</b></p> <ul style="list-style-type: none"> <li>- P.xii: "high quality care for mental and substance-use conditions that is crucial to overall good health."</li> </ul>
Butler, 2008	Prepared for Agency for Healthcare Research and Quality	<p><b>Burden of mental illness:</b></p> <ul style="list-style-type: none"> <li>- P.9: Mental illness can exacerbate care of physical illness</li> </ul> <p><b>Separation of mental health from physical health:</b></p> <ul style="list-style-type: none"> <li>- P.10: Historical practice of separating mental and physical health</li> <li>- P.10: "collaboration is taking place between providers from what has been two parallel health systems representing historically different perspectives and approaches to health and health care"</li> </ul> <p><b>Call to end this separation:</b></p> <ul style="list-style-type: none"> <li>- P.27: Recognition that "separation of mental and physical health into different medical specialties encourages providers to focus on only the conditions that fit within their specialty"</li> <li>- P.9: Integration leads to improved care of "whole patient"</li> </ul> <p><b>Collaborative care:</b></p> <ul style="list-style-type: none"> <li>- P.9: Aim of integrated care aligns with New Freedom Commission call for better coordination of care between primary and mental health care and dissemination of evidence based models to improve care at this interface</li> <li>- P.9: "Integrating mental health into primary care settings brings the care to where the patient is."</li> </ul> <p><b>Systems based approach:</b></p> <ul style="list-style-type: none"> <li>- P.11: "Models of collaborative integrated care will not be sufficient without system wide integration. Integration takes place at many levels, including organizations and financial, and is aided or hindered by the cultural integration of mental health, medical health domains and world views."</li> </ul> <p><b>Role of advocates:</b></p> <p><b>Contributions and gaps of research:</b></p> <ul style="list-style-type: none"> <li>- Focus of review is assessing quality and gaps in research</li> </ul> <p><b>Need for societal resolve:</b></p>

## APPENDIX B: Methods

### STUDY DESIGN

The aim of this study is to gain greater insight into how integrated models came to be widely used, the role of evidence, policy, and advocacy in the spread of the idea, and whether this new model will become a permanent fixture in the care of mental illness. In order to do this, this research triangulates three methods: a careful review of the literature, a systematic review of primary government policy documents, and in-depth policy interviews with key stakeholders and other experts in the field. The review of the literature and the systematic review of government documents allowed for process tracing within the scholarly literature and government documents to trace the development of the idea of integrated care and to identify what ideas and groups may have played an important role in the spread of the model of integrated care. The interviews provided further insight into important variables in the spread of integrated care, as well as thoughts on the sustainability of this model.

### METHODS

#### Stakeholder Identification and Recruitment

For the in-depth interviews, I decided to perform a within-case analysis focusing on key stakeholders in North Carolina. I chose to focus only on North Carolina for two reasons. First, this more narrow focus gave more in-depth insight into how a new idea is spread and implemented locally, which is important given that implementation, in any state, must occur within a local context of state policies and local movements. While the exact political, institutional, and historical context found in North Carolina is likely different in certain ways from other states, the insight into how innovation occurs and the role of local policy makers, researchers, and physicians may illustrate real lessons and challenges of implementing new models that have gained national attention, but must come to realization in a local setting.

Second, North Carolina has gained national attention for its innovative Medicaid program, Community Care of North Carolina, which has helped advance integrated care in the state through its Behavioral Health Initiative (Community Care of North Carolina 2014c), and the ICARE (Integrated, Collaborative, Accessible, Respectful, Evidence-based) project which operated from 2006-2009 and piloted and studied integrated care models self-identified itself as “establishing a national reputation” as a pioneer in integrative care (ICARE 2009). Currently, North Carolina is in a process of reforming the Medicaid system and integrated care has been included in reform proposals. (North Carolina Department of Health and Human Services 2014) Given both the long standing and current support of integrated care, the spread of integrated care in North Carolina is an interesting case study of successes, challenges, and the complexity of the spread innovative ideas in a local context.

