

## Poject HEAL

## ANNUAL REPORT

2020

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# OUR MISSION IS TO BREAK DOWN SYSTEMIC, HEALTHCARE, AND FINANCIAL BARRIERS TO EATING DISORDER TREATMENT

Póject HEAL



#### DEAR PROJECT HEAL FRIENDS & FAMILY,

2020 flipped so many aspects of our lives, routines, and expectations on their head. At Project HEAL, this last year brought changes in leadership, mission clarity, program delivery, staff and board composition, financial partnerships, and our strategic vision for the future.

Most importantly, 2020 dramatically and uniquely impacted people struggling with eating disorders. So many of the unprecedented stressors and challenges that made 2020 a year for the history books also **directly exacerbated the prevalence and symptoms of eating disorders**: loss of community, loss of structure, loss of income & healthcare, etc.

As a licensed eating disorder therapist stepping into the role of CEO last April, I knew that **Project HEAL had a responsibility to laser-focus our efforts** to address the persistent and growing gaps in equitable access to eating disorder treatment.

Throughout this report, you'll learn more about how Project HEAL has refocused our mission to meet the greatest needs of our community today and be introduced to all of the partners that are helping us along the way. We are committed to the quality and growth of our treatment access programs so that we can ultimately say "YES!" to as many people as possible who have been unable to get the life-saving care they need.

I'm so glad you're with us, and I look forward to all that's possible together - this year and beyond.

Warmly,

Rebecca Eyre, MA, LMHC
Chief Executive Officer



## THE PROBLEM WE'RE SOLVING

#### **Equitable Access to Eating Disorder Treatment**

In the United States, at least 10% of the population will suffer from an eating disorder in their lifetime - or 30 million people. Despite this prevalence, only 20% receive treatment. The remaining 24 million people cannot access the care they need due to insurmountable financial and insurance barriers, in addition to pervasive systemic barriers and bias within our culture and healthcare systems.

The lack of access to care has serious consequences: eating disorders are the second most fatal mental illness (after Opioid Use Disorder), with one person dying as a direct result of an eating disorder every 52 minutes.

## PROJECT HEAL IS THE ONLY MAJOR NONPROFIT IN THE U.S. EXCLUSIVELY FOCUSED ON EQUITABLE EATING DISORDER TREATMENT ACCESS

The stereotype of who has an eating disorder – white, young, female, thin, affluent – is not a full picture of the problem, but it exists for a reason: this is the subgroup that has been the primary focus of research, media, and treatment marketing, and has therefore been much more likely to have the privilege of access to quality treatment. However, research is clear that people of every ethnicity, age, gender, body shape and size, ability, sexual orientation, and socioeconomic status struggle with eating disorders.

Yet our broken healthcare system prevents the full spectrum of eating disorder sufferers from utilizing the resources required to achieve recovery. Project HEAL's goal is to change this system, and in the meantime, provide life-saving support to people with eating disorders who are unfairly denied appropriate care.

Against the backdrop of an already inequitable landscape, the current COVID-19 pandemic has created conditions that have increased eating disorder risk and exacerbated barriers to care, especially for marginalized communities. In 2020, 100% of our applicants reported being directly affected bv COVID-19. whether new/worsened eating disorder behaviors or by job/income/insurance loss. On top of that, the vast majority of applicants had some aspect of their identity that falls outside of the dominant eating disorder narrative, representing a barrier to care. Specifically, 20% were BIPOC, 38% were LGBTO+, 8% were transgender or gender non-conforming, 29% were not medically underweight, 59% were older than 24, 13% had a disability, and 3% were men.

We receive hundreds of applications every year from people who are struggling to access the eating disorder treatment they need to survive (let alone thrive), and the number of people we can support is directly correlated to the funding we receive.



## **COMMON BARRIERS TO TREATMENT**

Extensive barriers to accessing eating disorder treatment exist for the vast majority of individuals suffering. Project HEAL works to break down the most pervasive systemic, healthcare, and financial barriers to treatment to give every person a shot at recovery.

