THREE-YEAR STRATEGIC PLAN

2022–2024

For External Use

Prepared by: Rebecca Eyre, MA, LMHC, Chief Executive Officer
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MISSION, VISION & VALUES

OUR MISSION

is to break down systemic, healthcare, and financial barriers to eating disorder healing.

OUR VISION

is for everyone with an eating disorder to have access to the resources and opportunities they need to heal.
Equity Matters
We believe that everyone deserves the opportunity to recover and has the right to quality mental health care — regardless of age, race, gender identity, sexual orientation, size, ability, or financial means. We exist to create equity in the eating disorder treatment landscape, and we know this means we must be willing to be disruptive in the process. We’re committed to anti-racism, anti-oppression, gender equity, and taking action to create justice.

Healing is Possible
We believe that recovery from an eating disorder is possible when people have access to the resources and opportunities they need. With one person dying of an eating disorder every 52 minutes, we know that many cannot afford to wait for the systemic changes that we and so many others are working on behind the scenes, so we approach treatment access through a harm reduction lens. We are committed to both the long-term vision of what eating disorder treatment can and must be and the promise to save as many lives as we can in the meantime.

All Bodies are Good Bodies
We stand against any and all beliefs, biases, or messages that compare bodies against constructed ideals, equate health with appearance, define beauty, or assign value or worth to any individuals over others. We are anti-diet and fat-positive. We are committed to body liberation in all its forms. We are committed to empathy and treating all humans with dignity.

We’re Better Together
We believe that our mission is not possible without partnership, community, and connection. We are committed to always listening, always learning, staying innovative, practicing flexibility, and fostering resilience.
**PROJECT HEAL’S STORY**

Project HEAL was founded in 2008 by Kristina Safran and Liana Rosenman when they were both just 15 years old. They met in treatment for their own eating disorders, where they noticed how expensive treatment was and how often insurance companies denied coverage for the full course of treatment required to recover. Fueled by their shared passion to make eating disorder recovery possible for all, they began fundraising to pay for treatment for those who could not afford it and whose insurance would not cover it. Thus, Project HEAL was born.

*Learn more about our founders’ stories here.*

Over the course of the last 13 years, Project HEAL has grown into one of the most impactful and well-respected eating disorder nonprofits in the U.S. We’ve helped hundreds of people access free eating disorder treatment, and we’ve emerged as one of the leading voices that believe genuine healing from an eating disorder is possible – with proper access to quality, identity-affirming support.

In April 2020, Project HEAL hired a new CEO to forge a new path for the organization. Rebecca Eyre, a licensed eating disorder therapist herself, has both sharpened and expanded Project HEAL’s approach to eating disorder treatment access. We expanded what was once our “Treatment Access Program” into three distinct direct service programs: 1) the Treatment Placement Program, 2) the Insurance Navigation Program, and 3) the Cash Assistance Program. We’ve also righted a past wrong by directly and openly addressing the many systemic barriers that marginalized communities uniquely face when seeking eating disorder care. In alignment with these changes, Project HEAL underwent a rebrand and a recalibration of our mission, vision, and values statements, as well as implementing Diversity, Equity, and Inclusion practices at every level of the organization’s operations.

Today, Project HEAL is the only national eating disorder nonprofit with a Board of Directors and staff that closely reflects the identities of the entire eating disorder community, with program offerings specifically designed to effectively serve eating disorder sufferers beyond the narrow stereotype of young, white women and girls with anorexia nervosa. Project HEAL aims to be a resource for all people with eating disorders, and we believe that in order to do that effectively, we must be bold and intersectional in our efforts to ensure that those who have long felt – and often are – ignored and excluded are intentionally considered and included.
AN OVERVIEW OF EATING DISORDERS

DIAGNOSIS
The American Psychiatric Association (APA) has laid out the following primary eating disorder diagnoses in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5):

1. Avoidant/Restrictive Food Intake Disorder (ARFID)
2. Anorexia Nervosa (AN)
   - Restricting Type
   - Binge/Purge Type
3. Bulimia Nervosa (BN)
4. Binge Eating Disorder (BED)
5. Other Specified Feeding or Eating Disorder (OSFED)
   - Including “Atypical” AN
6. Unspecified Feeding or Eating Disorder (UFED)
   - Subclinical eating disorders

INCIDENCE
Eating disorders are extremely common in the United States. The most recent data shows that at least one in ten people in the U.S. will be diagnosed with an eating disorder in their lifetime - that’s nearly 30 million people. However, given research that also proves how grossly misunderstood and commonly undiagnosed eating disorders are, it is widely asserted that the incidence rate is actually much higher than that. Some experts suggest that eating disorders affect up to half of the American population, and “disordered eating” affects the vast majority.

SEVERITY
Eating disorders are the second most fatal mental illness, second only to Opioid Use Disorder. One person dies as a direct result of their eating disorder every 52 minutes, whether through medical complications or by suicide. Again, due to a lack of diagnosis and research, it is believed that the fatality rate is even more devastating than we know.

STEREOTYPE VS. REALITY
Eating disorders do not discriminate. Eating disorders affect people of all genders, ages, races, ethnicities, body shapes & weights, sexual orientations, and socioeconomic statuses.