I used non-probability and convenience sampling to identify potential participants based on positions of leadership within relevant organizations and institutions and expertise related to integrated care. In order to gain a breadth of perspectives, I wanted to identify participants who were involved directly with models of integrated care, advocacy groups, government agencies involved in healthcare, and academia. The goal was to balance participants such that I have at least one representing each of the four domains of elective government, government bureaucracy, advocacy, and academia, as well as professionals working at integrated models. To identify participants, I relied on my own knowledge of persons involved in integrated care and mental health. I also looked at resources from the North Carolina Foundation for Advanced Health Programs which sponsored the ICARE program and continues to be a resource and advocate of integrated care in the state. I also reviewed transcripts of 2014 hearing for the North Carolina Medicaid Reform Advisory Group (MRAG) which focused specifically on integrated care and looked to see which mental health advocacy groups testified to MRAG. The positions of the six original potential respondents I identified included medical director of an

integrated mental health facility, executive director of a mental health advocacy group, legislative consultant on mental health, state representative, director of an integrated care research organization, and Acting Director of the North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services.

This was not an exclusive list of persons important to the integrated care model. My goal was to identify people in all of the domains listed above, involved in the implementation, promotion, and policy making for the integrated care model. I planned to then use a rolling reputational method to identify further potential participants in all of these domains by asking each interviewee who they thought I should interview. My goal was to interview 6-10 persons that would broadly represent the domains of government, advocacy, clinical, and academia.

The potential respondents were recruited via email using email addresses that were publicly available. If I did not receive a response within one week, I sent a follow up email. I interviewed anyone who responded and was willing to be interviewed. I was able to complete interviews with five of the six initial persons. One state representative referred me to his colleague who works in the legislature as a consultant on mental health issues to interview in his place. I originally planned to identify further potential respondents; however, given the time restraints of this project and since the six respondents were broadly representative of the four domains and identified similar concepts and themes, I did not contact further participants.

## **Interview Protocol**

With the guidance of my faculty advisor, I designed a comprehensive structured interview protocol. To design the interview questions, I identified the four key questions that I wanted to answer with my research, came up with key constructs needed to answer those questions, and then created interview questions to operationalize those constructs. The four key questions were: 1) How does an idea become a widespread paradigm and subsequently

how does that larger paradigm translate into policy and into implementation in actual patient care; 2) Who are the key players and what are the key features that have allowed integration to become a widespread idea; 3) What role might advocates and beliefs play in this process compared to the role of research and evidence; and 4) Further, going forward, what is it that helps an idea become a permanent fixture in policy and practice? The constructs that I strove to operationalize in the interview questions were: the process of how an idea becomes a paradigm, process of how paradigm becomes policy, key players, key features of the idea that allow for spread, the role of advocacy, research, policy, and the interaction of the three, and the predicted success or failure of the integrated care model.

I received training on interview skills from my faculty advisor. The interview was designed to be completed by telephone. Four were completed by telephone, one in person, and one via email response. The interviews lasted between 30 minutes and one hour. I recorded all interviews and transcribed them. Respondents were offered the opportunity to review the transcription for accuracy if they desired. Because I interviewed policy experts only on their area of policy expertise, I requested consent to identify them as this strengthens the credibility of the research, but also offered anonymity if desired. All participants agreed to be identified by name and title. They also all agreed for direct quotes to be used. The research study was approved by University of North Carolina at Chapel Hill institutional review board.

