



Transgender Health Benefits
negotiating for inclusive coverage



Transgender Law Center

Making Authentic Lives Possible



P R O J E C T
H E A L T H

HARNESING EDUCATION,
ADVOCACY & LEADERSHIP
FOR TRANSGENDER HEALTH

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Introduction

Did you know that transgender employees are regularly denied routine treatment, or coverage of treatment, by doctors and insurance carriers?

While the behavior of medical professionals may be out of your control, **you can change the way your insurance carrier treats your transgender employees.** The next time your health benefits contract is up for renewal, you can go to the negotiation table armed and ready to protect all of your employees. This guide gives you the information you need to clear each hurdle on your way to achieving equitable health benefits.

While written specifically for human resource managers, benefits specialists, and union representatives, it is also a useful tool for individual employees, Lesbian, Gay, Bisexual, and Transgender (LGBT) employee resource groups (ERGs), diversity committees, and others who are advocating for equitable benefits. In addition to those negotiating for transgender-inclusive coverage in employer-based plans, we expect that people interested in removing exclusions from other types of group coverage, such as student health plans and individual plans, will also find this information useful.

The guide is divided into two main sections:

- » In **Part 1**, you'll find the background and context you need to understand and communicate about transgender people, transgender health care, and health insurance exclusions.
- » **Part 2** gives you specific strategies for achieving the two critical milestones you'll need to ensure equitable health benefits: securing organizational commitment and negotiating with insurance carriers.

Whether your workplace is a multinational corporation or mom-and-pop shop, whether for-profit or non-profit, this guide can help you. In the following pages, we provide you with the concepts, terms, context, facts, and arguments to use, and how to approach the people you'll argue with. Once you've read through, it's up to you to build your team, make your plan, and put it into action. No one can accomplish this monumental task alone, but the right team working together can achieve equity in health benefits for all coworkers. Remember, this guide only exists because people like you took on the challenge, learned how to win, and kept going through adversity. Follow their lead and you are bound to succeed.



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Part 1: Setting the Stage

Human resource professionals and transgender employees seeking to have transgender-related health care included in their insurance plans often contact Transgender Law Center with the very simple question, “Where do I start?” This section answers that question, from vocabulary and definitions to the nitty-gritty of cost calculations.

Transgender people in your workplace

Before we go any further, let’s make sure we’re on the same page with vocabulary. Even if you and your team are already confident on these terms, you may need to teach them to others who are potential allies—or antagonists—to your cause.

Terms and definitions

Gender identity is a person’s internal, deeply-felt sense of being male, female, both genders or neither. All people have a gender identity, whether or not they are transgender. Non-transgender people understand their gender identity and their physical sex to be the same; transgender people often do not.

Gender expression is an individual’s characteristics and behaviors such as appearance, dress, mannerisms, speech patterns, and social interactions that are perceived as masculine or feminine.

Gender non-conforming describes a person who has, or is perceived to have, gender characteristics and/or behaviors that do not conform to traditional or societal expectations.

Transgender is an umbrella term that can be used to describe people whose gender identity and/or expression is different from their sex assigned at birth. A person whose sex assigned at birth was female but who identifies as male is a transgender man (also known as female-to-male transgender person, or FTM). A person whose sex assigned at birth was male but who identifies as female is a transgender woman (also known as male-to-female transgender person, or MTF).

Transsexual refers to people who seek medical treatment (or who desire to do so) to transition from one gender to another.

Transition is the process of changing one’s gender from the sex assigned at birth to one’s gender identity. There are many different ways to transition. For some people, it is a complex process that takes place over a long period of time, while for others it is a one- or two-step process that happens more quickly. Transition may include “coming out”: telling one’s family, friends, and/or co-workers; changing one’s name and/or sex on legal documents; accessing hormone therapy; and possibly accessing medically necessary surgical procedures.

Employment non-discrimination

As of April 2013, 16 states and the District of Columbia have laws that explicitly ban discrimination in the workplace based on gender identity or expression. Additionally, in a 2012 decision (*Macy v. Holder*), the federal Equal Employment Opportunity Commission ruled that Title VII of the Civil Rights Act, the law that bans sex discrimination, protects transgender people from workplace discrimination across the entire country.

Throughout the nation, private industry is implementing protections of its own. As of 2013, 57% of the Fortune 500 companies have explicit policies that bar discrimination based on gender identity in their workplaces, up from 3% in 2002 (Human Rights Campaign Corporate Equality Index).

Access to equal and inclusive health care benefits, however, has not kept pace with nondiscrimination protections. In fact, only 42% of the 688 companies in the Human Rights Campaign's (HRC) Corporate Equality Index in 2013 offer insurance plans that include coverage that meet the health care needs of transgender employees, while 84% have non-discrimination policies that include gender identity.

Transgender health care

Transgender health care includes culturally appropriate, knowledgeable primary care, access to gender-specific care, and transition-related care. Like everyone, transgender and gender non-conforming people need access to quality primary care that includes preventative care (such as screening for diseases like cancer and diabetes); acute care of injuries and illnesses; and diagnosis and management of chronic diseases. Access to gender-specific care (such as prostate cancer screening for transgender women and pap smears for transgender men) is also an important part of preventive medicine.

For transgender people, the disconnect between gender identity and physical manifestations of our birth sex can cause distress, sometimes leading to a condition called **gender dysphoria** (also called Gender Identity Disorder). Gender dysphoria and its treatment are discussed in many standard medical and psychiatric texts. It is also listed in the International Classification of Diseases (ICD-9, ICD-10, and ICD-11), under the name Transsexualism.

Gender dysphoria is classified under the diagnosis of Gender Identity Disorder (GID) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the tool used by mental health care providers to categorize illnesses. In the forthcoming 5th edition of the DSM (DSM-V), the condition will be referred to as "gender dysphoria." Gender Identity Disorder/gender dysphoria is characterized by significant and persistent distress between the individual's physical sex and their gender identity.

Left untreated, gender dysphoria can lead to debilitating anxiety and depression, with serious medical consequences and a significantly increased risk of suicide, substance use, and other mental health conditions. Treatment for gender dysphoria often includes gender transition, which has been proven to successfully alleviate the distress and its resulting symptoms.

Insurance carriers have historically been reluctant to offer packages that include coverage for treatments related to gender dysphoria. When these packages are available, they are often limited in scope and do not follow internationally recognized standards of care. By limiting access to health care options for employers, insurance carriers tie the hands of physicians and patients by not paying for what for what a doctor has determined to be the most effective treatments for an employee's condition.

Insurers justify these exclusions by classifying treatments as cosmetic, experimental, and/or not medically necessary, despite scientific evidence to the contrary. However, the same treatments are frequently provided



To learn about best practices for working with transgender colleagues, see our other publications: “Tips for Working with Transgender Coworkers” and “Model Transgender Employer Policy”.

