DBSA

Depression and Bipolar
Support Alliance

August 29, 2016

Ms. Cecilia Munoz
Director, Domestic Policy Council
The White House
1600 Pennsylvania Ave., NW
Washington, DC 20050

RE: Mental Health and Substance Use Disorder Parity Task Force

Dear Ms. Munoz:

The Depression and Bipolar Support Alliance (DBSA) applauds the President and his team for creating the Mental Health and Substance Use Disorder Parity Task Force and appreciate this opportunity to address key issues about how mental parity is being implemented. We are pleased with the broad range of activities that have taken place to date and look forward to seeing continued improvement in this area.

About DBSA

DBSA is the leading peer-directed national organization focusing on mood disorders: depression and bipolar disorder. Unlike any other organization of its kind, DBSA is created for and led by individuals who themselves live with a mood disorder, with our bylaws stipulating that more than 50 percent of both the governing board of directors and paid professional staff must be people who have, or have had, depression or bipolar disorder. This first-person lived experience informs everything that we do.

DBSA envisions wellness for people with mood disorders. And, we believe that an open and collaborative approach to treatment—one that accounts for a person's mental, emotional, and physical health—is what allows people to achieve what they personally define as wellness. DBSA has a long history of providing cutting-edge, interactive online tools and resources that allow individuals to understand, choose, manage, and evolve their treatment plans. Additionally, our network of 300 chapters across the country offer more than 700 free, in-person support groups. These programs, enable DBSA to reach over three million people each year with current, readily understandable information about depression and bipolar disorder; connections to treatment and community resources; and—crucially—the hope that wellness is possible.

Ultimately, we believe that our balanced, person-centered, wellness-oriented approach is what has allowed us to educate, empower, support, and inspire individuals to achieve the lives they want to lead for our more than 30 years in existence. It is from this perspective of experience and relationships that we believe that DBSA is uniquely positioned to provide comment and share stories from our participants.

General Comments

Task Force Goal 1: Promote compliance with parity best practices

One of the most common concerns we hear from our participants is the lack of transparency provided by health insurance plans for treatment limitations, particularly those that are non-quantitative. The failure by health plans to disclose their non-quantitative treatment limitations (NQTL's) leaves plan beneficiaries unable to fully understand what benefits are available. As a result it restricts their ability to challenge an insurance plan's adverse decisions regarding a treatment plan. This is particularly serious when the plan beneficiaries are experiencing a mental health episode and unable to adequately advocate for their needs. It should be the responsibility of the health insurance plans to ensure full compliance with the parity laws and regulations—not the burden of the patient to wade through a morass of complex rules and requirements to ensure they are receiving the benefits due to them.

We applaud the fact that the Office of Personnel Management (OPM)—through an Executive Order—applied mental health parity requirements to the Federal Employees Health Benefit Program (FEHBP). However, we are concerned about reports that many people have been denied adequate coverage through a number of unspecified determinations. We would like to see OPM step up the collection of data on parity enforcement and require that participating plans adequately ensure compliance to the letter of the regulations.

One of the most serious concerns is lax enforcement on the part of regulators at the federal and state level. These concerns include: plan disclosure requirements, lack of network adequacy standards, restrictions on facility types and levels of care, and lack of parity in pre-authorizations, concurrent and retrospective reviews. We encourage the Task Force to work with regulators to increase their enforcement actions and assist plan beneficiaries by developing an easy process to report and resolve potential violations.

Task Force Goal 2: Support the development of tools and resources providing a roadmap to parity implementation and enforcement

As noted above we are very concerned about the lack of resources available at the federal and state level to educate plan beneficiaries about their rights. Just as concerning is the lack of resources dedicated to oversight and enforcement of the law. We commend the excellent work that has been done by the Kennedy Forum, Scattergood Foundation and Legal Action Center and are very proud of the Parity Implementation Education presentation that DBSA has developed and presented around the country (see attached). We stand ready to work with federal partners to assist with patient education through our extensive network, as this is a key aspect in ensuring that plan beneficiaries know their legal rights. Additionally, we strongly encourage regulatory agencies to improve their public education efforts through development of web-based materials and training of consumer affairs offices at both national and regional levels.

Task Force Goal 3: Develop additional agency guidance as needed to facilitate the implementation of parity

We concur with the Parity Implementation Coalition that additional enforceable guidance and regulations need to be developed. These actions should provide clarity to health insurance plans and eliminate ambiguity about whether practices are or are not compliant with parity laws. The guidance should also include specific examples of reporting processes that group health insurance plans may use for disclosing parity information.