### **Coding and Analysis**

I created a systematic coding procedure to allow for quantitative and qualitative analysis of themes and constructs found in the transcribed interview responses. I started with 12 constructs, based on the original constructs I wished to capture through interviewing, as well as the responses I had received during interviews. As I coded interviews, if a new construct arose that was important I added it to the codebook and analyzed the other interviews for this same

construct. For some of the concepts, I explicitly asked participants about their important, thus giving them an opportunity to disagree. However, most questions were open ended, so for many concepts, participants either mentioned them spontaneously as important or did not refer to them at all. Some of the constructs were coded as either 'agree', 'disagree', or 'did not refer to concept'. Others were categorical and responses were organized into a number of categories based on interview responses. After coding all of the interviews, for the variables with multiple categories, I separated each category into its own variable and coded each of these as either "agree", "disagree", or "did not refer". I ended with a total of 65 categories. Ideally, I would have had a second reader also code interviews. However given the time and resource constraints, it is an accepted limitation of this study that there was only a single coder. Coded responses were then qualitatively analyzed for common themes. Direct quotes from interviews were used to illustrate these themes.

## INTERVIEW PROTOCOL AND CONSENT

### **The Integration of Mental Health Care and Primary Care: Understanding the Rise of a Paradigm and Its Sustainability**

**A study by Rachel Weiner at the University of North Carolina at Chapel Hill**

#### **Information Sheet**

**IRB Study #**

**Consent Form Version Date:** 22 April 2014

**Principal Investigator:** Rachel Weiner, MD/MPH Candidate

**UNC-Chapel Hill Department:** Public Health Leadership Program

**Faculty Advisor:** Sue Tolleson-Rinehart, PhD

**UNC-Chapel Hill Department:** Assistant Chair for Faculty Development,  
Department of Pediatrics  
Associate Director, HC&P MPH, SPH

**Advisor Phone #:** (919) 843-9477

**Advisor e-mail:** [suetr@unc.edu](mailto:suetr@unc.edu)

**Study Contact telephone number:** (704) 608-7842

**Study Contact email:** [rachel\\_weiner@med.unc.edu](mailto:rachel_weiner@med.unc.edu)

**[Introductory script, embedding fact sheet and consent information]:**

Hello, I am Rachel Weiner. Thank you so much for talking with me today. I am a fourth-year medical student at the UNC Chapel Hill taking a year away from medical school to work on a master's degree in public health. I am doing this research for my master's paper.

I have asked to interview you because of your special knowledge of models of integrated care in mental health. I am talking to people like you who are in several different positions. I am interested in your views about how integrated models came to be widely used and a part of policy and your view on if this new model will become a permanent fixture in the care of mental illness.

My faculty adviser is Dr. Sue Tolleson-Rinehart. She is a faculty member in the UNC Schools of Medicine and Public Health. My only purpose is to gain a better understanding of this process. My advisor and I do hope that we will be able to publish results from this study in a scholarly journal.

The interview has several open-ended questions. The interview should last anywhere from 20 minutes to one hour depending on your time and what you want to tell me. I would like to record this interview on a digital voice recorder to make sure that I have an accurate record of your comments. I will not record this interview without your permission. If you do grant permission for this conversation to be recorded, you have the right to revoke recording permission at any time. I will transcribe the interview, and I will give you a copy of the transcript at your request.

The audiotapes made of the interview will be stored digitally on my computer and on the computer of my faculty advisor. Transcripts will be encoded on these computers as well, and they will be controlled by a password. Dr. Tolleson-Rinehart and I will be the only people who have the passwords. We will delete the audiotape files after the transcripts have been made.

Your participation in this study is completely voluntary. Your choice of whether to participate will not influence your future relations with the University of North Carolina at Chapel Hill. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time. At any point in the interview, you may refuse to answer a question or stop participation altogether.

This study has been approved by the UNC Institutional Review Board and you are welcome to contact the IRB about the study at 919-966-3113 or by email to [IRB\\_subjects@unc.edu](mailto:IRB_subjects@unc.edu).

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact me by phone at **(704) 608-7842** or by e-mail at [rachel\\_weiner@med.unc.edu](mailto:rachel_weiner@med.unc.edu).