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**“An established body of research studies demonstrates the effectiveness and medical necessity of mental health, hormone, and sex reassignment surgery as forms of therapeutic treatment for many people diagnosed with Gender Identity Disorder.”
- American Medical Association, 2008**



to non-transgender people for other conditions when prescribed by their physician and are routinely covered by insurance companies. Some examples include hormone replacement therapy, hysterectomy, and mastectomy.

Many medical organizations have issued statements on the efficacy and medical necessity of treatment for gender dysphoria, including the American Medical Association. See Appendix A for a list of statements from medical organizations regarding the medical necessity of clinically appropriate treatment for gender dysphoria.

In addition, there are well-established protocols and recommendations for treatment regimens by such organizations as the World Professional Association for Transgender Health, the University of California San Francisco Center of Excellence for Transgender Health, Vancouver Coastal Health, and others. All this is to say that, counter to assertions sometimes made by insurance carriers, medical treatment for gender dysphoria is well-developed, and not at all experimental.

Insurance exclusions

Insurance carriers deny transgender people coverage in two ways. First, carriers consider a prior diagnosis of gender dysphoria or Gender Identity Disorder to be a pre-existing condition, and deny a transgender person's application for health coverage. Thanks to the Affordable Care Act, pre-existing conditions of any kind will no longer be valid criteria for denying coverage in the United States as of January 1, 2014.

Secondly, unless your company has negotiated for an equitable benefits package, it is likely that your current contract contains exclusions for “sex reassignment surgery” or “gender reassignment.” Employees can find these exclusions listed in the Evidence of Coverage (EOC) or Certificate of Coverage provided to them by your insurance carrier. Exclusions for treatment of gender dysphoria in health care contracts have historically been the standard in the United States, though as of May 2013, four states (California, Colorado, Oregon, and Vermont), as well as the District of Columbia, have laws and regulations that prohibit categorical exclusions for transgender health care.

Most other western democracies and many developing nations cover treatment for gender dysphoria. If your company does business in more than one country, you may be able to argue that all employees companywide deserve access to the same medical benefits regardless of where they live.

It is also worth noting that a majority of insurance carriers already have available an equitable benefits policy that does include transition-related care. To whom they offer this option is another matter. Availability of these plans often depends on the size of the employer, their negotiating leverage, and how a company offers insurance to their employees. If you ensure large numbers of people through that carrier, it is more likely that they will be willing to offer you an inclusive plan, because you have greater negotiating power, although smaller employers have been successful as well.

The bottom line is that insurance carriers already provide these benefits, although they typically do so in limited cases. The next section is designed to help you gain access to them for your employees by arming you with tools and information that will allow you to negotiate from a stronger position.

The argument for (and against) equitable benefits

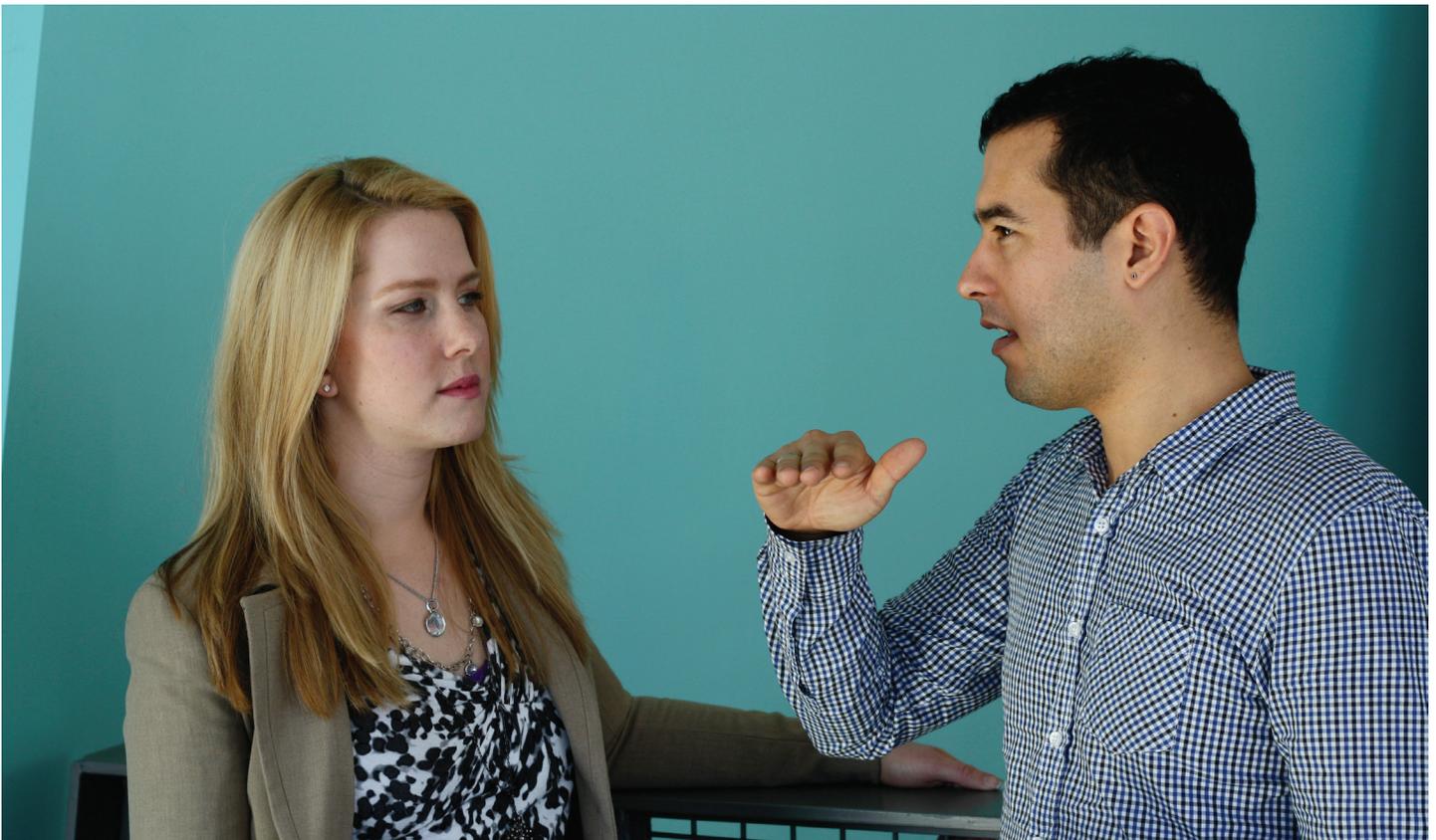
Equitable benefits that are fully inclusive need to cover the broad range of medically necessary treatments referred to in the World Professional Association for Transgender Health (WPATH) Standards of Care. This includes coverage of mental health, hormonal therapies, and surgical treatments for your transgender employees. It is important to note that surgical and other treatments are not limited to genital surgery. This section lays out the facts around costs and benefits of equitable health coverage at your company.

