No Parity without Clarity: The Challenge of Laws without Rules

Testimony of

Patrick J. Kennedy

Member of Congress, 1st District, Rhode Island, 1995-2011

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Mr. Chairman, thank you for inviting me here today to testify on the consequences of delay in the rulemaking process. It is my understanding that you have asked me to come before you because of my experiences in sponsoring the Mental Health Parity and Addiction Equity Act, MHPAEA, in 2008, while I was still a member of Congress, and, since then, in seeking implementation of that law, still a central focus of my activities as a private citizen.

Five years ago, when my father and I sponsored the Mental Health Parity and Addiction Equity Act (MHPAEA) and shepherded it through the House and Senate, we thought its signing by President Bush was the end of a process. In fact, it was barely the beginning.

As the theme of this Judiciary Committee Hearing indicates, a lot of ambitious laws get passed without anyone really being sure how they will be enforced—and, worse, without a clear roadmap for how those underlying rules will be researched and written and overseen in a reasonable amount of time. But the five-year wait for clarity on mental health parity is a particularly good—or particularly bad—example of the problem and the challenge. And I'm pleased to have the opportunity to share what has happened to this historic law, which also turned out to be the last one my father worked on—and my father and I worked on together—before he died.

The concept of parity began to emerge more than twenty years ago, when people with mental health diagnoses found themselves paying higher copays for mental health treatment and routinely facing arbitrary limits on such basic provisions of their policies as the dollar amounts of their coverage or the number of visits they could make to certain treatment settings. Many found their insurance cancelled after they reached those limits. It was evident that these limits were grossly out of line with the standards applied to coverage for other conditions. The quest for parity was seen as a simple question of fairness; it was an attempt to bring a halt to blatant discrimination against people with mental illnesses or substance use disorders.

As you know, parity laws of some sort were ultimately passed in over thirty states, and President Clinton signed a symbolically important federal law in 1996. These were all real advances that improved the lives of some people with mental health diagnoses and substance use disorders, but they were only incremental steps. The largest plans were not affected by the state laws, and the 1996 federal law was very limited in its scope. It took another dozen years to arrive at the law we ultimately passed in 2008. One reason for this was the need for legislators to reconcile different visions of what parity meant. On the House side, where I sat, and here in the Senate, those of us working on the bill heard a steady stream of stories – from the tales of individuals and families left with high bills and no access to the treatments they needed to the fears of insurers and employers that the costs of parity would be unbearably high. As frustrating as it was for a dozen years to go by before MHPAEA was passed and signed, I believe the final product reflected the best of the legislative process; it is a thoughtful and fair policy solution to a real inequity in our system that recognizes the different perspectives of the full "community of mental health."

As I say, those of us who had worked long and hard on this legislation felt pretty good about our ability to balance competing interests and draft language that could be supported by members of both chambers and both parties. Naively, it turns out, we believed we had done the heavy lifting and thought the regulatory process would simply operationalize the solution we had achieved. In truth, the Mental Health Parity and Addiction Equity Act instead entered a kind of twilight zone in which everyone with an interest in it was left to imagine what it meant. The prolonged regulatory process created an environment in which competing visions of parity could flourish with little guidance from the controlling authorities.

At best, insurance regulation is confusing, given the distribution of responsibilities among various state and federal agencies, depending on the types of policies, among other things. This parity law complicates matters even more. The Departments of Health and Human Services, Labor, and the Treasury all have authority over parts of the law. And MHPAEA even includes an important provision giving stronger areas of state law precedence over the federal statute. There's no question that developing regulations and enforcement mechanisms for the law is not easy. But this is the job of the executive branch of government, and it is not unreasonable to expect it to be done in a timely manner.

As I mentioned, parity laws have been passed in the majority of states over the past 20 years. Not only are these laws highly variable in the provisions they include, but regulatory and enforcement efforts in those states have largely been governed by a wait-and-see attitude. Few states have wanted to get out ahead of the federal government, especially when the largest plans – those with the greatest influence in the market – are regulated at the federal level.

Finally, it is important to understand that regulation of MHPAEA also has implications for the actions of unrelated departments and agencies and the programs they run. For example, we want to make sure that the VA's health programs for the veterans it serves are incompliance with parity. And, although outside of the scope of MHPAEA, Medicare still has a distance to cover in its journey to parity.