When most people conjure up a mental image of someone with an eating disorder, they picture a white, adolescent, underweight girl - by default, she is presumably cisgender, able-bodied, and heterosexual. (This is vividly confirmed by a simple Google Image search for “person with an eating disorder.”) Although this stereotype permeates both our culture and our medical system, it is extremely inaccurate. While there absolutely are many young white girls
struggling with Anorexia who need and deserve quality treatment in order to survive their illness - many of whom cannot afford it - that subgroup is far from the majority in any way that would justify this common misconception.

The following statistics put into troubling context the extreme homogeneity of the eating disorder field, and highlight both the inequities present in the existing eating disorder treatment landscape and the inaccuracy of our cultural understanding of eating disorders.

- Less than 6% of people with eating disorders are medically underweight.
- Binge Eating Disorder is more common than Anorexia Nervosa or Bulimia Nervosa combined.
- 25-40% of people with eating disorders are men or boys.
- Transgender and gender nonconforming individuals are at least 4x as likely to struggle with an eating disorder than their cisgender counterparts.
- Bingeing and purging behaviors are more common among Black and Latina women than white women.
- Black women are 25% less likely to be diagnosed as white women with the exact same eating disorder behaviors.
- High weight people with eating disorders are exponentially more likely to be encouraged to engage in eating disorder behaviors (restriction, over-exercise, etc) in order to lose weight than to be screened for an eating disorder by their doctors.
- While eating disorders typically onset in adolescence or early adulthood, they often persist into older adulthood - especially when untreated. At least 13% of people in residential treatment for an eating disorder are aged 41-55.

CONSEQUENCES OF A STEREOTYPE

One of the main reasons we see such a singular image and hear such a narrow story is that affluent, young, white cis women with Anorexia Nervosa are:

- more likely to be appropriately diagnosed by a medical provider, due to lack of training and implicit bias among clinicians
- more likely to have their treatment covered by their insurance, due to “medical instability” requirements for treatment authorization
- more likely to be able to afford treatment, due to economic inequities in the U.S.
- more likely to benefit from treatment, because people with their shared identities were the focus of the eating disorder research which has become the template for “evidence-based care.”

As a result, these individuals are more likely to recover, more likely to become a recovery advocate, and more likely to become an eating disorder provider themselves. This cycle of privilege has kept the eating disorder stereotype intact despite its inaccuracy, and has contributed to the eating disorder field being the most flagrant case study for healthcare disparity, inequity, homogeneity, and bias in the U.S.
AN OVERVIEW OF THE EATING DISORDER FIELD

“The eating disorder field” includes a variety of key players that are best distilled into three core categories: treatment providers, researchers, and nonprofits. Although the eating disorder field is extremely - and appropriately - complex (given the complexity of these illnesses), it remains a very niche area of work that has neither adequate funding nor the volume and variety of people needed to address its vast needs. In other words, it is like a small family plagued by scarcity that often disagrees on how to manage its limited resources.

TREATMENT OPTIONS

Treatment providers operate in a wide variety of settings, otherwise known as Levels of Care (LOC). These are the widely recognized LOC that are the focal point of healthcare coverage advocacy.

- Outpatient Services (OP)
  - Therapy
  - Dietetics
  - Psychiatry
  - Medical
- Intensive Outpatient Programs (IOP)
- Partial Hospitalization Programs (PHP) / Day Treatment
- Residential Treatment Centers (RTC)
- Inpatient / Hospitalization (IP)

For adolescents, there are three core modalities that evidence suggests are effective at treating eating disorders:

- Family Based Therapy (FBT) - OP therapy
- Intensive Family Treatment (IFT) - one full week of care for the entire family
- Recovery at Home – Virtual, bundled, modified FBT (e.g. Equip)

There are alternatives to these models that are often more affordable and don’t always require licensure to provide, including:

- Clinician-led support groups
- Peer-led support groups
- Peer mentorship
- Coaches (e.g. Carolyn Costin Institute)
- Self-help

TREATMENT COSTS

Eating disorder treatment is extremely expensive, full stop.
The vast majority of outpatient eating disorder providers are not paneled with insurance and have full practices with private pay clients, the average session costing $150. Higher LOC are even steeper: IOP typically costs $1,500/week, while RTC and IP cost an average of $2,000/day. The University of California San Diego estimates that the average eating disorder treatment episode costs $80,000.

Although these higher LOC are often technically covered by private insurance, these plans often have LOC exclusions, short-term authorizations, and medical necessity requirements. Government funded insurance (Medicare, Medicaid, etc) almost universally excludes anything beyond OP and IP, rendering most of the spectrum of care inaccessible, and leaving its planholders (often low-income or disabled people) without adequate care.

Most eating disorder clinicians estimate that full recovery from an eating disorder takes around two years of dedicated, uninterrupted care at a variety of LOC. If a person were to start in IP, step down to RTC, step down to PHP, step down to IOP, and finish with an adequate number of OP sessions focused on relapse prevention, this would take around two years, and would cost around $250,000. The number of people who have these available funds or insurance who will provide coverage for this full course of treatment without unfair denials is extremely low - perhaps in the hundreds.

**TREATMENT PROVIDERS**

Eating disorder therapists account for a dismal 0.52% of mental health providers.

According to the U.S. Department of Labor's Bureau of Labor Statistics, there are more than 577,000 mental health professionals practicing in the U.S. today whose main focus is the treatment (and/or diagnosis) of a mental health or substance abuse concern.