Conclusion

On behalf of our participants and the millions of Americans who face mental health challenges every day, we thank the Mental Health and Substance Use Disorder Parity Task Force for the considerable time and effort that has been put into developing regulations that more effectively ensure equal health care benefits for individuals seeking mental health care.

We appreciate the opportunity to present these comments and look forward to an opportunity to discuss them in more detail with you and the task force. It is imperative that all individuals who live with mental health conditions are able to easily and fairly access the health insurance benefits that are due to them. Your work in this area is most appreciated.

Sincerely,

Allen Doederlein

Allen Doederlein
President
Depression and Bipolar Support Alliance

Attachment 1

Parity Implementation Stories Collected by the Depression and Bipolar Support Alliance

Over the past two years DBSA has collected a number of reports regarding the experiences DBSA participants have had addressing parity issues within the health care system. Listed below is a representative sample of these stories to help put a face on the issues that they have faced. For reasons of confidentiality we have removed the names of the individuals reporting the story.

Mother whose daughter lives with multiple mental health conditions

My daughter has battled anxiety, OCD, and a mood disorder for quite some time. She finally had to go to an assessment center in Wisconsin in March for 30 days and then to a residential treatment center in Asheville, NC after that. We pulled her from the program early for a variety of reasons and we are currently looking for an IOP for her age in our area, but there are none for adolescents under the age of 14. There is a tremendous need for change in this area. I am a child & adolescent therapist myself and am well aware of the need for this type of program.

Insurance has denied all of her claims for the RTC in Asheville that she attended from April through August 2015. I appealed the denial and they denied it again, stating it wasn't medically necessary, even though doctors stated it was necessary. I am going to the final appeal stage, but have been told they probably still won't pay. I am a single mom and I cannot afford the $10,000 a month for a RTC! Her father and I both had to take out loans to make the payments that totaled around $52,000. I am enraged that if my daughter had a physical ailment that insurance would have paid, but since she has mental health issues there is a total denial of payment for claims. The system has to change.

Mother whose daughter lives with bipolar disorder

Our daughter has bipolar mood disorder and takes Depakote ER. Last month upon going to pick up her medicine, which was usually $25 dollars, I was told my copay would be $186! The pharmacy told me that insurance wanted us to change to the generic form of Depakote. We have Blue Cross Blue Shield insurance. We can NOT afford this amount every month.

I called BCBS and was told I could appeal this with a letter from her psychiatrist stating why the generic was not strong enough for her along with a request to expedite this request.

6 years ago when our daughter was hospitalized and diagnosed with bipolar, the Dr. (same one she has now) released her with a script for the generic form of Depakote ER. Her anxiety and psychotic symptoms increased, and she couldn't sleep. She had to go right back in the hospital. Her Dr. wrote this in a letter to BCBS. On October 9, 2015 they denied our daughter the right to stay on the regular Depakote ER and still only pay $25. I found this out by phone. BCBS stated that they would mail me a copy of the Dr.'s letter and their decision.

Insurance should not mandate what medicine is best for our daughter's condition. Her Dr. has known and treated her for 6 years. He is the one who should be deciding what medicine works best for her. I hope you can help us with our problem.

Man living with depression

I would like to share my story of how treatment for difficult to treat depression has been denied in two different forms by two different insurance companies.

First, I will mention only briefly the first occurrence with the first insurance as I no longer have it, but nonetheless, has to be known. Additionally, I will compromise the act of diplomacy for the sake of making this information public knowledge not just for consumers to make informed decisions, but for law makers to be aware of what has occurred to at least one patient that has been in great need of mental health treatment.

The first case occurred with Group and Pension Administrators (GPA). At the time I had coverage by this insurance, I was initially cleared to receive electro-convulsive therapy (ECT) for a number of treatments for a certain time period. However, the treatment facility agreed with both my psychiatrist's and my decision to continue ECT as "maintenance treatment." However, GPA did not cover this continued treatment that was clinically necessary for my wellness. Additionally, my doctor further explained that the church of Scientology, with their amount of resources such as money and influence over the law, put barriers to such helpful treatments. Thus, the church of scientology also serves as an entity that sabotages mental health treatment due to their radical beliefs.