Addressing cost

Businesses weigh the cost output of health care coverage against the cost savings associated with lower rates of absenteeism, increased employee retention, decreased turnover, talent attraction and retention, and greater access to markets that value an employer's commitment to diversity. Employers consider all of these factors when making decisions about benefits packages, in addition to supporting equal benefits as a matter of fairness.

While we now have real-life examples that strongly indicate that cost is minimal, there are no actuarial studies that are publicly available yet to further support this. That's because insurance carriers do not reveal the cost of treatment and large self-insured employers typically do not release their data because of privacy concerns.

Many people have the misconception that adding coverage for transition-related care will lead to a large increase in premiums. Sometimes employers will hire consultants to estimate their costs for covering treatment for gender dysphoria. These consultants may make their calculations based on three faulty assumptions: all transgender people would undergo surgery as part of their treatment plan; each of them



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will have the most costly surgery; and transgender people will continue to need surgeries in every year that they are employed.

Basing calculations on these flawed assumptions leads to astronomical estimations of cost. However, the evidence shows that coverage for gender dysphoria represents only a miniscule increase in overall costs.

Conversations about cost are often used as a diversion from other reasons that employers or insurance carriers are unwilling to cover transition-related care. There will always be people, driven by prejudice, who will find any excuse to oppose this coverage. Cost is an easy target. While it is important to address cost, we want to do so in a way that ensures that treatment for gender dysphoria is put at the same level as treatment for other medical conditions and that the cost estimates are not overinflated to create an artificial barrier to coverage.

Reality check: the low cost of equitable benefits

Utilization rates play a large role in cost. For example, from 2001 through 2006, the City and County of San Francisco's inclusive benefit plan paid for 37 surgical procedures (costing them just over \$383,000). A detailed analysis of the City of San Francisco's actual cost and utilization can be found in the transgender issues section of the *Human Rights Campaign's website* (www.hrc.org).

The experience of the University of California also serves as a good source of information about utilization. According to Shane Snowdon, former Director of the UC San Francisco LGBT Center and one of the advocates responsible for the adoption of equitable benefits at the University of California, the UC system paid for a total of 28 procedures from July 1, 2005 through December 31st, 2010. That is an average of just over five procedures per year in an employee pool of more than 150,000 faculty and staff at the UC's ten campuses, five medical centers, three national laboratories and systemwide offices.

“Corporations are accountable to shareholders who scrutinize decisions that impact the company's bottom line. It was critical for us to make the case about how these benefits fit into our strategy for attracting and keeping the best talent possible.”

-Paula Jones, Human Resources, Genentech



When the City of San Francisco began providing this benefit in 2001, they significantly overestimated the cost of coverage. The benefit was funded, at first, through a surcharge on employees. According to a report by the City's Human Rights Commission, “From July 2001 through July 2006, the grand total of reported monies collected is \$5.6 million. The grand total of reported monies expended is \$386,417.” The City and County had overestimated the cost by more than 14 times and the amount expended has been only a tiny fraction of the total collected.

Even more to the point, “Due to its obvious affordability, as of July 1, 2006, the pricing for the benefit changed.

While the benefit design remained the same, beneficial cost data led Kaiser and Blue Shield to no longer separately rate and price the transgender benefit—in other words, to treat the benefit the same as other medical procedures such as gall bladder removal or heart surgery.” Please see the references section for a link to the report on the City and County of San Francisco's experience regarding cost.

It is clear from the experience of the City and County of San Francisco that Kaiser Permanente and Blue

Shield of California found the cost of managing the surcharge fund more expensive than integrating the benefit into their existing policy. The fact that the integrated benefit did not increase rates speaks volumes about the insurance carrier's knowledge that the cost and risk of offering this benefit is minimal, as proven by the experiences of offering the benefit.

Looking at the large scale, we can consider the case of the state of California. In 2012, the California Department of Insurance published an economic impact assessment of removing exclusions for transition-related procedures on the scope of all private PPO plans in the state. They concluded that removing exclusions throughout the state, "would have an insignificant and immaterial economic impact on the creation or elimination of jobs, the creation or elimination of new businesses, and the expansion of businesses in the State of California." They went on to say that providing affirming care to transgender people likely decreases the overall cost of care, since the initiation of transition-related care is associated with strong decreases in risky behaviors (smoking, drug and alcohol abuse) and suicide attempts, and strong increases in measures of mental health.

The benefits of equitable coverage

The costs of coverage, no matter how small in the overall picture, are real considerations. Those costs, though, are balanced against other considerations. Good benefits packages are very helpful in attracting and maintaining the best talent and reducing employee turnover.

There is a direct and proven link between employee benefits and job satisfaction. In 2007 MetLife conducted a study that showed that 80% of employees who were satisfied with their benefits packages expressed strong job satisfaction. Furthermore, 70% said their benefits package was a reason for joining their current employer and 83 percent said it was a factor in staying with the business. More than half of employers rank "retaining employees" as their top benefits goal.

In an updated version of that report published in 2009, MetLife reported that, "In addition to the link between benefits satisfaction and job satisfaction there is, not surprisingly, a link between benefits satisfaction and employee loyalty. Employers should carefully consider the value of benefits as a driver of both job satisfaction and loyalty—and potentially, retention."

When a transgender person is unable to obtain transition-related care, it can have serious effects on that person's economic stability and physical health. Given the widespread exclusions for transition-related care, employees must often cover the cost of hormones, therapy, and/or transition-related surgeries out-of-pocket and may not be able to find safe and affordable medical providers who offer this care.

Many transgender people empty their retirement accounts and borrow funds from relatives to obtain the care that their doctor has prescribed. While the financial impact for an insurance company is small, given their overall output of funds for medical treatments, the costs of transition-related care are often out of reach for an individual. After all, the reason we obtain health insurance is to prevent any one person from

"Covering the new procedure is expected to cost the city [of Portland] about \$32,000 a year, an increase of .08 percent to the city's \$42 million self-insurance fund. But those in favor of the proposal, including all of the city commissioners and the mayor, said that increase was small and worth the price."
–Beth Slovic, writing for The Oregonian, 2011



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having to bear the total costs of their medical treatment by sharing the costs within the pool.