The big picture, then, is that the regulatory delay has held up not just the definitive implementation of MHPAEA, but it has stalled similar but unrelated efforts to end discrimination in multiple other settings. MHPAEA is the law, but parity is a concept that is advancing in the same way that other concepts of justice have advanced. The law is meant to guarantee non-discrimination in covered insurance policies, but behavior change occurs in many settings that are technically beyond the reach of the law.

Just to recap, MHPAEA was passed and signed into law on October 3, 2008, and its provisions became effective exactly one year later. Many insurance plans follow the calendar year; the effective date for them was January 1, 2010. The Interim Final Rule for MHPAEA was issued on February 2, 2010, effective April 5, 2010, and applicable to plan years beginning on or after July 1, 2010. We have been waiting for the Final Rule ever since then – over three years. We hear it is due out at any moment. But we've heard that a lot of times already.

What has happened during that period? The answer isn't pretty. The insurance industry has struggled to understand its obligations, and its response has been patchy. Some carriers have understood that parity provides opportunities for them to provide better service to their members and the employers who purchase much of the coverage they provide. They have tried earnestly to look ahead at the changes in the field wrought by the Affordable Care Act and have adjusted their practices to ensure access to comprehensive care that complies with both laws, as best they can determine.

At the same time, other carriers have taken this delay as an opportunity to continue or, indeed, institute practices that meet neither the spirit nor the letter of the law. But with the rule still not final, they appear to have reasoned, who’s to tell them not to. The result is that some families have faced the very discriminatory practices the law was meant to end.

Nature abhors a vacuum, the saying goes, and in this instance an unfiltered mix has swirled into the void left by the unfinished rule. Clearly, this is a situation that holds the potential to harm individuals and families not receiving the coverage they believe the law has guaranteed them, but it also contains many perils for insurers and the businesses that purchase their products. How can they formulate a reliable business plan without a firm understanding of their industry’s future obligations under the parity law? How can they assemble insurance plans providing coverage for an appropriate range of services if they don’t know what parameters the rule will place around those services?

We are also seeing cases brought to court in several states in which individuals are claiming they were denied benefits they believe the parity law should have guaranteed them. I can’t say whether private legal action would have been taken if the final rule had come out. But I do know that we are already seeing different courts head in several directions. I have to believe that clear guidance on the federal law would have put judges on firmer legal ground when hearing such claims.

I want to stop here and acknowledge that achieving parity is proving to be a process. I’ve already alluded to the long legislative journey that brought us to passage on October 3, 2008. We don't have time today to detail the many twists and turns in that journey, but I will say that we were on a continuous learning curve throughout. I believe that, at its best, the regulatory and enforcement process should also be one of regular information sharing and improvement, as well. The truth is that we are moving into waters no one has navigated before us, and we'll have to be vigilant about taking soundings and recalibrating our course as we move forward. But we must move forward, and the chief concern I want to express to this committee is that the failure to provide firm guidance – the lack of a final rule – has allowed us to drift off course. My father's memoir was titled, "True Compass," referring to his inner sense of direction in the causes of greatest importance to him. Having a rule sooner in the process would have given us a mark on which to set our compass in this important leg of the parity voyage.

I hope we all can learn from the experiences we have had with the parity law and its delayed rule. But I also want to express the view that the journey will continue even after the rule is issued – which, incidentally, could be any time. We have to be clear that implementation and enforcement of even a "final" rule will require constant vigilance. All the stakeholders must come together and figure out exactly what parity can be and must be, and to create a roadmap to equality in coverage of disease of all the organs of the body.

I should point out, however, one aspect of the wait for this final rule that is unique. Since the passage of the Mental Health Parity act in 2008, we have also lived through the passage of the Patient Protection and Affordable Care Act (ACA) in March 2010. That law offers its own unique version of establishing mental health parity, and it may very well be that the endless delays over the final rule for the 2008 law grow out of the endless controversies over the 2010 law. The ACA guarantees that pre-existing conditions won't be used to prevent us from insurance coverage, and also goes further in guaranteeing parity than our bill did. The ACA also expands coverage for early intervention and prevention, which dares us to confront our strategies and evidence deficits in both of these areas.

In the meantime, we are anxiously awaiting the crucial “final rule” on mental health parity. The protections of that final rule, along with those in the ACA, can provide a new kind of safety net for those with mental illnesses, addictions and intellectual disabilities. Then we have to start testing just how safe that net is.