#### Systemic Barriers >>

- Harmful stereotypes resulting in bias and blindspots among parents, teachers, doctors, and other adults who might typically be able to help with early detection & intervention
- Standardized care based on a small subset of patient profiles, limited research, and narrow diagnostic information
- Gender requirements and exclusions for admission at higher levels of care
- Weight stigma in admission criteria and treatment planning
- Lack of eating disorder screening and diagnosis training in medical community at large, resulting in missed diagnoses, misguided diet recommendations, and ultimately, harm
- Lack of multicultural education and training among eating disorder providers
- Lack of diversity among eating disorder professionals
- Lack of eating disorder providers and treatment facilities outside of major urban areas
- Inappropriate treatment recommendations informed by profit-driven business models

"EATING DISORDERS DON'T HAVE A RACE, GENDER, SEXUAL ORIENTATION, OR WEIGHT. IF YOU'RE STRUGGLING WITH EATING BEHAVIORS OR THOUGHTS, REGARDLESS OF YOUR IDENTITY, YOU DESERVE TO RECEIVE HELP."

#### Healthcare Barriers >>

- 28.9 million nonelderly people in the U.S. were uninsured as of 2019 according to the U.S. Census Bureau
- 3 out of 10 Americans lost their healthcare coverage in 2020
- The federal Mental Health Parity Act requires that insurance companies cover mental health diagnoses on par with medical diagnoses; however, this still excludes the majority of evidence-based eating disorder treatment which are neither hospital-based nor office-based (as all medical treatment is)
- Most insurance companies have "medical necessity" requirements to authorize eating disorder treatment that allows them to deny treatment to eating disorder sufferers, despite the fact that these are mental health conditions that do not always result in abnormal labs or measurable medical instability
- It is extremely common for insurance companies to discontinue coverage prematurely against the clinical & medical advice of the patient's direct treatment providers
- Most private insurance plans have very high deductibles and out-of-pocket-maximums, leading people to pay out-of-pocket for the majority of their care, despite being insured
- Many insurance plans have exclusions for residential, partial hospitalization, and intensive outpatient treatment, as well as exclusions or limitations for dietitian services, despite all of these treatments being clinically indicated for eating disorder recovery
- Most high-quality outpatient eating disorder specialists are not in-network with insurance companies, primarily due to administrative overhead limitations and low reimbursement rates, which results in most eating disorder patients paying for appointments themselves (if they can afford it)

#### Financial Barriers >>

- Inpatient treatment costs an average of \$2,500/day for 1-3 months
- Residential treatment costs an average of \$2,000/day for 1-3 months
- Partial-hospitalization costs an average of \$1,500/day for 2-4 months
- Intensive outpatient treatment costs an average of \$1,500/week for 3-9 months
- Outpatient therapy and dietitian services cost an average of \$150/session for 1-4 sessions/week for 6-24 months





Treatment Access & Peer Support

# IMPACT IN THE RECOVERY COMMUNITY

### 182,216 people reached

For the first nine months of 2020, Project HEAL operated two arms of our program delivery model: treatment access and peer support. These services worked to both close the gap to clinical treatment for individuals unable to access care as well as support those in their recovery through weekly in-person and virtual peer-support and mentorship.

#### TREATMENT ACCESS PROGRAM IMPACT IN 2020>>

214 people served



Said "yes" to 52% of all treatment access applicants, up from a 10% acceptance rate in 2019 \$1,840,265

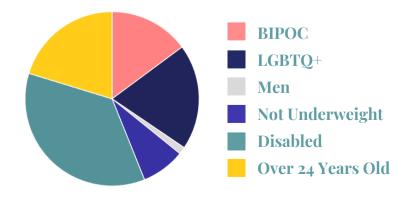
Total value of services delivered and treatment accessed

100%

of individuals served were impacted by COVID-19 (financially, symptomatically, or otherwise)

### Who we helped get life-saving treatment in 2020:

Project HEAL is committed to being a resource for those most often excluded from or harmed by traditional healthcare and treatment systems.



#### **IMPACT IN THE RECOVERY COMMUNITY**

## COMMUNITIES OF HEALING PROGRAM IMPACT IN 2020>>

In order for us to refocus on our founding mission of equitable treatment access, we formalized a partnership with <u>ANAD</u>, a fellow eating disorder nonprofit specializing in peer support, to transition our Communities of HEALing program to their collection of peer-support offerings.