Managers and human resources professionals are well aware that when an employee is unable to access necessary medical care or is dealing with significant financial stress, it can negatively impact their job performance. A productive workplace depends on employees who are able to focus on their jobs and do their best for the company. Stress, depression, and other emotional factors can impact the bottom line when they interfere with job performance.

“As Mayor, it is important to me that we attract and retain the best and brightest employees to the City of Portland. Offering non-discriminatory health care benefits—as leading employers like Nike, Google, Microsoft and IBM do—is one way to accomplish that goal,” Mayor Adams said. “Covering basic, medically-necessary care is a matter of fairness, and it’s the right thing to do.”
—Portland Mayor Sam Adams as quoted in the Portland Tribune, May 31, 2011



Providing equitable benefits can also be a valuable asset to your recruitment strategies. Job candidates, including lesbian, gay, and bisexual applicants, people of color, and allies, often factor fairness and equal treatment into their employment decisions. People want to work in a company that values all of its employees, and the ways in which minority employees are treated communicates a great deal about that.

Part 2: Getting to Equitable Benefits

As you begin, you will find that there are two major milestones as you work towards your goal. First, you will want to obtain a solid commitment from your company to pursue equitable benefits. Second, you will negotiate coverage with your insurance carrier(s). That solid commitment from your company often requires significant internal education and advocacy that translates into a much stronger negotiating position for your human resources staff. If your company is self-insured, the process is more straightforward—you just need to get a commitment from your employer to add these benefits.

While almost all insurance carriers offer at least one of their customers—typically large employers who have more negotiating power—an insurance package that includes transition-related care, they do not make it available to small and medium size businesses. As more employers of all sizes insist on equitable benefits packages, we expect that insurance carriers will begin to have standardized packages and the process will require less effort by employers. You can be a vital part of that process through your efforts to cover employees at your company.

Some efforts start with a single person, some with a group of employees, and still others with human resources staff who are responsible for negotiating for benefits. Regardless of where you start, there are always people whom you will need to educate, recruit, and support. These can include influential management and human resources staff. In some places, you may start out with these people already on your side. How you speak with them about the issue and what kind of information you need to provide depends on what position they hold within the organization and how they can support your goals.

Regardless of where the effort starts, engaging human resources staff—whose mission is to address the needs of employees and provide support—is critical. Knowing what questions to ask, who to ask, and how to communicate so that the issue resonates with those who make decisions is also important to your success.

Milestone 1: Getting employer commitment

Your goal is to get a commitment from your company to offer equitable benefits that include coverage for transition-related care. If your company is self-insured, your main focus will be on getting agreement within the company to offer these benefits and then adjusting your plan accordingly. If your business works with an insurance carrier, you will need to get a commitment from your leadership to include these benefits, and then approach your insurance carrier to obtain them.

Obtaining a commitment from your company requires strategic thinking, organizing fellow employees, articulating the business case for benefits, and buy-in from upper management. The most important predictor of success is the ability to make compelling arguments that emphasize that including equitable benefits is not only the right thing to do but is also a sound business decision.



When American Airlines announced that they would offer equitable benefits including coverage for gender reassignment surgery, they said, “American Airlines continually evaluates all of our benefits programs including health insurance coverage for our employees and retirees. These latest changes are one way we hope to ensure we remain the employer of choice for the best qualified candidates.”

–Lauri Curtis, American Airline’s Vice President of Diversity, Leadership & Engagement, in Passport Magazine, October 2011

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Each company has its own process for determining the scope of health care benefits for its employees. They also have varying levels of commitment to programs that promote diversity in hiring. These kinds of differences mean that there is no single formula for gaining your company's commitment. If your company has already committed to equitable benefits for all its employees, you will have an easier time making your case.

Five key strategies

To help you get started, we have identified five key strategies that will help you achieve your goal:

1. Gather information about your company's insurance context
2. Build a team of trans and non-trans employees to spearhead the effort
3. Create a simple action plan to guide your effort
4. Recruit allies in upper management who can champion the issue
5. Share personal stories about the importance of equitable coverage

The order in which you work on these strategies depends on the needs of your situation. For example, there may be a good deal of information you need to gather before you can create a plan of action. Finding like-minded employees and building a team first might produce a better plan. You might also take the issue to an existing employee group.

These strategies, which come from people who have successfully fought for equitable benefits within their own companies, will help you think through how to develop your action plan.

1. Gather information

In this section we will lay out questions that you and your team should consider before making a formal request. While you may not be able to find answers to all of the questions, gathering as much information as possible will help you design the best plan of action. A lack of preparation can create large roadblocks to your efforts with your company. When you are ready to approach human resources or management, you will be taken more seriously if you are well prepared.

You will need assistance from human resources staff, and perhaps management, to gather important information related to the company's current insurance landscape and benefits structure. This information will be vital to you during negotiations with insurance carriers around the scope of benefits, as well as in your conversations with management.

The information you should gather falls into three categories:

- » What are the existing company policies, protections, and commitment to diversity, including protections against discrimination based on gender identity?
- » What is included in your current benefits package? What are the existing exclusions for care?
- » What are your competitors doing?

Next, we'll look at ways to approach each of these in a way that can give you the answers you need to help build your action plan.

Company commitment to diversity

Leveraging existing company policies and commitment to diversity can be a powerful tool, and understanding your company's position can signal where you might start your efforts. For example, if company policy currently includes protections for transgender employees against discrimination, you can make the argument that equitable health care benefits for transgender employees are consistent with existing company policy. In circumstances where protections do not exist, a strictly medical framework may be the best way to approach decision makers. You may also want to consider proposing adding a policy to ban discrimination based on gender identity in your workplace.

Consider the following questions:

- » How strongly does the company consider diversity central to their mission or values? Are there specific statements or policies that you can find that support this?
- » How strongly does the company consider LGBT inclusion important to their mission or values? What are the actions the company has taken which communicate this?
- » Is the LGBT community a market that your company reaches or would like to reach?
- » Does the company emphasize diversity in hiring?
- » Does the company already have non-discrimination policies based on sexual orientation? What about gender identity or expression?
- » Is there an employee resource group (ERG) for LGBT people? Are transgender employees included and fully welcomed in the group?
- » Does the company have a history of addressing issues affecting LGBT employees in general? Is it a positive or negative history?
- » Does the company have a history of addressing transgender inclusion in the workplace? Is it a positive or negative history?
- » Have there been past efforts to advocate for benefits that include transition-related care? If so, what were the results? Who led the effort? Will they be a part of your efforts now? What lessons can you take away from that effort?
- » Is this organization likely to want to advocate for the best possible coverage (i.e. a model plan that others in your industry could use as an example) or is the organization likely to follow the lead of others in the industry?