The second case is currently ongoing and involves coverage by Humana as my employer chose to change insurance carriers to this health insurance for 2015. I applied for a research study that involves the use of a Deep Brain Stimulator (DBS) in order to treat my refractory depression, which has not responded well even to ECT when considered by a typically accepted response of perhaps several months of efficacy. In my case, I was requiring them monthly and was never able to wane off of that interval and this is still considered, "treatment-resistance" as the continued treatment for depression at this rate is not considered a "full response". On the basis of this argument, in addition to medical records demonstrating I have failed a high number of treatment modalities, which include a high number of different medications and in different combinations, trans-cranial magnetic stimulation, and acupuncture, the research team requested coverage from Humana for the surgical procedure of the installation of the DBS device, stating that albeit it is experimental, it is nonetheless my last treatment option. However, Humana did not see this argument as valid and refused to pay for the procedure on the grounds that this is considered, "experimental." Even when explained that it's a treatment of last resort they still refused to consider one of their client's well-being. Thus, from early January of 2015 when the claim was first filed, to near May 2015, the grievance claim is still not resolved. Do they happen to be aware that severe depression can lead to suicide? If this situation were regarding a treatment protocol for treating cancer, for example, would it have been any different? Either way, such delays can lead to death quickly.

The research team has been fighting rigorously with Humana since the beginning of this year when I first became insured by this insurance provider. The process has proceeded through at least one appeal and is currently at the IRO level, which is supposed to be the last step in requesting re-consideration of the favorable decision. As of April 6, 2015, the research assistant notified me an expected decision within two working business days and as of Friday, April 24, 2015, no final decision from Humana had been provided to us. This pattern had been previously repeated when having initially filed the claim and in appealing it.

It is important to note that the first client that the research team had installed a DBS device, her insurance, Blue-Cross Blue-Shield did not see this claim in the manner that Humana did; the research assistant reported that Blue-Cross Blue-Shield decided that this treatment modality for their client was justifiable and that approval of the claim according to the research assistant, took only “a few hours.”

It is also important to note that Humana had also previously denied payment for Latuda, a medication that was prescribed to me as a mood stabilizer in assisting with regulation of my depression. I attempted to advocate for myself by phoning them and explained to them this drug was of need, NOT choice, and that it was not on their “preferred list.” I explained that although my previous insurance had been paying for it fully, less the copay, I informed them that this was one of the last medicines in this class that I was on as the others I had tried either did not work, or had stopped working.

It can be clearly and accurately assumed that the previously mentioned insurance companies provided limitations that involved frequency of treatment, types of treatment, and limitation of treatment modalities, including the DBS procedure and a very valuable medication.

Female living with depression

My depression became morbid in 2004. I was assigned a wonderful doctor, who worked with me to get my depression under control. I was on Effexor CR, had a FULL, heavy workload at work, as was feeling wonderful! I went to pick up my prescription, and was rudely told by a new pharmacist that I would no longer be able to have the brand name, but that my insurance company (CIGNA) had changed me to the generic form. I called my doctor and found that NONE of this had been coordinated with her. She gave me some Effexor CR so I could ween from one to another, and I seemed fine. Of course I almost fell asleep driving to work, so the Cigna helpline just told me to take the medication after I got to work (there were additional side effects of the generic). After two years on this generic, I went to pick up my medication, and I was told that I would no longer be on ONE generic that the pharmacy would pick which one I would get. I when I questioned this, I was told to "shut up" or the pharmacist would cut me off. I took the new generic. Two days later I was in the fetal position in my bed, I was so depressed and anxious that I could hardly move. By the time I got to the doctor on Monday, I was shaking so bad, she considered hospitalizing me. She gave me more Effexor CR and then wanted to switch me to Pristiq (new, and a name brand that was years away from being generic). Pristiq only made my depression worse, we had to add Xanax to try to balance the anxiety. Nothing made my depression better - I spent 30 months living in constant agony because of my depression and anxiety.

I did use this time to do research. First, I found stories on patient forums where people had ended up in the hospital, having seizures, and attempting suicide because of the generic switch other patients and I were forced to undergo. I saw both at ABC News and at MedMD articles about bad reactions to different generic antidepressants. In the Journal of Family Practice (11/2010) the following quote appears in an article about generic drugs:

"Psychotropic agents. There has been a number of case reports of problems occurring following a switch from a brand-name antidepressant to a generic—or from 1 generic antidepressant to another. (See “Did a switch to a generic antidepressant cause relapse?” J Fam Pract. 2008;58:109-114.) In fact, the FDA cites some psychotropic drugs for which generic formulations may not be interchangeable—including amitriptyline/ perphenazine and venlafaxine—and others for which generic formulations may not be bioequivalent at all doses. (http://www.jfponline.com/the-publication/past-issue-single-view/generic-drugs-the-benefits-and-risks-of-making-the-switch/824516cd9e2a1252fdf32bcd235e6857.html). I was on Venlafaxine and should not have been switched at all. This information was available to Cigna at the time they forced my change. Now who do I sue for two and half lost years of my life. Yes I am that mad. The switching of drugs is as dangerous as being denied care - in fact, it's worse.