On September 1, 2020, Communities of HEALing transitioned its beneficiaries and Program Director to ANAD's team to provide uninterrupted peer support to individuals in recovery. We are so proud of this partnership and thrilled that our two organizations came together to creatively help more people at such a dire moment in history when eating disorder sufferers were hit especially hard.

**VANAD** 

We believe that all nonprofits in our field should strive to creatively consider how we can best work together to streamline rather than duplicate efforts, with the goal of helping as many people with eating disorders get the help they need and deserve.

PI

175

people served through Communities of HEALing

81
people reached in mentorship program

94
people reached in support groups





## DIVERSITY, EQUITY & INCLUSION

Project HEAL has the honor and duty to serve people who are experiencing systemic barriers in their quest for eating disorder recovery as a result of their identity and lived experience. As an organization that serves marginalized individuals, it is essential that we are equipped to do so mindfully and that we have staff and board directors who reflect and understand the identities and experiences of the people we serve. Prior to 2020, this was an area that we had not adequately prioritized and we consider this a marked failure on our part - one that we are committed to prioritize going forward.

We want to thank Nicole Seawright, Esq. for leading our staff and volunteers in a training called *Identity, Inclusion, and Equity: Building Strong Communities*. We want to thank Em Reim Ifrach, LPC, NCC, CEDCAT-S, REAT, ATR-BC, ATCS, CLAT, and Mara Gottlieb, PhD for leading our staff, volunteers, and board members in a training called *The Body Politic: Body & Weight Liberation as Social Justice*, focused on the intersections of racism, classism, and fatphobia. We want to thank Tema Okun of DismantlingRacism.org and Daniel Buford of the People's Institute for Survival and Beyond for creating a guide called *White Supremacy Culture at Work* that our staff were able to use as a guide for our team to reset both our organizational and internal team values to ensure our culture is safer and stronger for everyone. And last but not least, we want to thank *The Pivotal Paradigm Project* for their wisdom and leadership guiding our Board of Directors through a multipart anti-racism training and structural evaluation process - the visible fruits of which you can read in the statement and commitments below.

In 2020, we were thrilled to add Em Reim Ifrach and Dr. Erikka Dzirasa to our Board of Directors. Em and Erikka bring their expertise and passion for raising awareness about BIPOC, TGNCI, and high weight eating disorder experiences to our board to better shape our programming to serve those of our beneficiaries who belong to those communities.

In 2021, we are hiring two new staff members and adding up to 6 new board members with a commitment to considering the ways in which the people who lead and serve at Project HEAL both represent and understand the experiences of our beneficiaries. We know beyond a shadow of a doubt that with a wider variety of voices and perspectives at Project HEAL, we will only get better and better at supporting the eating disorder community members that need us most.

## Diversity, Equity & Inclusion Statement

Project HEAL's mission is to break down systemic, healthcare, and financial barriers to eating disorder treatment. Equity is a part of our values: we exist to create equity in the eating disorder treatment landscape, therefore we must be willing to take disruptive action in the process. We are committed to anti-racism, antioppression, gender equity, and taking the necessary measures to create iustice. To do effectively, we will ensure we have representation of marginalized groups on our board and staff to give voice to those underrepresented in this work. To support an inclusive environment where clients feel empowered to receive services, our Board of Directors has participated in training on identity, socialization, and bias. Finally, our Executive Leadership has taken steps to ensure their own growth and development in the areas of diversity, equity, and inclusion.

We will continue to develop these and other proficiencies to drive equitable decision making and treatment for all.



#### THREE (3) DEI STRATEGIC PILLARS

BOARD DEVELOPMENT BOARD &
STAFF
DIVERSITY

EXECUTIVE DEVELOPMENT

## STRENGTHEN THE BOARD WITH ONGOING DEVELOPMENT

The Board of Directors has taken the initial steps of diversity, equity, and inclusion training and reflection. Because this work is ongoing, the board will continue this work in subsequent years.

## INCREASE BOARD & STAFF REPRESENTATION

Project HEAL has made a commitment to representation. As a result of this commitment, in 2021 we plan to add new board and staff that are both representative and knowledgeable of eating disorder treatment in underrepresented communities.