Current health insurance landscape

It will help you create your plan if you conduct an assessment of how your company provides health benefits and who provides them. In addition, you should clearly understand your company's decision-making process about health insurance benefits so that you can determine the best way to go about getting what you want, who will make the decision, and what may motivate them.

Here are some questions to consider:

- » Is the company self-insured or do they purchase insurance from an insurance carrier or broker?
- » What insurance plans and carriers are employees able to choose from?

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- » What other groups or people have requested changes to benefits for other conditions (for example, for the treatment of autism or gastric bypass surgery for medically necessary weight loss). What can we learn from their experiences?
- » What is the timeline for insurance contract negotiations? When are the policies up for renegotiation?
- » Who makes internal decisions about what benefits are covered? At what level are decisions like this made? Human resources? Management team? CEO? Board of Directors? Which of them are LGBT friendly? Do any of these decision makers have any personal experience with transgender issues or people?
- » Who do we know who can influence the decision maker(s)?
- » What other considerations exist that will impact the decision-making process?

Evaluating your current benefits package

Benefits policies that are fully inclusive put both the patient and medical providers in control of what medically necessary treatments can be utilized to treat medical conditions, including GID or Gender Dysphoria. Yet, even when insurance carriers offer inclusive benefits packages, they almost always still contain some restrictions that stop short of providing comprehensive coverage.

Most of the information you need can be found in the employee's *Evidence of Coverage* (EOC) that employees receive each year when your company's enters into a new insurance contract; it will also be helpful if your



human resources staff can provide you with additional information. Excluded treatments and conditions are often hidden deep within the EOC. Closely examine the company's current insurance contracts to find these limitations.

For example, some EOCs specifically exclude "ALL treatments related to gender transition." Others specifically exclude "sex reassignment surgery" without referencing hormone or mental health therapy. In the latter case, we may presume that only surgical treatments are excluded. This turns out to not always be the case, and an employee may find other treatments denied as well.

Medical terminology can be confusing; we suggest investigating any unfamiliar terms to see if they apply to transition-related care. See **Appendix B** for a glossary of insurance vocabulary.

Consider the following questions:

- » Are there any specific exclusions of coverage for procedures in the Evidence of Coverage (EOC) document?
- » Are there exclusions relating to transgender health needs? If so, are the exclusions complete and categorical, or are some procedures (e.g., surgeries, or specific types of surgeries) excluded explicitly?
- » If there are exclusions for care relating to transgender health needs, are there benefit caps? Lifetime, annual, or both? What is the dollar amount for the cap?
- » Does the exclusion language attempt to differentiate between "cosmetic" and "medically necessary" treatments?
- » Are hormone replacement therapy, hysterectomy, oophorectomy, orchiectomy, mastectomy, and/or breast reconstruction covered procedures for clinical indications not relating to gender transition (e.g., cancer)?
- » What is your competition doing?

Companies are in competition with one another in many different ways and that includes competing for the best talent. When you make your case you may be asked what the company's competitors are doing. Having this information ready and showing how competitors may be gaining an advantage over you by adopting equitable benefits packages is critical.

For larger companies, the *Human Rights Campaign's Corporate Equality Index* is a useful tool. Each participating company is scored on a number of factors including whether they provide benefits that include transition-related care to their employees. In order to achieve a 100% rating, companies now must provide equitable coverage for their employees. The HRC web site, www.hrc.org, is a good place to start to gather this information.

2. Build a team

Build a team of transgender and non-transgender employees to spearhead the effort. Good arguments are enormously powerful, but sometimes people and companies will ignore even the soundest data until a number of voices within the company have joined together to insist that attention be paid to the information.

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Consider, too, that there may be employees at your company who have a transgender family member, such as a spouse, parent, child, or sibling. These people may already be well-versed in the issues and can provide important voices in the conversation.

“The most important thing we were able to do was to get a very highly placed champion to become a bulldog about trans-inclusive coverage. Someone who will not take no for an answer and someone who can ensure that their staff pursues negotiations with vigor.”
–Shane Snowdon, Director, UC San Francisco LGBT Center



Building partnerships and finding allies can make all the difference between success and failure in your efforts. The more people who are making the case that treatment for GID needs to be part of your benefits package, the more likely it is that management will listen to you.

The path toward equitable benefits almost always begins with an individual or group of employees who are committed to making change. Sometimes these are LGBT employee resource groups or company diversity

committees, and other times it is just one or two employees who understand the importance of equitable benefits and approach their employer about providing coverage.

Gather team information

Sometimes it is easy for management to dismiss the concerns of people who will directly benefit from a policy change, so it is critical to engage people in this process who will not directly benefit from the change. It is much more difficult for them to dismiss a diverse group with a range of interests.

Some questions that you and your team can ask yourselves that will help you move forward:

- » Who are our key allies on this issue right now? Who are the people in the organization’s leadership who are most supportive of them? What is their organizational role? What is our connection to or relationship with them? Why do they care about this issue, and what part of it matters most to them?
- » What has been done to bring the issue of transgender-inclusion to light within the organization? Who has been involved? For how long? What other transgender issues have been raised?
- » Who are, if any, our lesbian, gay, and bisexual allies? Family and friend allies?
- » What have been the key barriers or obstacles to change? (People? Issues? Costs?)
- » What questions should we be prepared to answer? What do we think the objections will be and how can we address these?
- » Are there transgender people in the workplace who are facing these medical needs?
- » How many transgender employees work for the company and are out about their transgender status? Do we know any spouses or children of employees who need this treatment?
- » What stakes and visions do each of us have around this issue?

3. Create your action plan

Now that you know more about your company's health insurance coverage, who sets policy, how you might influence those decision makers, and what strengths and vulnerabilities your team has, you have the information you will need to begin to create an action plan to guide your efforts.

Your plan should ideally include:

- » Timelines based on your company's annual health benefit negotiation schedule
- » A list of who to approach and the arguments you believe will be most effective in talking with them about including benefits
- » A list of your current and potential allies
- » A specific request of what needs to be covered that is currently not a part of your existing insurance policy
- » Stories of the way in which your company has been negatively impacted by these exclusions; for example, employees who have been unable to get medically necessary treatment, talented people who have chosen to work for competitors, etc.
- » Some of the answers to these questions may not be available until you have completed the other steps outlined in this section, but keep moving forward.

4. Recruit an ally in upper management who can champion the issue

One of the most important relationships that you will need to build during this process is with someone in management who can both convey your interests and become a champion for equitable benefits.

As you search for this person, here are some things to bear in mind:

- » Choose management allies who are or can influence a decision maker
- » Begin with allies who have supported LGBT issues in the past and are committed to diversity efforts

5. Use personal stories that touch your allies' hearts

Once you've found your allies, make sure that you provide them with all of the information they will need to make an effective argument. That may mean allowing them to share personal stories, providing them with documentation about the medical necessity of treating gender dysphoria, or offering a list of your competitors who offer equitable benefits packages.