I am on Fetzima now - the strongest dose possible. I am barely coping. I am still on Xanax. I do not believe I would be where I was if it wasn't for the drug switch.

Male living with depression

Three years ago my health insurance agreed to pay for TMS. The treatment worked beautifully in ways medication alone never did. I continued with maintenance treatments for a year and a half when my insurance suddenly stopped paying for it. Their reason was "it's experimental". They cut me off after a year and a half of great results.

I found myself hospitalized for depression and suicidality. Then my insurance decided to start paying for maintenance treatments again. They've been paying for the past year and a half now

Depression and Bipolar Support Alliance

GRASSROOTS ADVOCACY

Accessing Mental Health Care -

How to Maximize Your Benefits

OUR VOICES MATTER: Help change the conversation about mental health

Before We Begin

The following educational presentation may touch on topics and issues related to policies, regulations, and other legal matters.

The presentation is in no way intended as personal, individual legal advice.

Because circumstances may vary, you should seek legal advice from a licensed attorney in your jurisdiction..

Options to Access Health Insurance

For each of the statements below, please mark either true or false.

	True	**False**
The government is responsible for catching parity violations when they happen.	○	○
An insurance plan is allowed to set high co-pays for psychiatric medications.	○	○
An insurance plan is allowed to have a separate deductible for mental health.	○	○
The 1st step to filing an appeal is to file a complaint with the federal government.	○	○
Parity means people have equal benefits for physical and mental health.	○	○

Options to Access Health Insurance

Group Health

- Employer Sponsored
- 50+ employees
- Small group plans less than 50 employees

Healthcare Marketplace/Exchanges

- State and Federal depending on State
  - Individual
  - Family

Government Programs

- Medicaid and Children’s Health Insurance Program
- Medicare
- Federal Employees Health Benefits Plan
- Tricare/DOD

Important Insurance Termonology

For each of the statements below, determine if true or false.

	True	False
Deductable, is the amount of money you pay before your insurance company will start paying money for a claim.	○	○
CoInsurance, is a percentage (%) you pay for a claim.	○	○
Copay, is a fixed dollar ($) amount you pay for a claim.	○	○
In-network, are providers (doctors, hospitals) are part of your insurance network.	○	○

What is Parity?

TO

If I Can See my:

Primary Dr 12 times a year

Then I Can See my:

Psychiatrist 12 times a year

If My Deductable:

Is $500 for Medical

Then :

This includes
Mental Health Services
(not separate)