Yet both laws come with the same challenge. Both dare us to define what parity is and should be: how it will be operationalized and, perhaps more important, how it will be enforced, especially for patients with severe mental illnesses who, like victims of cancer, could have permanent, life-threatening and unnecessary setbacks because of restricted or refused care.

This year, we are celebrating the 50th anniversary of President Kennedy’s Community Mental Health Act of 1963. It has provided the vision for recent mental health policy in this country, and for that is to be applauded. But the anniversary also gives us pause and forces us to face up to the fact that, in many places, President Kennedy’s vision was never realized.

What we know about the aftermath of the Community Mental Health Act of 1963 is that many of its well-meaning goals were underfunded and ultimately undermined—and, just two years later, when Medicare and Medicaid offered healthcare to the first time to many older and disabled Americans, it was a form of healthcare that treated certain diseases of the brain differently than all others. Just as “separate but equal” was being rejected as a formula for educating our children, a form of it was being embraced so that treatment for mental illness was made separate and not even equal.

The confluence of the Affordable Care Act and the Mental Health Parity Act represents a second chance to fulfill the promise of JFK’s plea that Americans with mental illnesses, addictions and developmental disabilities “no longer be alien to our affections or beyond the help of our communities.” But this will only happen if we come together to help make these laws work for us. Because, as I urge the committee to keep in mind, the reason to have these interim and final rules written faster, but also with more information gathered, is because so much needs to happen *after* the rules are published.

Because this coming Monday is Veterans’ Day, I want to make sure I stress one other extremely important reason for us to get implementation of the parity law right, and that is that no one stands to gain more from true parity than the men and women who have served our country and now need treatment for the invisible wounds they have brought home from Iraq and Afghanistan. Only some of our veterans receive services in the VA system. Many have come back to work for employers who provide their health coverage. We owe it to the men and women who have given so much for our country to guarantee they have access to the services that will enable them to flourish in our society. We need to make sure they are able to receive the best, evidence-based rehabilitation and services, just as we do for their brothers in arms with mangled limbs or other obvious wounds. When I think of the parity law, I always think of it as the best welcome home we can offer to our returning warriors.

Without actually seeing the final rules on Mental Health Parity, we already have a pretty good idea of what is still missing from them. Even with MHPAEA and ACA in place, we will still need more language, real-world scenarios, case law and perhaps additional regulations to guarantee the two most basic medical rights for those with brain diseases:

1) Patients must have access to the services they need in the setting that is most appropriate to their symptoms and situation, in a way that is no better than, but no worse than medical/surgical care. This means equal access to evidence-based treatments (medication,

psychotherapy, etc), equal access to inpatient, outpatient and intermediate care, and the elimination of "fail first" requirements that do not exist in the treatment of any other illnesses.

2) The process by which cases can be reviewed for compliance must be fully transparent, and a consistent level of enforcement must be maintained at the federal, state and local levels.

We believe the current laws already require both of these, but with little action to date to make them a reality, we can’t be certain the laws will be observed.

We call upon the federal government to finally create operative definitions of three concepts that are crucial to the future of care of brain diseases. They are:

1) “Parity”

2) “Essential Health Services” as they apply to brain health, with a definition symmetrical to all other illnesses for both treatment and preventive care

3) “Discrimination” as it pertains to the failure to provide parity in treatment of mental illness, addiction and developmental disorders.

Without modern, useful definitions of these three concepts, the new laws will never allow for proper oversight at the federal and state level. We must begin, immediately, a process to get to them—a process that all major stakeholders are part of, so none have an incentive to undermine or game it, as has happened in the past.

First, we need more information on current practice in mental health and addictions care, both in what is being covered and what isn’t and why. To that end, I’d like to suggest that the GAO look more closely into existing use of mental health services—including how it has changed over the five years since the parity law went into effect—and also into existing enforcement of mental health parity in the Department of Health and Human Services and the Department of Labor. We must make sure that the letter of the law is observed as implementation proceeds, and that is GAO’s task. But we also need to know that the right data is being collected for us to see whether the new policy embodied by the law is changing practice – in other words, whether people with mental health and substance use conditions are gaining access to the services they need at the same cost people with any other conditions would bear. We must have evidence that the experiences of the 1 out of 5 Americans with a mental health diagnosis prove the law is working.