Your allies in management will eventually go to bat for you and they are the experts on what kinds of arguments will have most sway with whoever makes the decisions. Listen to your allies and provide them with your best set of arguments so that they can make a compelling case.

Share personal stories about the importance of equitable coverage

Personal stories are a very powerful way of expressing the importance of equitable benefits. While facts and figures are important, the people with whom you are speaking need to understand how exclusions affect the physical and emotional health of employees. Stories are not a collection of facts to prove your

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point, but an explanation of how the current policy impacts you and those within your company. When employees tell their stories to management and human resources personnel, it can help them understand:

- » The importance of transition-related medical care to the employee's health and productivity
- » That the employees' physicians and medical care providers have determined that this treatment is medically necessary and well established
- » That employees must currently pay high out of pocket costs to transition or forego medically necessary treatments that their doctor has recommended. HR professionals know that either of these paths can be very disruptive for the employees.
- » The experiences of employees with GID on a personal level

Think about the following when you are putting stories together. These questions might apply to you or to employees that you are working with:

- » What has been your experience as a transgender employee or a family member of a transgender person in the company? How does this impact you as an employee?
- » Why are these benefits important to you? What kinds of health care barriers have you faced? What would having these benefits mean to you? How would your health and your work be improved if we added these benefits?

These stories can illustrate the impact exclusions have on employees and their families. As you tell your story, make sure that it comes from your heart. Make a connection with what you think decision makers will find most important. Finally, practice telling your story with someone on your team and keep it as short and focused as you possibly can. Presenting personal stories in a concise, professional, and authentic manner will benefit your efforts.

Moving forward

You have created and implemented your plan, recruited allies, prepared your arguments, and have an executive champion who advocates with decision makers to add these benefits. What happens next?

In some cases, companies readily recognize the value of adding these benefits and agree to do so. In other cases, you will need to continue to advocate for some time. Don't be discouraged—sometimes change may take a while. The company can only get to the right place if people keep asking and advocating for equitable benefits.

Once the company has made the decision to add equitable benefits, your next steps depend on how you provide health care coverage for your employees. If you are self-insured, you simply need to go through the steps to adjust your policy and inform employees of the new benefits.

If your company works with an insurance carrier, the next section will guide you through the process of taking your company's commitment to inclusive benefits into your negotiations with your insurance carrier.

Milestone 2: Negotiating with insurance carriers

The next step in this process is approaching the health insurance carrier. Whoever is responsible for negotiating with your insurance carrier will need to approach them to remove exclusions in the plan and obtain coverage for the treatment of GID.

Companies have the greatest success in negotiating coverage for transition-related care when they are able to provide a high level of information to the carrier throughout the process. People often expect the insurer to have access to superior data but then, to their surprise, have found that their health insurance representative is unfamiliar with this area of coverage. If your representative does not have the information you need, you may have to inquire further with the insurance company to find someone who does know or educate your representative yourself.

Be prepared for the chance that your representative may not even know the carrier has written inclusive coverage for other companies. In fact, your insurance carrier's representative may not even know where to start to obtain good information. You may need to supplement the representative's incomplete information in order to move negotiations forward in a timely manner.

The path to inclusion

Before approaching the carrier, it can be helpful to create a "roadmap" showing major intersections and potential issues.

Each step of the map centers on a key question, which we elaborate in the following sections.

The questions are:

- » What is the anticipated financial impact based on actual implementation in other places/companies?
- » What is covered?
- » How much is covered?
- » Where can services be performed?
- » Who is covered?

Gauging financial impact

One of the best ways to know whether a change to health benefits will have a financial impact is to ask the carrier to give a written estimate of the impact on premium costs. Often employers are reluctant to even ask, because they assume the cost of eliminating the GID treatment exclusions and "adding" a defined benefit will be high. Until the carrier is given an opportunity to give a cost estimate, it is difficult to predict what it will be. Some employers prepared for "the worst" have been surprised by carriers who estimated no increase whatsoever.

Too often, however, insurance carriers lack the resources to make accurate predictions of utilization costs for GID treatment services. In the face of unpredictable risk, actuaries will predict financial impacts based on a fictional "worst case" scenario. See page 9 in the previous section for a more detailed assessment of cost.

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What will be covered by “inclusion”?

Coverage should include services for transgender individuals who are at any life stage. At a minimum, plans should cover hormone replacement therapy, mental health services, and a range of genital and other surgeries.

Pharmaceutical schedules and formularies should be reviewed to ensure that doctors have access to the range of hormones and other medications utilized in the transition process (be aware that medications may differ for adolescents and adults, and may change across the lifespan), in the dosage levels and delivery modes required. These may include: injectible, transdermal or oral preparations of estrogen, testosterone, and anti-androgens, as well as gonadotropin-releasing hormone (GnRH) analogues (“blockers”), which impact the development of secondary sex characteristics.

How much is covered?

Caps are often used as a tool to minimize fears of unknown risk in areas of coverage with little utilization data. It is important to find out if there are annual or lifetime dollar caps on coverage. For a comprehensive employer-based plan covering a large pool of individuals, no separate cap should be necessary.

It is important to carefully assess any caps in relation to the anticipated cost of services, and the size of the insured pool. While smaller pools may need to utilize a lower cap, larger plans will incur no undue additional risk with a higher cap or no cap at all. Since the goal of providing health coverage is to ensure the health and well-being of employees and their families, this goal will be undercut unless the plan structure ensures access to medically necessary services.

Many MTF surgical procedures cost less than \$25,000; however, certain individuals may require surgeries which exceed \$50,000. For an FTM, a hysterectomy or chest surgery may cost \$10,000 (although when direct-billed through insurance this cost may rise above \$20,000 per operation).

In no case should an annual or lifetime cap include mental health care or services related to hormone replacement therapy, including laboratory tests to monitor the impact of hormones on the body. These services are typically already covered by most health plans without a cap, and are also required on an ongoing basis across the lifespan in contrast to surgical procedures which are typically performed only once.

Where can services be performed?

It is important that patients with GID be able to access knowledgeable and qualified medical providers, particularly for surgeries, which require specialized training. If your insurance plan is limited to in-network providers, there may not be appropriate surgeons on your list. Therefore, coverage of out-of-network providers should be available at in-network rates.

Many surgeons experienced in transgender transition-related procedures are out-of-network for many or all insurance plans. A plan which prohibits, places limits on, or demands a significantly increased co-payment for out-of-network coverage may severely limit where enrollees can have surgery. The inevitable consequence will be limits on the type of surgery individuals are able to access, and may prevent some individuals from accessing the type of surgery most appropriate to their clinical needs. Several health plans are reported to have streamlined this process for patients by providing direct pre-payment for services provided by out-of-network providers.