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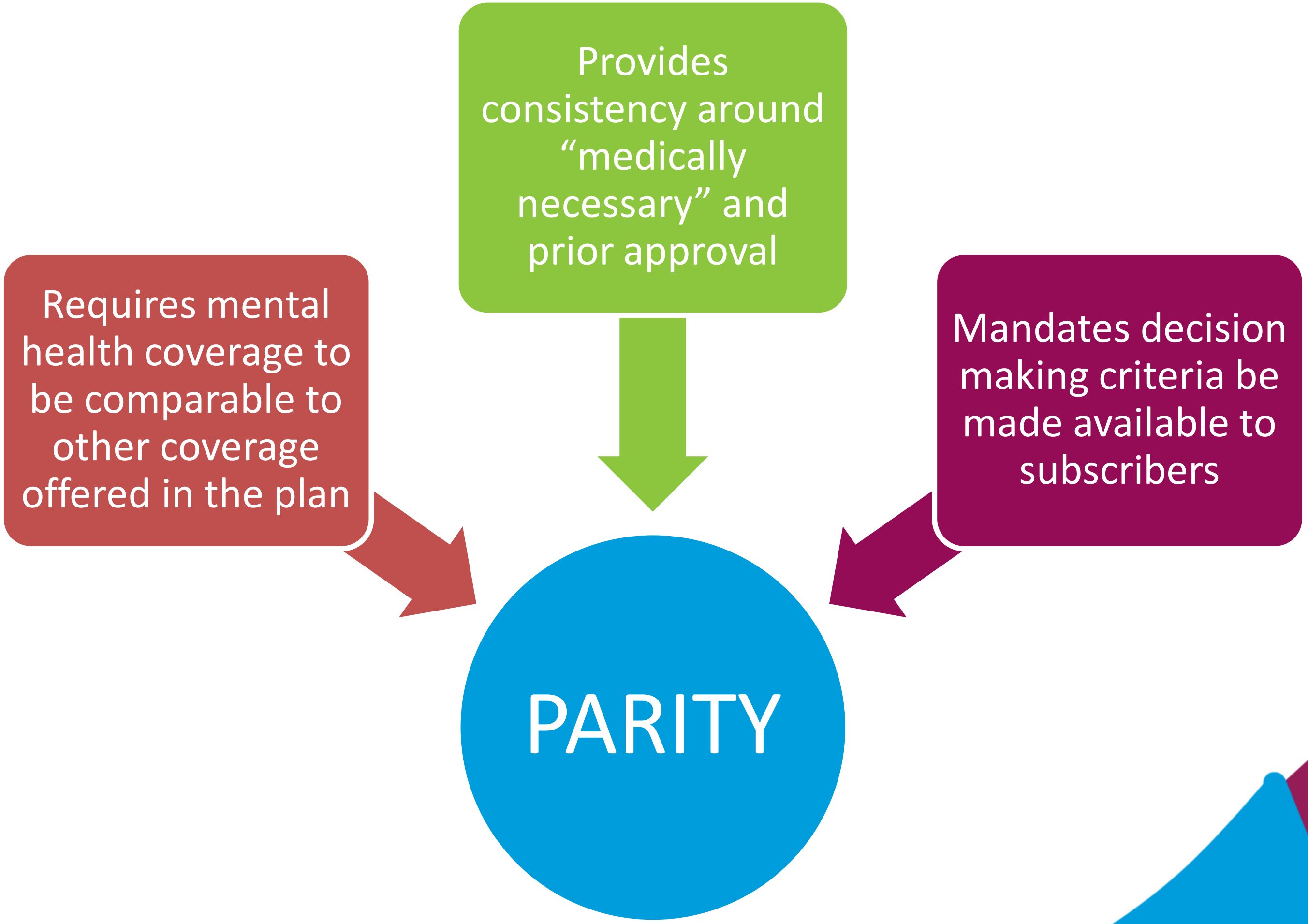
GRASSROOTS ADVOCACY

Mental Health Parity Increases Access to Care



Provides consistency around "medically necessary" and prior approval

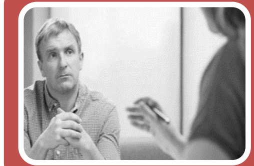
Requires mental health coverage to be comparable to other coverage offered in the plan

Mandates decision making criteria be made available to subscribers

PARITY

OUR VOICES MATTER: Help change the conversation about mental health

Comparable Coverage

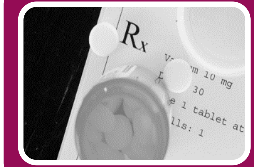


Outpatient

- In-network
- Out-of-network

Inpatient

- In-network
- Out-of-network



Prescription

Emergency

What is Medical Necessity?

- **Medical necessity** is a set of rules insurance plans use to decide if they are going to cover a treatment or service.
- *Each plan* can have it's own set of rules. However, **they must consider** the following:
- Is it reasonable?
- Is it necessary and/or appropriate?
- Is it based on evidenced based clinical standards of care?

