# StanfordSOCIAL INNOVATION<sup>Review</sup>

## *Features* The Crisis of Youth Mental Health

By Eliot Brenner

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Children and adolescents confront a mental health treatment gap in which many who need help do not get it. Philanthropy can help fill this gap by investing in new models of providing care.

# The Crisis of Youth Mental Health



ne in five children

in the United States has a diagnosable mental health condition. Unfortunately, access to care for these children is poor: At least 85 percent of those in need of treatment do not get it.<sup>1</sup> More than half of mental illness emerges before age 14, so getting children the help they need, in addition to ameliorating their immediate suffering, can also prevent future pain. The result of not getting help can be dire, as suicide is now the second leading cause of death for those between ages 10 and 34.<sup>2</sup>

Mental illness exacts a staggering cost on society. It leads most measures of economic burden for noncommunicable diseases. The World Economic Forum issued a report that mental illness has a greater impact on economic output than cancer, heart disease, or diabetes.<sup>3</sup> (See "Lost Economic Output by Noncommuni-

## **BY ELIOT BRENNER**

Illustration by Mike McQuade

cable Disease Type" on page 36.) The report's authors estimate the worldwide cost of mental illness to be \$16 trillion between 2011 and 2030. Other recent research has indicated that untreated anxiety and depression costs society \$1.15 trillion annually.<sup>4</sup>

While the economic burden of mental illness is staggering, the total spending devoted to addressing it is shockingly low.<sup>5</sup> (See "Total Spending on Mental Health Falls Short" on page 37.) In low-income countries, outlays are minuscule: less than 1 percent of total health budgets. But even in high-income countries such as the United States, the expenditure on mental health as a percent of total health budgets is grossly inadequate, given the prevalence of mental illness. Overall, it is widespread in children, its cost to society in terms of pain and suffering and financial burden is enormous, and its overall funding is insufficient.

Those who work in mental health call the shortfall between the percentage of people with a mental health condition and those who receive help the "treatment



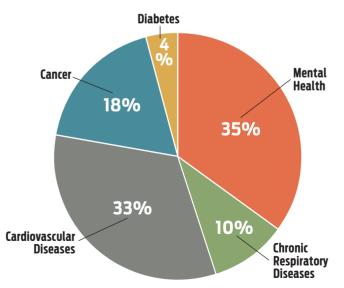
gap." Its persistence indicates a problem that government and business have failed to address. It is especially important to prevent children and adolescents from falling into the gap, because of the compounded costs of untreated mental illness that continues into adulthood. Private philanthropy is in a unique position to lead the effort, in collaboration with government, business, and the nonprofit sectors, to ensure that all children needing mental health treatment receive it. The availability of proven or promising interventions, growing public awareness of the importance of mental health, and the projections of significant private philanthropic funds becoming available in the next decade make this an opportune time for private philanthropy to lead the effort to close the gap.

#### MIND THE GAP

Why do children in need of mental health treatment not get it? The World Health Organization (WHO) outlines three primary components of access to health care: physical accessibility, financial affordability, and acceptability.<sup>6</sup> Physical accessibility involves health care's geographical proximity and availability at convenient times for the people who need it. Affordability means that those who want health care can get it without financial hardship. Acceptability means that people believe health care is effective and respectful of their social and cultural background.

During the past 30 years, health care has focused on "evidencebased medicine," which incorporates available scientific research into clinical decision making to ensure optimal patient care. This focus has spawned hundreds of scientifically tested, evidence-based mental health treatments, most of which use individual psychotherapy to address specific clinical problems, such as depression or anxiety. For the past two decades, mental health treatment researchers have been

## Lost Economic Output by Noncommunicable Disease Type



Mental illness has a greater impact on economic output than any other form of disease does.