- Clinical and counseling psychologists – 166,000
- Mental health and substance abuse social workers – 112,040
- Mental health counselors – 139,820
- Substance abuse counselors – 91,040
- Psychiatrists – 25,250
- Marriage and family therapists – 42,880

According to www.FindEDHelp.com, the nation’s leading eating disorder provider directory, there are 1,589 OP clinicians (including therapy, dietetics, psychiatry, and medical) specializing in eating disorder treatment in the U.S. Assuming that not everyone is registered with this site, Project HEAL generously estimates that there are a maximum of 3,000 therapists treating eating disorders in the U.S.

That’s one therapist for every 10,000 people who’ve been diagnosed with an eating disorder.
According to the **FEDUP Collective**, an organization focused on eating disorders in Transgender, Intersex, and Gender Diverse people, that has done extensive research on the eating disorder field for its advocacy efforts, there are **228 eating disorder treatment centers in the U.S.** With an average census of 25 people per program, there are around **6,000 available treatment spots in the U.S.** That’s **one spot for every 5,000 people** who have been diagnosed with an eating disorder.

The most comprehensive list of BIPOC (Black, Indigenous & People of Color) and LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Queer, etc) eating disorder providers has also been aggregated by FEDUP Collective. It lists just **57 BIPOC and LGBTQ+ providers**. Assuming that this list is not comprehensive, Project HEAL generously estimates that there are a maximum of **150 BIPOC or LGBTQ+ eating disorder providers in the U.S.** That’s **around 5%** of the eating disorder provider field.

For an illness that does not discriminate and affects people across all identities and demographics, the eating disorder field is extremely homogeneous, being primarily composed of providers who themselves fit the eating disorder stereotype: cis, white women.

The eating disorder field is also dangerously small. If 30 million people in the U.S. are diagnosed with an eating disorder, but there are only 9,000 treatment options, it is no wonder that only **10% of people with eating disorders ever receive treatment.** Add into the equation how expensive treatment is, how often it is not covered by insurance, how clustered these treatment options are in large metropolitan areas, and how many of them are strictly limited to treating women and girls who are considered “medically unstable,” it is apparent that the eating disorder treatment landscape was not designed to help the entire population of eating disorder sufferers – but rather, just a small portion of it.

**NOTE:** It is important to also keep in mind that many people who struggle with eating disorders are never diagnosed and are not reflected in the 30 million statistic. Anecdotally, for every person **I (Rebecca) know who has been diagnosed with an eating disorder, I know at least five others who identify as having struggled with an eating disorder but were never officially diagnosed. Taking into consideration research that shows only 17% of Black women, 41% of Latina women, and 44% of white women are accurately diagnosed by doctors when presenting with an eating disorder, it is safe to say that, due to misconceptions and lack of eating disorder education among providers, most eating disorders go undetected and undiagnosed in the U.S. today. If there are even more people with eating disorders in the U.S. than data shows, then the deficiency of available treatment options becomes that much more problematic.**

Both the diminutive volume of eating disorder providers and the uniformity of their identities can largely be attributed to a broken education system. Eating disorder treatment training is not offered in most Masters level therapy or dietetic programs, nor is it included in Doctoral level medical residencies. Most of these clinical programs include eating disorders as a single
hour or day in their curriculum and do not go beyond the diagnostic criteria, often focusing in-class case studies on clinical presentations that reflect the eating disorder stereotype.

This means that anyone interested in treating eating disorders must pursue this education independently. Naturally, the majority of people who have followed this path have been people whose lives have been directly impacted by eating disorders, whether afflicting them personally or someone they know. Given the longstanding eating disorder stereotype, and the narrow population of people for whom the eating disorder treatment landscape was designed, those people have tended to be included in that identity pool – cisgender white women. Not only is this demonstrated in the demographics of the field, but it is strikingly visible at eating disorder conferences and in treatment center staff photos.

EATING DISORDER TRAINING
For the past few decades, the primary (for many years, the only) organization offering eating disorder training has been the International Association of Eating Disorder Providers (IAEDP). The cost to obtain IAEDP certification and membership is $4,150, followed by annual membership fees, mandatory conference attendance, and certification renewal costs of $3,800 per year. These financial barriers have also resulted in keeping the eating disorder field limited to individuals who can afford these high costs.

EATING DISORDER NONPROFITS
While there are a number of small, local eating disorder nonprofits across the country, there are only a handful of national eating disorder nonprofits, of which Project HEAL is one. While there are some programmatic overlaps and duplications, each organization has a different focus and function.

<table>
<thead>
<tr>
<th>Organization</th>
<th>Offerings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project HEAL</td>
<td>Treatment access programs, research, education, advocacy</td>
</tr>
<tr>
<td>NEDA</td>
<td>Helpline, research funding, general info</td>
</tr>
<tr>
<td>ANAD</td>
<td>Helpline, virtual peer-led support groups, peer mentorship</td>
</tr>
<tr>
<td>The Alliance</td>
<td>Helpline, virtual clinician-led support groups, OP treatment in FL</td>
</tr>
<tr>
<td>NCEED</td>
<td>Medical community-facing education; only federally funded ED org</td>
</tr>
<tr>
<td>IAEDP</td>
<td>Certification program for eating disorder specialists</td>
</tr>
<tr>
<td>AED</td>
<td>Membership org, ICED conference highlighting ED research</td>
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**EATING DISORDER FUNDING**

Annually, it is estimated that all nine of the national eating disorder nonprofits listed above collectively raise just **33¢ per person affected**, totalling around $10 million.