Criteria Requirements:
A Critical Protection

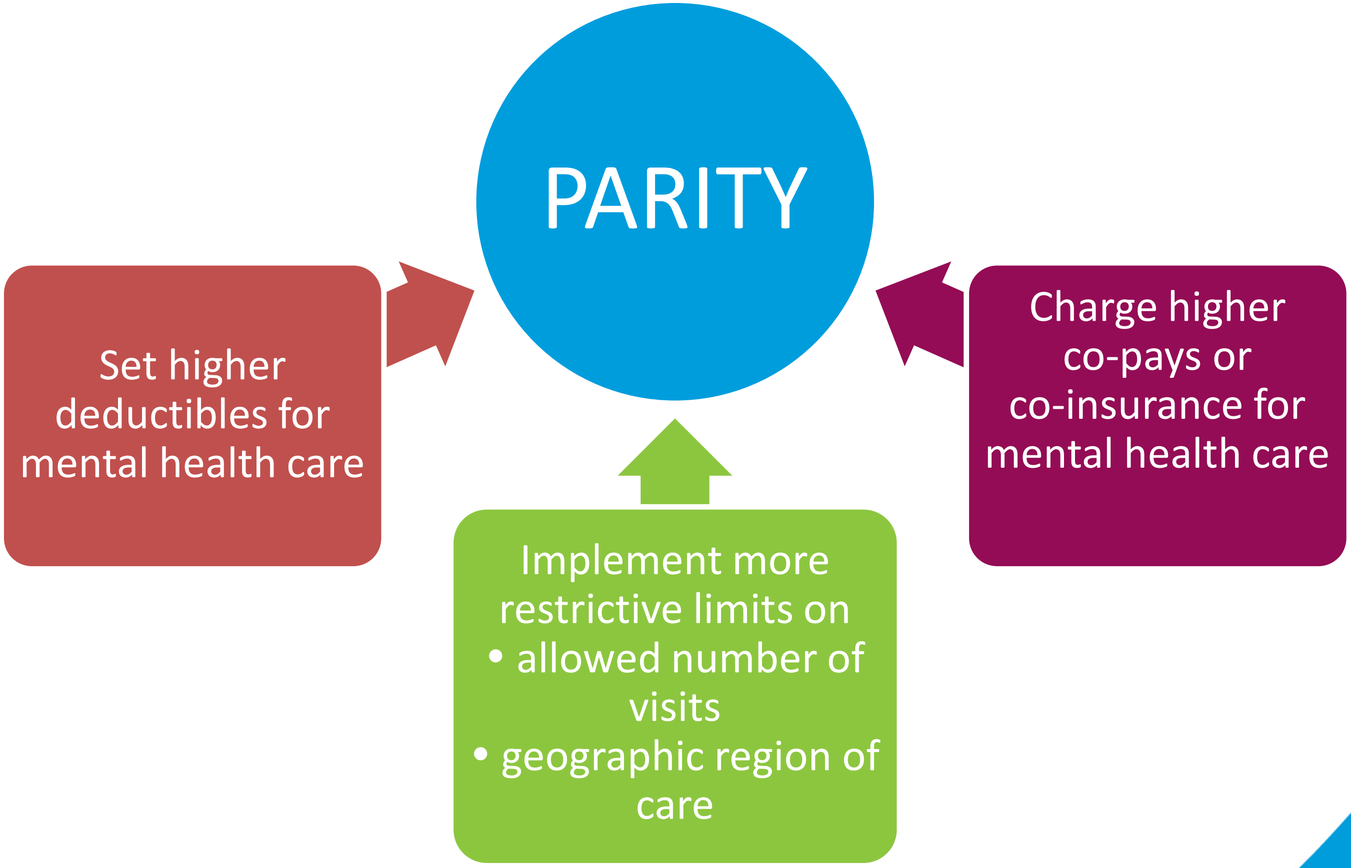
Key Point #1

- Requires plans to give information to any potential member, current member, or contracted healthcare provider

Key Point #2

- Requires criteria used to determine medical necessity be made available within 30 days upon request

What Insurance Plans Can’t Do



PARITY

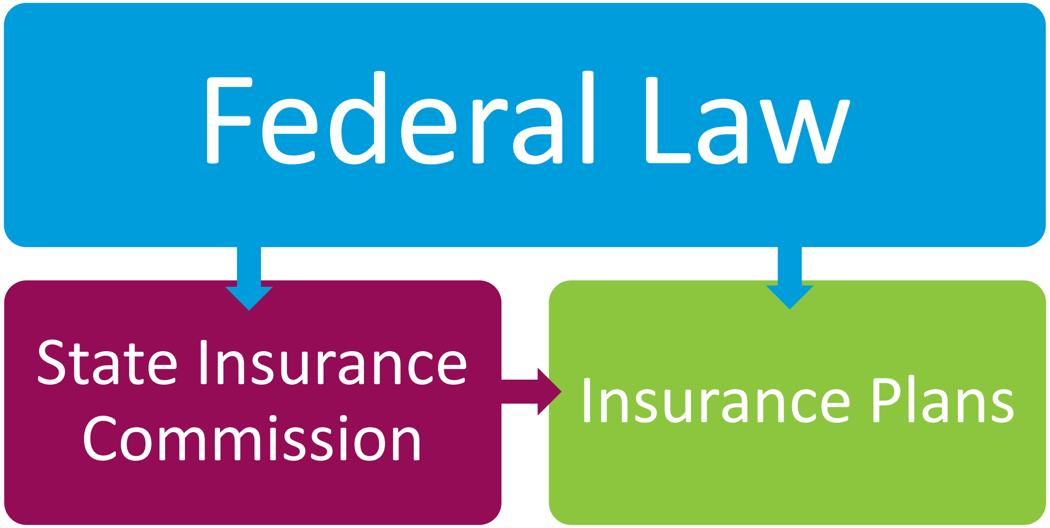
Set higher deductibles for mental health care

Implement more restrictive limits on
- allowed number of visits
- geographic region of care

Charge higher co-pays or co-insurance for mental health care

Who regulates parity?