Dr. Tolleson-Rinehart and I intend to try to publish the results of this project and will be glad to make findings available to you. If you want to ask Dr. Tolleson-Rinehart any questions, please send a message to [suetr@unc.edu](mailto:suetr@unc.edu) or call 919-843-9477.

Before we continue, would you please agree or disagree to each of the statements I am about to read?

I AGREE to have this interview tape recorded,

☐ Yes ☐ No

I GIVE PERMISSION for the following information to be included in publications resulting from this study

**My name:** ☐ Yes ☐ No

**My title:** ☐ Yes ☐ No

**Direct quotes from this interview:** ☐ Yes ☐ No

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Name of Participant (please print)

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Date

Thank you for your help with my project! Now we are ready to begin.

### **General Questions [for all respondents]**

To give you an idea of what I'm trying to understand, the "big picture," for me, is trying to learn how an idea becomes a paradigm and then a policy and a context for clinical practice.

Specifically, I am interested in the process of how the integration of mental health care and primary care came to be a model for practices in North Carolina and, on a larger scale, a part of the Affordable Care Act

So most of my questions are intended to get your insights on the emergence of this new policy.

1. First, integrated models of care have become widespread and they seem to be seen as one current solution to address poor health outcomes for persons with mental illness. I would like your own expert opinion on what you see as important variables in the spread of this idea. Are there certain groups or persons who were important in this spread?

Probe:

Which groups or advocates do you think played important roles in furthering this idea?

Has academic research made any difference, in your view?

And politicians and policymakers? Whom would you say were most important in this case?

2. I am interested in your perspective on the drivers that were responsible for getting integrated care in the Affordable Care Act. Who were the most important players?

And once again, do you think policymakers were using research evidence? That is, were they trying to make “evidence-based policy” here?

3. What is it about the model of integrated care that makes this an idea that has taken hold? What features of this model, do you see as particularly powerful in capturing the imagination and hope of providers, policy makers, and advocates?

4. I am trying to understand which variables may have been most important in this policy arena. When they talk about integrated models of care, I think a lot of people talk about the idea of treating people holistically and treating the whole person.

Do you think those beliefs helped to drive the inclusion of integrated care in the Affordable Care Act? Or were other things that were more important?

Do you think those beliefs helped to drive the implementation of integrated models of care at the local level as well?

5. A lot of the research I have read shows positive benefits for the integrated care model. But very little of this research has come out of mental health settings.

Is research and evidence driving the spread of this paradigm of collocating primary and mental health care, do you think? Or is it more that these new attempts to colocate will wind up driving the research and evidence, instead?

6. Integrated care is still a relatively young idea. Do you think it will continue to be important in the future?

Why/ why not?

What features of this model will allow it to be successful? And what features make it less likely to remain important?

[If yes to #6] The dissemination of new ideas in medicine is often quite slow.

What features of the integrated care model, could help with dissemination?

What are some challenges/ barriers to its spread?

### **[Questions for Medical Director]**

I have just a few more questions. I would like to understand more about the implementation of an integrated model of care at [name of clinic/hospital].

Who were the key players in implementing this model?

What role did advocacy, research, and policy play?

Its allies clearly think that integrated models of care are sustainable. In your view, what are the things that make it most or least sustainable?

What challenges do you foresee in the future?

### **[Question for Advocacy Group]**

What role has your organization specifically played in the spread of integrated models of care?

[If they are advocates] What are the most important reasons for your advocacy of integrated care?

[if they are not advocates of the model] What are the biggest concerns your group has about the model of integrated care?

**[For all respondents]**

Last question! Your public position on this issue has made you easy to identify and you have shown that you are a real expert on this topic! Could you suggest 2 other people in North Carolina whom, in your judgment, I should be speaking to?

[if you need contact information] could someone in your office help me get contact information for \_\_\_\_\_?

**Thank you so very much for your time and thoughts!** Do you have any additional questions or comments? Would you like a copy of this interview once it is transcribed? Thank you again!