Annually, funding for eating disorder research is just **73¢ per person affected**, totalling around $21 million. Compare this to autism research which receives $58.65/person affected and schizophrenia research which receives $86.97/person affected - despite neither autism nor schizophrenia being as common or fatal as eating disorders.
BARRIERS TO EATING DISORDER HEALING IN THE UNITED STATES

The most recent research estimates that only 10% of people in the U.S. who are diagnosed with an eating disorder will ever receive treatment. This is attributed to the myriad barriers that people with eating disorders (ED) in the U.S. face when they’re in need of care – which can be understood in the following categories: systemic, cultural, healthcare, qualitative, financial, logistic, current, and personal.

SYSTEMIC
- Existing treatment was primarily researched on and subsequently designed for white adolescent cisgender girls with Anorexia
- Lack of diverse representation among treatment providers
- Lack of disability accommodations
- Explicit and implicit biases including fatphobia, transphobia, ageism, racism, and sexism among eating disorder providers
- Weight requirements in DSM-5 diagnosis for AN and ARFID
- Weight discrimination in admission criteria for higher levels of care
- Weight goals based on sexed criteria
- Gendered admission criteria at treatment centers
- Treatment plans and medical records based on legal sex
- Lack of weight-bearing furniture and size-inclusive medical equipment at facilities
- Lack of research about eating disorders among or including marginalized communities and identities
- Lack of ED research funding
- Lack of federal funding for EDs compared to other diagnoses
- Lack of lobbying for EDs in healthcare policies

CULTURAL
- Social stigma around seeking mental healthcare
- Glorification of thinness – positive reinforcement for illness
- Fatphobia in schools
- Toxic masculinity impacting cis men’s ability to acknowledge their struggle or seek help
- Lack of accurate representation in media
- Lack of awareness of EDs within mental health advocacy

HEALTHCARE
- People don’t understand their insurance
- Insurance won’t cover every level of care
- People have to jump through hoops to secure coverage in the U.S.
- Unfair denial of coverage for clinically appropriate treatment
- Premature discharges as determined by subjective evals by people who have never met the client
- Insurance only covers “evidence-based care,” but the evidence is outdated and limited to the “dominant” population
- Distrust between insurance and providers
○ Prioritizing substance use disorders / treating people with co-occurring disorders but neglecting to treat the ED
○ Psych hospitals and trauma treatment centers ignore EDs
○ Lack of screening for eating disorders in PCP appointments
○ Clinical presentation changes rapidly making authorizations emergencies
○ Medical instability as a requirement for intensive care
○ Lack of OP providers accepting insurance
○ 28 million uninsured people in the U.S. alone
○ Short windows of open enrollment for ACA
○ Immigration / documentation for insurance
○ Government funded insurance only covers IP, OP, and occasionally PHP/IOP if they’re based in a hospital
○ Law prohibiting government funds to pay for facilities that have 16 or more beds
○ Law prohibiting government funds to pay for facilities that don’t have 24-hour nursing
○ Medicaid plans sold as different names that mislead planholders
○ Lack of ED knowledge among UR authorization staff / doc:doc reviewers

QUALITATIVE
○ Lack of ability to treat co-occurring mental health issues
○ Lack of ED knowledge in medical community

○ Lack of ED knowledge in clinical community
○ Lack of coordination at level of care (LOC) transition
○ Lack of family involvement in care
○ Abusive family members required to be involved in care
○ Pathologizing dietary restrictions
○ Lack of standardized treatment protocols
○ Inaccurate / biased diagnoses by treatment centers
○ ED providers commonly lack understanding of sports / athletics
○ ED providers lack understanding of working with pregnant clients
○ Binge Eating Disorder not taken seriously
○ Religious dietary needs unmet in treatment centers
○ Lack of outcome definitions
○ Too few treatment centers
○ Waitlists for all levels of care
○ Medical liability fears among treatment centers
○ Provider to client ratios
○ Provider burnout
○ Provider certification both out of date and expensive

FINANCIAL
○ Poverty
○ Exorbitantly expensive
○ High deductibles
○ High OOPM
○ High co-pays
○ Inability to pay bills/rent while not working to go to treatment
○ Lack of credit to consider going into debt for treatment

LOGISTIC
○ Geographic barriers
○ Travel and transportation barriers
○ Language barriers
○ Lack of authoritative, centralized database of eating disorder providers
○ Virtual care requires reliable technology and privacy
○ Inability to take time off of work
○ Inability to find childcare
○ Inability to find pet care

CURRENT
○ COVID-19: lockdowns, vaccination requirements, travel, job loss, insurance loss

PERSONAL
○ Shame
○ Denial
○ Bootstrap mentality
○ Lack of family or social support
○ The difficulty of recovering in a culture obsessed with thinness, dieting and fitness
○ High expectations for “fanciness” of facilities leading to higher costs
○ Fear of, or resistance to, giving up the ED
○ Inaccurate self-diagnosis
○ Terror of surrendering freedoms for treatment
○ Past treatment trauma
○ Clients’ lack of trust in providers re: profits
PROJECT HEAL’S PROGRAMS AS OF 2021

TREATMENT PLACEMENT PROGRAM

Free, extended, or steeply sliding scale eating disorder treatment generously donated by one of our HEALers Circle partners at every level of care, including:

- Inpatient
- Residential
- Partial Hospitalization/Day Treatment
- Intensive Outpatient
- Outpatient therapy
- Outpatient dietitian & nutrition
- Eating disorder coaching
- Intensive Family Therapy
- Virtual Modified FBT (Equip)