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Watch for barriers to access

Some carriers who have established policies for accessing transition-related care use out-dated standards of care, and thus violate the WPATH Standards of Care with eligibility requirements that are overly narrow. Be sure that your insurance carrier is aware of up to date information about this. Some plans prohibit eligibility for those who are HIV-positive, while others have lengthy waiting periods or unnecessary and unrelated psychological testing, such as IQ tests or depression indexes. Some plans require a formal diagnosis of GID and/or “transsexualism” which may limit access by those who identify as something other than transsexual. Finally, some carriers have a complicated process for prior authorizations that take months or even years to complete.

Watch out for new exclusions

In addition to ensuring specific inclusion of transition-related care, line item exclusions relating to transgender individuals and their care should also be eliminated. Check to be sure that no new ones are added when the overall exclusion is lifted. Some plans have specified inclusion of some transition-related services including surgeries, but have kept their overall exclusion language intact. This practice contributes to misinformation from plan representatives and those seeking to access care. Plan language should not include characterizations of any particular set of services as “not medically necessary.”

Nomenclature can also be a barrier. Insurance plan language should be reviewed to ensure all health services are covered for all enrollees regardless of sex/gender. For example: gynecological pelvic exams should be covered for any enrollee who has a vagina, uterus, or ovaries, and not just to women; FTM individuals may retain these body parts across the lifespan. Similarly, prostate exams must be covered for any enrollee who has a prostate, and not just men; transgender women retain a prostate even after genital surgery.

Follow-through & follow-up

Benefits administrators and union representatives should engage in ongoing monitoring to ensure that the plan language and structure provides continuing access to needed services. It is important to be sure that employees are able to access and utilize their benefits, including transition-related care. If you make progress but the plan still maintains some barriers, such as an annual or lifetime caps, keep working at it. You can continue to incrementally expand the benefits and make your plan more inclusive over the years. In addition, aggregate utilization information should be compiled annually and shared, so that more companies and individuals have access to reliable, current, and realistic data about coverage.

Some employers may have a more difficult time leveraging inclusive coverage. Small employers, or any group plan with a small number of enrollees, face greater difficulties in offering new benefits because their risk is greater. You may seek to combine forces with other small businesses who use the same carrier. Sometimes small businesses and organizations participate in a pool to obtain health insurance, reducing costs by increasing the number of individuals covered. You may need to convince the administrators of that pool to advocate to your insurance company.

Finally, keep at it. Access to coverage for the treatment of gender dysphoria has been continually expanding; the more voices asking for it, the more likely it is that your insurance company will offer it. After all, they need to keep their customers (you!) happy enough with the plan to continue to do business with them.

Conclusion

After reading this guide, you may be feeling inspired, excited, empowered, and utterly overwhelmed. It's easy to get lost in the details of insurance intricacies, especially if you're new to the advocacy world. In a long and complicated process like negotiating for inclusive coverage, setbacks will arise and so will frustrations. When you find yourself lost, confused, or not sure what to do next, take a step back and review what you already know.

In Part I, you learned that:

- » Transgender people work in all areas of the economy, but are often unable to take full advantage of their health benefits because of exclusionary language in insurance policies;
- » The cost of equitable benefits is minuscule, and calculations that show otherwise are based on faulty logic and fuzzy math;
- » Supplying needed medical care to transgender employees improves productivity and reduces stress-related problems; and
- » Having inclusive coverage makes it easier to recruit and retain highly qualified employees from diverse backgrounds.



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In Part II, you learned how to get to inclusive coverage, first by getting commitment from decision-makers in your organization, and then by winning at the negotiation table with your insurance carrier. To secure employer commitment, you need to:

- » Gather information about how decisions are made at your company, who chooses insurance plans, what the timeline is for contract negotiations, what other groups or people have advocated for internal change, and what the current benefits package looks like;
- » Build a team of advocates that includes transgender and non-transgender employees;
- » Make a plan to engage in the insurance negotiation process, including who to talk to, how to approach them, and when to start;
- » Recruit an ally in upper management who can champion the issue; and
- » Use personal stories that touch your allies' hearts.

Once you've gained commitment to inclusive health benefits from your employer, it's time to talk to the insurance carrier. To reach success there, you'll:

- » Gauge the estimated financial impact of inclusive benefits;
- » Determine what procedures will be covered, for whom, and to what extent;
- » Watch out for new exclusions; and
- » Follow through each step of the way.

Achieving inclusive benefits might seem fanciful from your vantage point now, but there's no magic required. With the right amount of information, determination, and old-fashioned elbow grease, you can and will gain what you need to ensure that all employees, regardless of gender identity, can access the health care they need and live happy, productive lives. The path may be long, but you've already taken the first step. Persevere, and you will win.

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Appendix A: Statements of Medical Necessity

Major medical journals in the 1950s began publishing articles on health care for transgender people. In the 1960s, American physicians began providing care for transgender people in academic medical centers such as Stanford, University of Minnesota, Johns Hopkins, and Northwestern University. Throughout the 1970s, dozens more university transgender health programs opened. The science was clear then, and is even more certain today, that transgender people benefit significantly from such care.

As far back as the 1980s, the need for transition-related care was supported by medical research, and since that time, the evidence has grown even more robust and universally accepted. Recently, medical and mental health associations have taken strong positions supporting the medical necessity of transition-related care and equitable benefits packages:

The American Medical Association

The American Medical Association's (AMA) passed a resolution in 2008, excerpted here:

“An established body of medical research demonstrates the effectiveness of mental health care, hormone therapy, and sex reassignment surgery as forms of therapeutic treatment for many people diagnosed with GID, and...Whereas, health experts in GID, including WPATH, have rejected the myth that such treatments are ‘cosmetic’ or ‘experimental’ and have recognized that these treatments can provide safe and effective treatment for a serious health condition... the AMA support public and private health insurance coverage for treatment of gender identity disorder...the AMA oppose categorical exclusions of coverage for treatment of gender identity disorder when prescribed by a physician.”

The American Psychological Association

The American Psychological Association (APA) states that it “recognizes the efficacy, benefit and medical necessity of gender transition treatments for appropriately evaluated individuals and calls upon public and private insurers to cover these medical necessary treatments.”

The Endocrine Society

In 2009, the Endocrine Society, the world's oldest and largest professional association for endocrinologists published clinical guidelines for Endocrine Treatment of Transsexual Persons, providing more detailed guidance for hormone treatment consistent with the WPATH Standards. The guidelines emphasize that hormone therapy for GID is safe, effective, and similar to hormone protocols for many non-transgender patients.