Specifically, we must be able to know what people with mental health problems are spending out of pocket, and whether they have to go out of network or travel long distances to find the providers they need. If they do, is their experience different from that of someone with, say, diabetes who is covered by the same insurance plan?

As preventive care and early intervention are now required and covered as never before, can we make sure that a “checkup from the neck-up” is routinely done, and “mental health first aid” is taught like all other first aid?

And if there is a difference between the experiences of people with mental health or substance use problems and those of people with other conditions, we must be able to say, “That’s not parity.”

We are, of course, sensitive to the privacy needs of people with mental illnesses, addictions and intellectual disabilities. But we are also mindful that the new laws are supposed to protect them from their illnesses affecting the quality and equality of their care. The need for confidentiality at the federal, state and local levels when investigating alleged parity violations is important to fairness in the process. However, the current lack of transparency prevents others from learning from the experience. Perhaps the departments of Labor, Health and Human Services, and the Treasury could develop a system like the one used by the Internal Revenue

Service and the Department of Justice where tax opinions and antitrust opinions are provided based on a set of facts without names and made public so that the industry benefits from a common understanding of what is and is not acceptable conduct. We need some kind of system to create true “de-identified transparency” so that everyone can see and understand the emerging picture of parity under these new laws.

It is not the government’s job to bring together all the different stakeholders who will need to help interpret and agree on definitions that allow for the real-world challenges of care to be addressed. That is up to us.

To that end, over the past year, my former congressional colleague, Jim Ramstad, and I held our own local hearings on how parity was playing out in the real world. And two weeks ago, we held a historic meeting at the JFK Library to celebrate the 50th Anniversary of my uncle, President Kennedy’s signing of the Community Mental Health act, and to jumpstart a new collaboration between *all* the stakeholders in the “community of mental health.” It is called, appropriately, The Kennedy Forum. We engaged a large and varied group, including Vice President Biden, Secretary Sebelius, and many local, state, and federal officials, along with insurers, business leaders, researchers, providers, and, most of all, people who every day live with mental illnesses, addictions, and intellectual disabilities – all in all, a group of people who don’t often meet together.

My goal with the Kennedy Forum was to assemble all parts of the community and help them to recognize their common interest in being involved at this critical point in time so that we can be sure we do all we can to pave the way for access to and provision of effective and equitable services for the foreseeable future. As with implementation of the parity law itself, we won’t have such an opportunity again in our lifetimes.

It was inspiring to hear the directors of the Department of Health and Human Services, the National Institute of Mental Health, the National Institute of Drug Addiction, the Administrator of the Substance Abuse and Mental Health Services Administration, the president of the American Psychiatric Association, even the medical director of one of the more open-minded health insurance companies and one of the top attorneys challenging them, sit together in small conferences to try to find common ground. This is the beginning of a process by which all the people affected by the final rule on Mental Health Parity will try to work together to actually achieve that parity. It is the kind of consensus building that you would like to see come of the process of post-law rule writing, but seldom does.

For example, in the aftermath of the Kennedy Forum, the leaders of the top caregiver organizations involved in the conditions covered by the law—the American Psychiatric Association, American Psychological Association, American Medical Association, National Association of Social Workers, the National Council for Behavioral Health and the National Association of State Mental Health Program Directors—have agreed to attend an historic meeting to put aside their parochial interests and find common ground on how to make the most of this opportunity to provide accessible quality mental health care in the post-parity and affordable-caring world. In the words of APA President Dr. Jeffrey Lieberman, "true mental health care is not just the job of psychiatrists and psychologists, or mental health providers, but all health care professionals working in diverse settings ranging from hospitals and offices to student health services in schools and universities."

Over the next year, in partnership with our sister organization, One Mind for Research, we plan to convene additional events. Their goal will be to provide an easy conduit of communication between groups often barricaded in their own silos.

None of this will be easy. We have been grappling with these challenges and prejudices for centuries, ever since founding father Dr. Benjamin Rush wrote the first American textbook on mental illness as medical disease in 1812. But, just as the Civil Rights Act of the 1960s gave our nation a process of confronting long-held racial prejudice, the confluence of the ACA and the Mental Health Parity Act offer a process of confronting our long-held medical prejudices, and the damage they cause to patients, families and caregivers every day. And I remain hopeful that what we have done during our five-year wait for a final rule on parity can be a model both for how to best use the time between law and final rule, and how to shorten it.