SOURCE: Adapted from David E. Bloom, et al., "The Global Economic Burden of Noncommunicable Diseases," Geneva: World Economic Forum, 2011. ELIOT BRENNER (@eliotmbrenner) is president and CEO of the Child Guidance Center of Southern Connecticut.

optimistic that implementation science might help improve physical access to evidence-based care. Implementation science is the study of systematically developing and testing strategies for spreading, scaling, and sustaining evidence-based treatments. But implementation science has had, at best, marginal effects on access to evidence-based mental health care. For example, a recent study showed that for children using publicly funded services in the United States, only 2 percent received an evidence-based treatment based on scientific research.<sup>7</sup>

Some states, such as Connecticut, have invested considerable public funds into increasing access to evidence-based treatments and have achieved better results.<sup>8</sup> For example, at the children's behavioral health agency that I lead, the Child Guidance Center of Southern Connecticut, 8 percent of the 1,386 children we served in 2017 received an evidence-based treatment that adhered to strict standards that the developers of these treatments established. Although this figure is four times the US average, most of the children we served are not getting these treatments. Instead, they are receiving individual psychotherapy that, while helpful, may not always be as effective as evidence-based practice. Unfortunately, even in a state like Connecticut, where evidence-based treatments are more geographically accessible, there are often wait lists for these treatments that render them inaccessible for the vast majority of children.

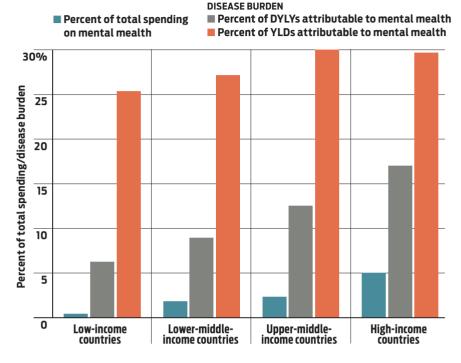
The numbers we serve at the Child Guidance Center with an evidence-based model are relatively small because it requires such extensive staff training and consultation. None of the state grants we receive to implement and sustain evidence-based practices comes close to covering the costs of these practices. Researchers who recently examined the costs of sustaining one evidence-based treatment in Connecticut calculated an incremental per-patient annual expense of \$1,896.9 For the Child Guidance Center of Southern Connecticut to treat all children in need of outpatient or homebased services with an evidence-based practice like the one these researchers highlighted, it would cost an additional \$2,627,856 (1,386 patients at \$1,896 each). This expense would increase our \$5.2 million annual budget by more than 50 percent and would require twice the amount of funding we currently receive from the state of Connecticut to deliver these services. We serve a small percentage of the roughly 56,200 Connecticut children who receive behavioral health care through Medicaid. To cover all of these publicly funded children with evidence-based treatment would cost an additional \$106,555,200 annually. No state is flush enough in these austere times to absorb that kind of incremental cost. Thus, evidence-based treatments as they are currently delivered are not affordable.

While there is considerable scientific support for evidence-based psychosocial interventions for children's mental health problems, this research is based primarily on studies of non-Hispanic white children. There is much less evidence supporting these interventions for ethnic minority youth.<sup>10</sup> Cultural factors, such as perceived stigmas and different conceptions of mental illness or treatment, likely influence the effectiveness of existing evidence-based interventions, as does a dramatic shortage of ethnic-minority mental health clinicians. Approximately 90 percent of mental health clinicians in the United States are non-Hispanic white, but 30 percent of people in the United States belong to a racial or ethnic minority.<sup>11</sup> In states that have growing immigrant populations, such as Connecticut, competition is fierce among nonprofit mental health agencies seeking to hire qualified bilingual clinicians, because there simply aren't enough of them to serve the expanding population. Consequently, the acceptability of evidence-based mental health interventions among racial or ethnic minority populations is inconsistent.

The shortage of racial and ethnic minority mental health clinicians is part of a much larger problem. Given the prevalence of mental health needs, there are not enough clinicians of any race or culture. Recent estimates of the number of mental health clinicians range between 550,000 and 700,000, which is clearly not enough when 25 percent of people in the United States-approximately 80 million people-have a mental health disorder.<sup>12</sup> In addition, most providers do not treat children, which is why only 15 percent of children who need treatment get it. Alan Kazdin, an internationally renowned psychologist and longtime developer and advocate of evidencebased treatments, has concluded that using the dominant model of psychosocial treatmentindividual psychotherapy with a mental health professional in an office-based setting-to address the treatment gap is not possible. He writes:

## **Total Spending on Mental Health Falls Short**

All countries, from the poorest to the wealthiest, spend a minuscule amount of money on mental illness relative to the total burden it exacts on their citizens' lives.