Barriers broken down by this program:

- Exorbitant costs of treatment
- Govt-funded insurance lack of coverage
- Lack of coverage for every LOC
- Weight discrimination in admission criteria for higher levels of care
- Unfair insurance denials
- Premature discharges
- Medical instability a requirement for intensive care
- Lack of OP providers accepting insurance
- 28M uninsured people in the U.S.
- Immigration/documentation for insurance

INSURANCE NAVIGATION PROGRAM

Individualized case management and advocacy with insurance, including:

- Support getting new insurance on ACA marketplace
- Static resources in both English and Spanish
  - Health Insurance Glossary
  - ED Insurance Q&A
  - ED Treatment Levels of Care
  - Single Case Agreements
  - Appealing Insurance Denials
  - Advocating for Treatment with Medicaid
  - Medicaid Treatment Centers
  - Legal Support for ED Litigation

Barriers broken down by this program:

- People don’t understand their insurance
- Making people jump through hoops to get coverage
- Lack of in-network facilities
- Lack of OP providers accepting insurance
- Lack of coverage for every LOC
- Govt-funded insurance lack of coverage
- Unfair insurance denials
- Premature discharges
- Medical instability a requirement for intensive care
- 28 million uninsured people in the U.S.
- Language barriers
CASH ASSISTANCE PROGRAM

Financial aid for tertiary costs associated with treatment, including:

- Deductibles
- Co-pays
- Travel (flights, gas cards)
- Lodging (hotels, rent)
- Groceries
- Prescriptions

(Currently includes direct provider payments for BIPOC and TGNCI providers to connect beneficiaries to identity-affirming care)

Barriers broken down by this program:

- Exorbitant costs of treatment
- High deductibles
- High OOPMs
- High co-pays
- Inability to pay bills/rent while not working to go to treatment
- Lack of credit to consider going into debt for treatment
- Lack of geographic proximity to appropriate care
- COVID-19 impact
PROJECT HEAL’S ACTIVITIES & ASSETS AS OF 2021

RESEARCH
In 2019, Project HEAL began conversations with The Kennedy Forum and other leaders in the eating disorder field to establish what we called the Eating Disorder Equity Task Force. The Kennedy Forum’s focus on mental health parity brought them into Project HEAL’s orbit because they realized that eating disorders are a striking case study of the most egregious parity violations in mental healthcare.

What we quickly learned was that, despite having 11 years of qualitative data about barriers to eating disorder treatment access, we needed quantitative data on which to base our agenda and determine effective strategies. We put the task force on hold and began conversations with leading eating disorder researchers from prominent universities, and a literature review revealed that no quantitative research into the barriers to eating disorder treatment in the U.S. had ever been conducted. While everyone with any experience with eating disorders knew firsthand how many barriers exist, these barriers had never been clearly identified or measured. In order to ensure the impactfulness of a task force, we needed to start with data.

In 2020, Project HEAL partnered with the Eating Anxiety Treatment Laboratory & Clinic (EAT Lab) at The University of Louisville to assess the extensive treatment barriers that exist for people with eating disorders. This study has four (4) primary goals and will use a large data sample of individuals who have either received treatment or who have tried to access treatment services:

➔ To quantify the systemic barriers that people in the U.S. face when seeking eating disorder treatment.
➔ To quantify the healthcare and financial barriers that people in the U.S. face when seeking eating disorder treatment.
➔ To identify patterns and trends in the systemic, healthcare, and financial barriers that people in the U.S. face when seeking eating disorder treatment, and determine which barriers are more or less commonly experienced by people of different geographies, ages, races, genders, sexual orientations, body sizes, insurance plans, diagnostic profiles, and treatment histories.
➔ To obtain data to support future efforts to reform the eating disorder treatment landscape, and to influence future policy and legal changes within all levels of the healthcare system to ensure equitable healthcare access for people with eating disorders in the U.S.

As of the writing of this strategic plan, over 1,000 people have participated in the study and we anticipate reaching an N of 1,250 before the study closes in early 2022. We’ve also anonymized and analyzed 3,191 historical applications for Project HEAL’s treatment access programs.
This research gives Project HEAL a significant volume of information that should provide meaningful and actionable data about barriers to eating disorder treatment in the U.S. We will be publishing an academic paper with our findings, as well as creating an Eating Disorder Treatment Access Report for wide distribution in the eating disorder field. With hard numbers in hand to complement our many stories and experiences, we anticipate that we will be able to unify the eating disorder field towards dismantling the barriers that people face when seeking treatment, and gain traction in policy conversations with insurance payers as well as state and federal lawmakers.

**COMMUNITY EDUCATION**

Over the years, Project HEAL has built a strong virtual community across the country and around the world. With a social media audience of **146,157** people, a mailing list of **18,661** people, and a blog readership of over **5,000**, Project HEAL has the unique opportunity to speak out on issues affecting people with eating disorders and to influence the eating disorder field on the whole.

We know that in order for Project HEAL to fulfill its mission to break down barriers to eating disorder healing, we must be having conversations that inform our community about the realities of eating disorders and inspire them to take action – whether within their community or in their own personal healing process.

We also believe that in our efforts to break down systemic barriers in particular, a big part of that is **information**. As long as people maintain their own misconceptions about eating disorders, the stereotype remains intact to grave effect. So we have intentionally prioritized education that dispels myths, expands the conversation, and centers the voices of those who have long been silenced or ignored in the eating disorder community.