#### SUPPORT THE CEO'S LEARNING AROUND DIVERSITY, EQUITY, AND INCLUSION

The CEO has committed to continuing learning and connecting to improve equitable decision making.

## OUR VISION IS FOR EVERY PERSON WITH AN EATING DISORDER TO HAVE THE RESOURCES AND OPPORTUNITIES THEY NEED TO RECOVER.

Project HEAL



## **2021 & ONWARD**

As we move into a new year, we are excited to more fully live into our organization's mission, values, and commitments. With our three, going on four, programs helping individuals access treatment and groundbreaking research to advance the field, we are poised to reach more people in 2021 than ever before.

#### **PROGRAM MODEL**

What used to be our "Treatment Access Program" has now evolved into our three (3) core direct-service programs: Insurance Navigation, Treatment Placement, and Cash Assistance.

The scalability of our earlier models proved both cost-prohibitive and burdensome for our partners, plus it notably excluded important groups of people who are struggling to access care for different reasons. Our new model has three distinct programs (+ another program soon!) with services that can be customized to fit the needs of each applicant, and when possible, effectively leverage and maximize the benefits and resources that they may already have.



#### INSURANCE NAVIGATION

Specialized support to optimize a beneficiary's existing insurance benefits, advocate for a Single Case Agreement when coverage is denied, or advise applicant in selecting a new plan.



#### TREATMENT PLACEMENT

Free placement with a partner treatment facility or provider in cases where beneficiary is either uninsured or underinsured with no other option to access the appropriate level of care.



#### **CASH ASSISTANCE**

One-time cash assistance to help beneficiary pay down co-pays, high-deductibles, out-of-pocket maximums, travel, or other tertiary costs associated with going to treatment.

#### PILOT PROGRAM: CLINICAL ASSESSMENT >>

In 2020, we piloted free clinical assessments for Project HEAL applicants who did not fully understand their diagnoses or know what kind of treatment might be appropriate for them. In 2021, this program will be launched and scaled as a distinct program offering with the help of clinical volunteers and interns. Our hope is to be able to offer our beneficiaries an accessible and unbiased perspective that is currently unavailable to most. We will also use these assessments to ensure that our beneficiaries are indeed fighting for access to the clinically-appropriate level of care.

## BARRIERS TO TREATMENT ACCESS RESEARCH STUDY

It is widely understood that myriad barriers exist for individuals seeking eating disorder treatment, but until now, no quantitative research has been conducted in the U.S. to define these barriers.

In 2020, Project HEAL partnered with <u>Eating</u> <u>Anxiety Treatment Laboratory & Clinic</u> (EAT Lab) at The University of Louisville and received funding from <u>NEDA</u>'s Feeding Hope Fund to assess the extensive treatment barriers that exist for people with eating disorders. <u>This study is now live</u> and will remain open until June 2021 with analysis completed this year.

Project HEAL will use the data gleaned from this important research to anchor our efforts to reform the eating disorder treatment landscape in the U.S. and to influence future policy and legal changes within the healthcare system.

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:





- (1) To quantify the systemic barriers that people in the U.S. face when seeking eating disorder treatment.
- (2) To quantify the healthcare and financial barriers that people in the U.S. face when seeking eating disorder treatment.
- (3) 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.
- (4) 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.





## **PARTNERS & COMMUNITY**

This year has been unpredictable for us all, in nearly every way. But one thing that has been a surprising silver lining in the pandemic and economic consequences of this year is how many partners, volunteers, HEALers Circle members, and Ambassadors have joined Project HEAL's mission.

#### **Board of Directors** >>

We used 2020 to begin to expand our board of directors and include new voices and vocational perspectives to make Project HEAL better and more effective in our mission. Thank you to our dedicated board for their commitment to our organization and the communities that we serve.

- Brian Beitler
- Amanda Crew
- Dr. Erikka Dzirasa
- Donna Friedman (Chair)
- Craig Kramer

- Paraag Marathe
- Em Reim Ifrach
- Liana Rosenman
- Kristina Saffran

#### **Volunteers** >>

Currently, our four (4) full-time staff and one (1) part-time staff work with a team of ten (10) role-specific national volunteers. These volunteers are critical in not only supporting the operational and administrative departments of the organization, but highly-trained and clinically-educated volunteers are also serving our beneficiaries directly as insurance navigation specialists and case management volunteers.