While the law was federal, implementation of the law is through your insurance commission.



Federal Law

State Insurance Commission

Insurance Plans

Barriers to Care Scenario 1

Susan

Susan received letter that she has exhausted her psychiatric out patient benefits.

Key Issues to Consider

- Treatment limitations

Why opportunity for appeal?

- Treatment limitations imposed on mental health benefits may not be more restrictive than those imposed on medical/surgical benefits

Potential Parity Issue

Barriers to Care Scenario 2

Kathryn

Kathryn finds a PHP program.

Key Issues to Consider

- Comparable Coverage
- In state vs. out of state coverage

Why opportunity for appeal?

- The insurance company does cover PHP, and has covered other outpatient treatments out of state in the recent past.
- Insurance companies need to offer comparable coverage.

🚫 **Potential Parity Issue**

Barriers to Care Scenario 3

Aaron

Aaron is a college student covered under Mom's plan

Key Issues to Consider

- Changes in prescription coverage
- Has the formulary been published

Why no opportunity for appeal?

- Insurance plans are free to change their formularies at any time.

○ **No Parity Issue**

Barriers to Care Scenario 4

John

John's doctor recommends clinically appropriate care. Insurer denies care based upon "medical necessity" with no further explanation.

Key Issues to Consider

- Medical necessity criteria used by insurer
- Opportunity for appeal

Why opportunity for appeal?

- MHPACA mandates that criteria for medical necessity determinations must be made available to any current or potential participants.
- ACA requires an "effective" appeals process and availability.

🚫 Potential Parity Issue

Barriers to Care Scenario 5

Laura

Laura is shocked to find out she must pay full price for her medication because of her new “high deductible” plan.

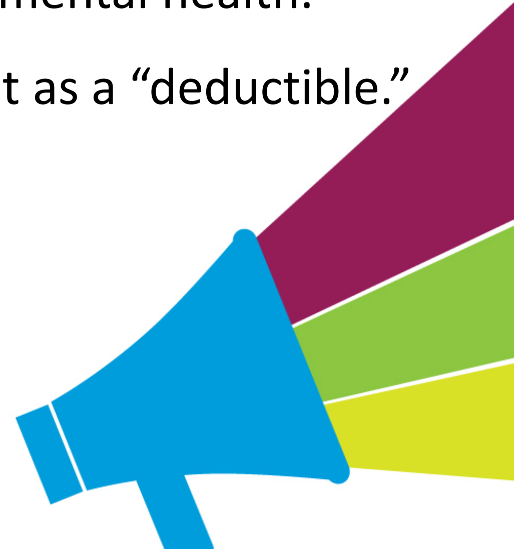
Key Issues to Consider

- High deductibles

Why no opportunity for appeal?

- Her high deductible includes BOTH physical & mental health.
- There is no dollar limits on what a plan may set as a “deductible.”

○ **No Parity Issue**



Steps to Appealing Coverage Denial

STEP 1: Collect relevant information

Gather General Information

- Plan name and #
- Member ID#
- Specific benefits denied
- Dates of denial
- Explanation for denial

Request Information from the Plan

- Description of non-quantitative treatment limitations
- Criteria for determining medically necessary
- Reason for denying the claim
- Any new evidence used to determine benefit decision
- Copies of all documents and records – free of charge

Steps to Appealing Coverage Denial

STEP 2: Take Action!

Solicit Support from Your Provider

- Ask provider to:
  - Act upon your behalf
  - Contact plan to provide additional supporting evidence

File an Internal Appeal

- Appeal verbally
- Explain the issue
- Learn where to send appeal information
- Write letter to appeal department
- include plan info
- explain facts of the denial
- explain the parity issue

Steps to Appealing Coverage Denial

STEP 3: Outside Review

Learn the Process

- Ask the plan if there is an outside review process
- If so, follow that procedure

Don’t Give Up!