In 2021, Project HEAL hosted dozens of high-impact conversations on social media and partnered with other organizations to provide community training about eating disorders. **60,928** people attended those conversations and trainings this year, furthering our mission and enriching our community.

**AMBASSADORS**

Project HEAL’s mission is made possible by our committed and passionate Ambassador Network. Ambassadors represent Project HEAL in their local community as champions and advocates for our mission by raising awareness and funds for eating disorder treatment access. The Ambassador role allows volunteers to support Project HEAL in a way that is flexible to meet the interests, needs, and bandwidth of each individual.

Currently, we have **763** Ambassadors worldwide.
PROJECT HEAL’S REACH & IMPACT IN 2021

294,585
PEOPLE REACHED
through research, community education, and eating disorder awareness content

TREATMENT ACCESS SUPPORT PROVIDED
321 PEOPLE

CASH VALUE OF SERVICES DELIVERED
$1,908,550
$1 expenses → $3.39 real-life impact
THE CASE FOR PROJECT HEAL’S EXPANSION

MISSION FULFILLMENT
Project HEAL was founded with the vision that everyone with an eating disorder would have access to the resources and opportunities they need to heal. Our focus as an organization has been on treatment access.

While we are honored to be able to provide access to free eating disorder treatment for hundreds of people a year, and proud that we’ve scaled our capacity to serve the eating disorder population exponentially for the past two years, we acknowledge that we are barely making a dent in the true scope of the problem. Millions of people remain undiagnosed and untreated in the U.S. Our existing programs, while life-changing for individuals we’re able to help, are not sufficiently addressing nearly as many of the barriers to healing that our mission behooves us to help break down – nor are they robust enough to serve more than a fraction of the eating disorder population at large.

With tens of millions of people struggling without support, and one person dying every 52 minutes, Project HEAL needs to expand our efforts to provide equitable access to eating disorder support.

INDUSTRY POSITIONING
Treatment access barriers are an area of the eating disorder field that is widely agreed to be one of the most glaring issues, but Project HEAL remains the only organization explicitly focused on addressing this issue by both changing the system so that it works for everyone, as well as providing direct services to undermine its immediate consequences for people with eating disorders today.

Over the past few years, the eating disorder community has become increasingly vocal about their frustrations with the limitations of the eating disorder field. Too many are unable to access care, and the vast majority feel excluded and ignored by the people and organizations they purport to serve. With body positivity and body liberation movements gaining global traction thanks to social media, a groundswell of mainstream support for LGBTQ+ and gender diverse individuals, and an unprecedented racial justice movement in America, people from all walks of life who are struggling with food and body issues are demanding change. More and more people are using their voices and their lived experiences to demonstrate the true diversity of the eating disorder community, which has highlighted the ways in which the eating disorder field and the American healthcare treatment system are failing them.

As the conversation about mental health has come to the fore in America due to the COVID-19 pandemic, and as eating disorder incidence has concurrently skyrocketed, the demand for equitable access to identity-affirming eating disorder treatment has never been higher. Project
HEAL has taken this call to action to heart, and with the limited resources we have, we’ve pivoted our programs to meet the moment head on. Our efforts to do so have resonated with the eating disorder community. We’ve been able to build trust with communities who have long felt ignored or harmed by the eating disorder field, and we take that trust seriously. While other eating disorder providers, researchers, and nonprofits have been called out, boycotted, and divested from, Project HEAL has been building relationships and establishing a shared vision of how we can truly transform the eating disorder treatment landscape so that it works for and includes everyone, rather than remaining a niche field with limited resources accessible only to the privileged few.
AN OVERVIEW OF PROJECT HEAL’S EXPANSION PLANS

There are a few clear next steps for Project HEAL to focus on over the next three years in order to better serve the eating disorder community and better fulfill our mission.

First, we need to build out more entry points and front-line offerings for people who are at the beginning of their eating disorder healing journey, rather than where we are now which is 2–3 steps into the journey once a person realizes they have an eating disorder and need care that they cannot access.

Second, we need to build out our leadership efforts and brand footprint. Currently, people within the eating disorder community know about, respect, and trust Project HEAL – but those outside of it in the broader mental health community and popular culture have never heard of us. We’ve never had a dedicated marketing or communications staff member, and we’ve never publicly promoted our programs to people who are not already in the eating disorder community. All of Project HEAL’s applicants, followers, partnerships, and press coverage have been through word of mouth, which is both remarkable and accounts for our limited brand awareness more broadly. Simply put, the more people know about us, then the greater our impact can be.

Thirdly, our existing programs must be improved to more effectively and ethically serve people with eating disorders. We need to ensure that our eating disorder insurance expertise is easily accessible to everyone in the U.S. and we need to improve our capacity to provide access to identity affirming care to the 27% of our applicants who are BIPOC and the 43% of our applicants who identify as LGBTQ+.

Lastly, we intend to launch two new programs to address two specific needs within the eating disorder field: under-diagnosis and the treatment provider shortage.

ENTRY POINTS & FRONT-LINE OFFERINGS

- Project HEAL will expand our website content to include more general information about eating disorders, eating disorder treatment options, and barriers to access. We will include links to our partners and fellow eating disorder nonprofits whose areas of work address these categories, as well as the most recent eating disorder research. Our website will be a reasonable first-stop on a person’s path to understanding eating disorders and what to do about them.
- Project HEAL will partner with the Crisis Textline to provide immediate, 24/7 support for individuals in crisis.
- Project HEAL will hire a full-time administrative assistant to helm a “front desk” phone line where individuals who want to learn more about Project HEAL or eating disorders can call and be pointed in the right direction. While this will not be a helpline per se, it
will make Project HEAL more accessible to the general public and allow us to ensure that fewer people who need eating disorder support slip through the cracks due to our organization’s inaccessibility.