American Academy of Family Physicians

In 2007, the American Academy of Family Physicians' (AAFP) issued Resolution 64, which stated that it opposes any form of discrimination against patients, especially transgender patients. It also stated that it supports insurance coverage of transition-related care.

World Professional Association for Transgender Health

WPATH set forth a statement in 2008 clarifying the medical necessity of treatment and need for insurance coverage in the United States. It states that sex reassignment “has proven to be beneficial and effective in the treatment of individuals with transsexualism, gender identity and/or gender dysphoria. Sex reassignment plays an undisputed role in contributing toward favorable outcomes...”

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Appendix B: Insurance Terminology

Actuarial Data and Methods: Analyzes rates of illness, disability, morbidity, mortality, fertility, etc. for any given population demographic. Also analyzes the effects of consumer choice, utilization of medical services and procedures, and the utilization of drugs and therapies, to aid in the design of benefit structures, reimbursement standards, and the effects of proposed government standards on the cost of health care.

Adverse Selection: A process in which less healthy people are disproportionately enrolled in an insurance pool (or “risk pool”).

Appeal: If you disagree with a public or private insurer’s denial of coverage for services or with the level of reimbursement for services you have already received, you may file an appeal. There are usually several levels of appeal.

Beneficiary: Someone who is eligible for or receiving benefits under an insurance policy or plan. The term is commonly applied to people receiving benefits under the Medicare or Medicaid programs.

Benefits: The health services covered by an insurance policy and the reimbursement levels for these services.

Co-premium: A fixed dollar amount paid annually by the insured person for health insurance. (The employer typically pays the remaining amount of the annual premium.)

Cosmetic Services: Procedures used primarily for improving appearance rather than for treating an illness or disease; generally excluded from coverage.

Deductible: A type of cost sharing where the insured party pays a specified amount of approved charges for covered medical services before the insurer will assume liability for all or part of the remaining covered services. Oftentimes, the insured has to make a yearly deductible.

Diagnosis Code: The first of these codes is the ICD-9-CM diagnosis code describing the principal diagnosis (i.e. the condition established after study to be chiefly responsible for causing this hospitalization). The remaining codes are the ICD-9-CM diagnosis codes corresponding to additional conditions that coexisted at the time of admission, or developed subsequently, and which had an effect on the treatment received or the length of stay.

Elective Surgery: A surgical procedure that is not associated with an emergency or maternity condition and can be scheduled for the convenience of the member or surgeon.

Fee for Service or Private Fee for Service Plan: This is private (commercial) health insurance that reimburses health care providers on the basis of a fee for each health service provided to the insured person.

Health Insurance: Insurance against loss through illness or injury of the insured person which provides reimbursement of, or direct payment for, medical expenses.

Health Maintenance Organization (HMO): [definition needs work] Prepaid medical plan in which members are limited to a specific network of providers. A group of doctors and other medical professionals offer care through the HMO for a flat monthly rate with no deductibles. However, only visits to professionals within the HMO network are covered by the policy. All visits, prescriptions and other care must be cleared by the HMO in order to be covered. HMOs are the least expensive, but also the least flexible of all the health insurance plans. They are geared more toward members of a group seeking health insurance. HMOs operate as insurers (meaning they spread health care costs across the people enrolled in the HMO) and as health care providers (meaning they directly provide or arrange for the necessary health care for their enrollees).

Mandatory Benefits: All states have laws specifying that licensed health insurance organizations to offer or include coverage for certain services, such as mental health services or substance abuse treatment. These mandates vary from state to state.

Medical Necessity and Medically Necessary Treatment: Treatment that, if it were omitted, would negatively affect the patient's life. However, there is little standardization about what is considered medically necessary. Plans are not always required to cover medically necessary services.

Out-of-pocket Costs: Total costs paid directly by consumers for insurance co-payment and deductibles, prescription or over-the-counter drugs, and other services.

PPO (Preferred Provider Organization): [definition needs work] A health care organization composed of physicians, hospitals, or other providers which provides health care services to plan members at a reduced fee. A PPO plan offers discounted rates on services from providers in the network: visits within the network require only the payment of a small fee. Often, if the individual seeks care outside the network, a smaller portion of the charges is reimbursed. PPO's may offer more flexibility than HMOs by allowing for visits to out-of-network professionals, albeit at a greater expense to the policy holder. Out-of-network expenses are often subject to a deductible and higher co-pays. A policy holder will have a primary physician within the network who will handle referrals to specialists that will be covered by the PPO. PPOs give policyholders a financial incentive—reasonable co-payments (also called co-pays)—to stay within the group's network of practitioners.

Pre-existing Condition: A health problem which was diagnosed or treated before a specified date prior to coverage in a new insurance policy. Benefits for such conditions can be excluded for a defined period of time after coverage begins. HIPAA requires coverage of pre-existing conditions if you can show proof of insurance within the last 63 days.

Review (Medical Review or Utilization Review): The process of determining the appropriateness of care or treatment. Usually part of claims adjudication.

Risk Adjustment: The way that payments to health plans are changed to take into account a person's health status.

Risk Assessment: (1) The means by which plans and policymakers estimate the anticipated claims costs of enrollees. (2) Identifying and measuring the presence of direct causes and risk factors which, based on scientific evidence or theory, are thought to directly influence the level of a specific health problem.

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Risk Pool: Health insurers pool together the actual and predicted health care costs of a group of people in order to better predict risk (future costs) and to spread those costs across a group. Theoretically, risk pools should include a balance of high and low risk people. A “Risk Pool” is (1) group of people insured together in one plan (e.g. all the employees at a given workplace and their dependents); (2) A group created through legislative programs which bring together individuals who cannot get insurance in the private market. Funding for the pool is subsidized through assessments on insurers or through government revenues. Maximum rates are tied to the rest of the market.

Self-funded (aka self-insured): In a self-funded arrangement, the employer assumes the risk of providing covered services to enrollees and pays directly for health care services of enrollees. Employers with 51+ employees may opt to self-fund. The coverage offered under these such plans is largely exempt from regulation under state insurance law, and instead falls under federal ERISA regulation. These large employers usually contract with other parties to administrate these health plans, usually a “Third Party Administrator,” a health insurer or an HMO. The employer pays the costs of claims and also pays a fee to the administrating entity to handle claims. Usually claims are managed much the same way as for other insurance or HMOs, with a focus on controlling costs. However, the sponsoring employer can choose to exert significant control over both the content of coverage and claims administration.

Underwriting: Medical underwriting is a process of determining whether or not to accept an individual applicant for coverage. Underwriting looks at past medical history to assess risk, and adjusts coverage and premiums based on this assessment.