- If there is no external procedure or if you are still denied:
- File an appeal with your state insurance commission or governing body
- File a complaint with the federal government
  - ERISA
- Seek legal representation

Resources

Parity Implementation Coalition www.parityispersonal.org

The Kennedy Forum—Parity Resource Guide for Addiction & Mental Health Consumers, Providers and Advocates https://parityispersonal.org/media/documents/KennedyForum-ResourceGuide_FINAL_1.pdf
https://www.paritytrack.org/

Substance Abuse and Mental Health Services Administration—What is Parity?
http://blog.samhsa.gov/2010/12/29/what-is-parity/#.Ve3rb5dPGjs

Department of Labor MHPAEA Fact Sheet
http://www.dol.gov/ebsa/newsroom/fsmhpaea.html

Department of Labor—How to File a Claim for Your Benefits
http://www.dol.gov/ebsa/publications/how_to_file_claim.html

Department of HHS—General health insurance information
http://www.healthcare.gov

Options to Access Health Insurance

For each of the statements below, please mark either true or false.

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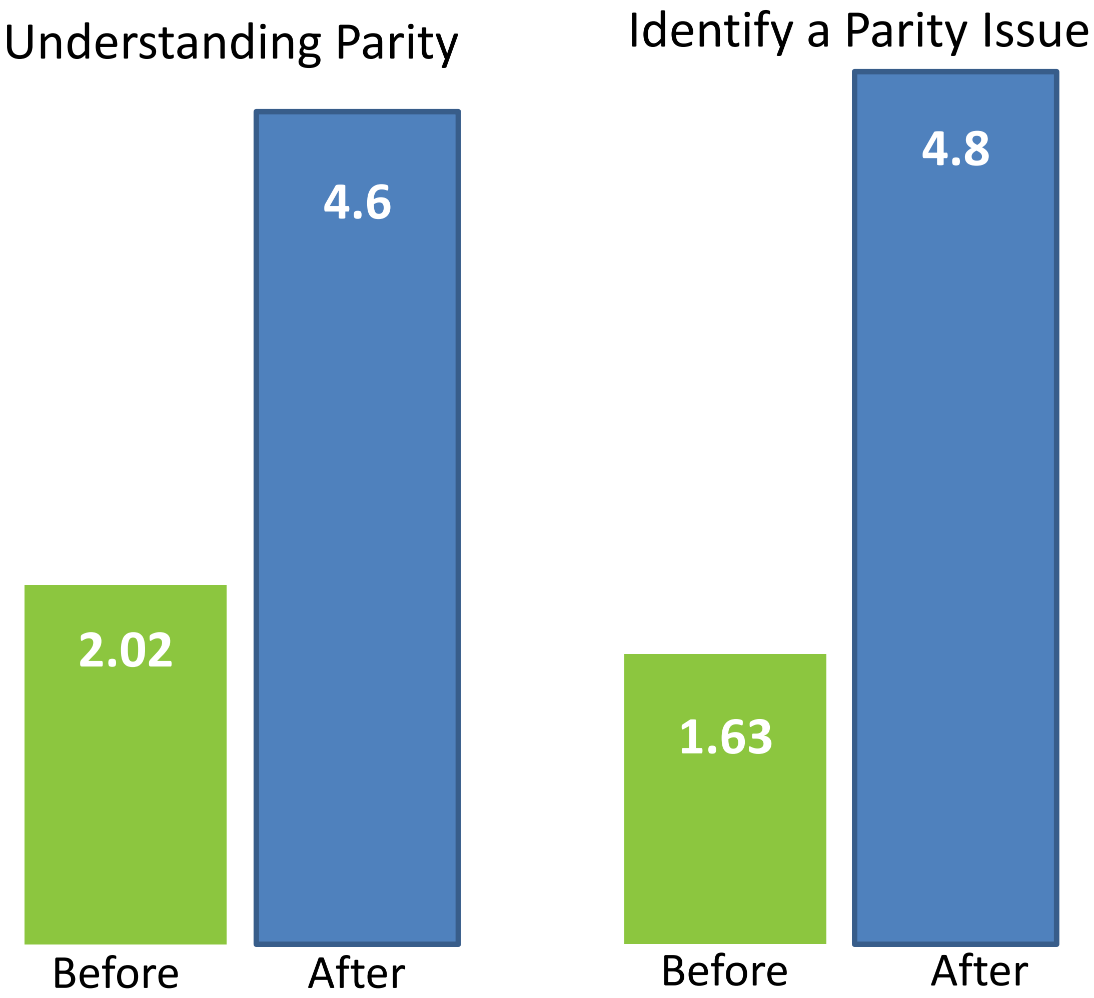
Parity means people have equal benefits for physical and mental health.	☒	○

Measuring Knowledge Gained



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