NATIONAL LEADERSHIP & BRAND FOOTPRINT

- Project HEAL’s active research into barriers to eating disorder treatment positions us as the national leader when it comes to equitable eating disorder treatment access. Once the research is complete, we will co-publish an academic paper with our research partners at the University of Louisville. This will form the basis of an easily digested **Eating Disorder Treatment Access Report** with infographics that covers the eating disorder and treatment access statistics we gleaned in our research. We will socialize and distribute this report throughout the eating disorder field (providers, researchers, nonprofits, etc) as well as with key stakeholders who have influence and capacity to help reform the eating disorder field (lawmakers, insurance payers, academic institutions, licensure boards, etc). We anticipate that this report will be a reference point for the eating disorder field for years to come.

- The data gathered through the Barriers to Treatment Access study will form the basis of an **Eating Disorder Task Force** – a motivated coalition of said stakeholders who will be called to join forces to dismantle the respective barriers that they are able to, and hopefully, to unify the eating disorder field towards committed action at long last.

- Project HEAL will devote resources to our **marketing and communications efforts** to position us as the leading eating disorder organization in the U.S. We will do more targeted press outreach, target search engine optimization (SEO), expand our community education efforts, and overall do a better job getting the word out about Project HEAL and what we do. These efforts will also expand our capacity for corporate partnerships and campaigns. In order for Project HEAL to achieve our mission, we need to become a widely recognized brand and a trusted partner with a broad reach.

PROGRAM IMPROVEMENTS

- Project HEAL will add a new component to our existing Treatment Placement Program called **Identity-Affirming Scholarships**. Given the limited diversity of eating disorder providers in the U.S. and the fact that most providers with marginalized identities themselves are understandably reluctant to join our HEALers Circle and donate their services, we will establish a protocol for compensating marginalized (in particular, Black, Indigenous, and transgender) providers for their services on behalf of our beneficiaries. With only 10% of our HEALers Circle representing BIPOC and LGBTQ+ identities, this solution helps us provide access to safe, appropriate care to the 27% of our applicants who are BIPOC and the 43% of our applicants who identify as LGBTQ+. Project HEAL will set aside a portion of our funding for Identity-Affirming Scholarships until such a point that our HEALers Circle is adequately diverse to properly serve the full scope of individuals with eating disorders who apply for our support.
● Project HEAL will develop an interactive online Insurance Navigation Portal that will allow people across the U.S. to better understand their insurance benefits, their patient rights, and how to advocate for the treatment they need. This portal will also include a chat feature that will allow the user to initiate contact with one of our insurance specialist volunteers who can help them with anything that the portal does not offer. Project HEAL holds a breadth of knowledge and expertise when it comes to advocating with insurance companies for appropriate eating disorder treatment coverage. Currently, the only way to access that knowledge and expertise is through our downloadable Insurance Navigation resources or by applying for support and being connected to one of our insurance specialist volunteers for case management. While this is an impactful program as is, it is time-heavy and laborious for both our beneficiaries and our team. This portal will allow us to help exponentially more people with more location- and plan-specific information. We will hire a team of developers to help us aggregate the intellectual property we already have and make it readily available for self-led exploration online.

NEW PROGRAMS
● Project HEAL is launching a Clinical Assessment Program – a new, high-capacity offering for individuals at the very beginning of their eating disorder healing journey. Currently, the only ways to obtain an ED diagnosis and treatment recommendation are to: 1) pay an ED specialist for an eval (around $250 unless you’re lucky to have someone in-network with availability), 2) see an existing provider who likely doesn’t have any eating disorder training which can lead to misdiagnosis or dismissal resulting in harm, or 3) contact an eating disorder treatment center for a free assessment but risk receiving a financially biased recommendation (assuming they accept your insurance). Project HEAL will provide a free, 1 hour phone assessment with clinician, followed by a comprehensive 10+ page document with diagnosis, recommendation, and referrals. We will also offer enrollment to one of our other programs if applicable. This program will address the inaccessibility and bias that currently leaves many people without access to impartial guidance about their condition and what treatment options are available to them.

● Project HEAL will launch a new Clinical Training Program that will offer free education for BIPOC and transgender therapists so they can become competent at treating eating disorders. We will be partnering with leaders in the eating disorder field to build the curriculum to include both traditional eating disorder protocols and intersectional content that addresses eating disorders in individuals who fall outside of the traditional eating disorder model. We will hire a seasoned eating disorder clinician with shared values and shared identities with our target population to design and lead delivery of the program. Individuals who complete the training program will be required to join our HEALers Circle for one year following completion, which will increase our Treatment Placement Program capacity, ultimately replacing our Identity-Affirming Scholarships. The program will be launched as a pilot program in
partnership with Black Therapists Rock. If we train even 10% of their 30,000 member network of therapists, we will effectively double the number of eating disorder therapists in the U.S. and radically transform the demographics of the field. We intend to offer the curriculum to people across all identities with a sliding scale that remains affordable for all. We will also offer the curriculum to Masters level therapy programs across the U.S. and advocate for the requirement of comparable curriculum in said programs as well as for state licensure. Ultimately, Project HEAL will infuse the eating disorder field with the volume and diversity of properly trained, identity-affirming providers it needs to offer treatment to all eating disorder sufferers who are ready to heal.
## Expansion Timeline