#### Ambassadors >>

In 2020, we revamped our Ambassador Network full of energetic volunteers raising both awareness and funds for Project HEAL within their local communities. We currently have over 400 Ambassadors who represent the mission and values of Project HEAL while increasing our ability to help more individuals access treatment.

#### HEALers Circle >>

Our HEALers Circle is made up of generous treatment programs and outpatient providers that donate pro bono care to select Project HEAL beneficiaries each year. Because of the HEALers Circle members listed below, more people with eating disorders can receive the life-saving treatment they need and have been unable to access.

#### **Leader in HEALing**

Columbia Department of Psychiatry Farrington Specialty Counseling **UCSD Intensive Family Treatment** Nourished Nutrition Therapy **Texoma Specialty Counseling** 

Wildflower Therapy Dianna Chillo-Havercamp

Pamela Polizzi

Dr. Colleen Reichmann Sinnergy Wellness Group

The Celestial Life Sage Nutrition, LLC RadLove Nutrition

MEDA

Whole Nutrition Services Attune Psychotherapy Jessica Steinbach Courtney Darsa Nutrition

Center for Emotional Wellness

River Bend Counseling Natalie Grantner, LCSW **Project Healing Hive** Meredith O'Brien Attune Psychotherapy

Lotus Counseling of Connecticut Healing Nutrition Therapy of LA **Authentic Recovery Coaching Services** Lori Lee Coaching

#### **Partner in HEALing**

**Avalon Hills** The Renfrew Center The Lotus Collaborative AP Counseling & Yoga Mindful Eats Nutrition Gaia Center for Embodied Healing

East Texas Eating Disorder Specialists

Sara Battista Psychotherapy Katherine Myers PLLC Elyse Metelka Nutrition Food Freedom, LLC

BALANCE Eating Disorder Treatment Center

**Big Picture Nutrition** 

Not Your Average Nutritionist

Marcella Cox

Jessica Singh Counseling

Sari Meltzer

Grounded Acupuncture **Nutrition Rewritten** 

Lotus Counseling of Connecticut

**Empower Counseling** 

Eathority

Wholly Health & Nutrition

Katy Gaston, RD

Equip

Debra Spector, MS, RDN, CDN

Rock Recovery **Sterling Nutrition** Metanoia Nutrition, LLC Tiffany Phillips

Lisa Iimenez

Danielle Maryott, LCSW Recover You. LLC Maureen O'Brien Havden Kapalka

Holly's Healing Heart Lisa Becker Coaching

Fit Food Coach

#### **Friend in HEALing**

Consulting

Moxie Mind Pancake Counseling Christina Frangione Nutrition Therapy Kim Wyman Bianca Sandoval Kelly Elise Ulmer, Ed.S., LPC, LMHC Michelle Chapman Counseling and





## **2020 FINANCIALS**

The economic challenges precipitated by the COVID-19 pandemic have directly affected many nonprofits, Project HEAL included. However, during a year of extraordinary challenge, we were so grateful to have the faithful support of so many as well as new partners that joined with us and funded our mission.

FY20 Revenue	
Individual Donations Foundations Corporations Merchandise	\$394,297 \$72,500 \$126,535 \$3,587
TOTAL REVENUE	\$596,919
FY20 Expenses	
Staff & Support	\$519,693
Direct Program Expenses Development Expenses	\$59,174 \$22,557
Operations & Management Expenses	\$91,146
TOTAL EXPENSES	\$692,570

#### A Note on Funding in the Eating Disorder Field >>

Even though eating disorders affect at least 10% of the U.S. population, they are and have historically been atrociously underfunded nationally with only \$0.73 raised annually for every person affected, compared to \$100+ per person for other important diagnoses like autism, Alzheimer's, or schizophrenia.

Project HEAL relies on charitable contributions to scale our programs, expand our team, and grow the impact we can make for equitable treatment access. Our goal is to continue to grow revenue in order to meet the extraordinary demand for treatment access support for the millions of people suffering without adequate care.

## PojectHEAL

www.theprojectheal.org