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<th>2022</th>
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<tr>
<td><strong>Q1</strong></td>
<td>Crisis Textline partnership begins</td>
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<tr>
<td></td>
<td>Identity-Affirming Scholarships available</td>
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<tr>
<td><strong>Q2</strong></td>
<td>Expanded website content published</td>
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<tr>
<td></td>
<td>“Front Desk” live</td>
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<tr>
<td></td>
<td>Insurance Navigation Program Manager hired</td>
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<tr>
<td></td>
<td>Clinical Assessment Program Manager hired</td>
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<tr>
<td></td>
<td>Clinical Assessment Program launched</td>
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<td></td>
<td>BTA Study academic paper published</td>
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<tr>
<td><strong>Q3</strong></td>
<td>Insurance Navigation Portal development begins</td>
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<tr>
<td><strong>Q4</strong></td>
<td>BTA Study 1-pager published and distributed</td>
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<tr>
<td></td>
<td>ED Equity Task Force launched</td>
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<table>
<thead>
<tr>
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<th>2023</th>
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<tbody>
<tr>
<td><strong>Q1</strong></td>
<td>Insurance Navigation Portal live</td>
</tr>
<tr>
<td></td>
<td>VP of Education hired</td>
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<tr>
<td></td>
<td>Clinical Training Program development begins</td>
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<tr>
<td><strong>Q2</strong></td>
<td>Clinical Training Program pilot launch (with <em>Black Therapists Rock!</em>)</td>
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<tr>
<td><strong>Q3</strong></td>
<td>Identity-Affirming Scholarships replaced by HEALers Circle placements</td>
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<td></td>
<td>powered by Clinical Training Program graduates</td>
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<tr>
<td><strong>Q4</strong></td>
<td>ED Equity Task Force 1st impact report published</td>
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<th>2024</th>
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<tbody>
<tr>
<td><strong>Q1</strong></td>
<td>Clinical Training Program live for all clinicians</td>
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<tr>
<td><strong>Q2</strong></td>
<td>Follow-up research in light of BTA Study begins</td>
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<tr>
<td><strong>Q4</strong></td>
<td>ED Equity Task Force 2nd impact report published</td>
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PROJECT HEAL IN 2024: THE VISION

This strategic plan is our roadmap to achieving our three-year vision for Project HEAL to become the leading eating disorder nonprofit in the United States.

By the end of 2024...

➔ Project HEAL will be known, respected, and trusted within the eating disorder field and the mental health field at large. We will be the first on the list of organizations to contact when eating disorders are in public discourse, and one of the primary places to send someone you love who is struggling with an eating disorder but doesn’t know where to start.

➔ People from all walks of life and almost all ends of the political spectrum who are struggling with an eating disorder will understand that Project HEAL is a welcoming, available, and transformative resource in their healing journey. Our Board of Directors and staff representation will meaningfully reflect the broad spectrum of communities we serve, and in word and action, will embody the organizational values that we lift up as our North Star.

➔ Project HEAL will be understood by lawmakers, insurance companies, researchers, and the mental healthcare industry to be a leading authority on all things eating disorders, with particular expertise in equitable treatment access and a proven track record of operating with a progressive, intersectional approach.

➔ Project HEAL will become one of the primary organizations training eating disorder providers, partnering with clinicians to provide equitable treatment access, and shaping the national consciousness about eating disorders and the hope for healing in modern-day America.

➔ We will maintain, cultivate, and nurture our positive relationships and impactful partnerships with all values-aligned organizations, providers, and donors.

➔ Project HEAL will be a coveted partner for corporations and influencers that seek to make a positive impact on American culture when it comes to mental health, systemic change, healthcare equity, body acceptance, and/or healing our nation’s relationship with food. We’ll offer substantive value beyond an exchange of goods or co-promotion – they will be proud to show their own audiences and communities who they are and what they value by aligning with Project HEAL.

➔ Above all, Project HEAL will deliver empathic, informed support for individuals with eating disorders. Our applicants and beneficiaries will feel consistently seen and provided for in their often isolating and arduous pursuit of eating disorder healing.
OUR MISSION

is to ensure healing is possible for and available to everyone in the U.S. who struggles with an eating disorder.

OUR VISION

is for everyone with an eating disorder to have easy & affordable access to the support, resources, and opportunities they need to heal.
EXPANDED OUTCOMES

➔ Increased and more accurate awareness about eating disorders in the general public

➔ Increased diagnosis rates, particularly among currently overlooked populations

➔ Increased volume of treatment options in the U.S.

➔ Increased diversity of treatment providers in the ED field

➔ Increased access to care for people with eating disorders through Project HEAL’s programs due to increases in both HEALers Circle partners and funding

➔ Increased access to care for people with eating disorders in general

➔ A better understanding of barriers to treatment access and strategies for overcoming them at both the structural and individual level

➔ A motivated coalition of industry leaders unified in transforming the eating disorder field

➔ Increased funding to eating disorder organizations due to increased awareness

➔ Increased funding for eating disorder research that includes or focuses on marginalized communities

➔ Moving towards ED treatment training inclusion in all clinical programs

➔ Moving towards ED competency requirements for state licensure for all clinicians