SOURCE: Mary DeSilva, et al., "Policy Actions to Achieve Integrated Community-Based Mental Health Services," *Health Affairs*, vol. 33, no. 9, 2014.

NOTE: This figure depicts spending by country income as a percentage of total health budgets compared with the economic burden of mental illness, as measured by years lived with disability (YLD) and disability-adjusted life years (DALY)—two widely used measures of disability. YLD is the total number of years that someone lives with an illness; DALY is the sum of the number of years lived with an illness; plus the years lost because of illness or early death. Adults living with a mental illness die 15 to 20 years sooner than others. Both YLD and DALY are elevated in mental illness, in part because 75 percent of all mental illness presents by age 24.

Expanding the workforce to deliver treatment with the usual, in person, one-to-one model of care with a trained mental health professional is not likely to have a major impact on reaching the vast number of people in need of services. The increased person power is not likely to provide treatments where they are needed, for the problems that are needed, and attract the cultural and ethnic mix of clientele that are essential.<sup>13</sup>

Kazdin is not suggesting that we stop providing individual, evidencebased treatments. Rather, he argues that we also need to develop new models of delivery to reach the vast majority of those who need help but are unlikely to receive individual therapy. The mental-health-care sector needs to develop innovative treatment delivery models and to test and implement existing new models. But to do so, it needs far more funding than it is currently receiving.

## THE STATE OF FUNDING

Getting a handle on mental health research funding is not easy. Analysts have used several methods to determine its status, one of which is to study bibliographic funder acknowledgments from published mental health research articles. In 2016, the RAND Corporation conducted a bibliographic study of the acknowledgments in 220,000

mental health research publications between 2009 and 2014.<sup>14</sup> The report found 1,900 funders that had more than 10 acknowledgments. Charities, foundations, and nonprofits represented 39 percent of these funders, government 33 percent, and academia 28 percent. The high percentage for papers funded by charities, foundations, and nonprofits suggests that foundations and charities may affect the field of mental health research more than public support does.

Researchers have also examined government and private funding of mental health research in the United States and the United Kingdom. The results reveal a startling lack of funding relative to the burden of mental illness. The largest funder of research in children's mental health in the United States, the National Institute of Mental Health (NIMH), decreased funding for child and adolescent services and intervention research by 42 percent from 2005 to 2015 (\$52 million to \$30 million annually).<sup>15</sup> Over the same period, the overall NIMH budget was flat and funding for neuroscience and basic behavioral research increased by 28 percent. Perhaps even more important, the \$30 million dedicated to child and adolescent mental health represented only a 2.1 percent share of the total NIMH budget authority of \$1.4 billion for 2015. This amount is disproportionately small, given that mental illness leads all measures of the economic cost of noncommunicable diseases.

The data from private philanthropic support for mental health research in the United States are not much better. While funding increased in absolute dollars from 2006 to 2015, it decreased as a percentage of foundation funding of health care, from 6.2 percent to 5.6 percent. (See "Philanthropic Funding for Mental Health Has Declined" on this page.<sup>16</sup>) These downward funding trends are consistent with earlier researchers who reported that from 1998 to 2006, philanthropic support for mental health funding decreased as a percentage of foundation funding of health care, from 10.5 percent to 6.3 percent.17 More important, as a percentage of overall foundation funding of mental health, support for children's mental health decreased from 37.1 percent to 34.2 percent and support for children's mental health research decreased from 3.8 percent to 1.6 percent.

We find the same tale in the United Kingdom. The private British mental health charity MQ found that UK government funding for mental health research for children and adults was 5.5 percent of the total budget. By comparison, cancer research was nearly four times higher, at 19.6 percent.<sup>18</sup> MQ also reported that mental health research accounts for just 3.1 percent of charityfunded research, compared with more than 30 percent for cancer, 13.5 percent for infection,

and 7.6 percent for cardiovascular research. For every £1 the UK government spends on cancer research, the general public invests £2.75; for heart and circulatory problems, it's £1.35. By contrast, for mental health research, the figure is £0.003, or a third of a penny.

## NEW DELIVERY MODELS

Such a paucity of research funding should concern everyone in the health-care industry, given the widespread incidence of children's mental illness and the high percentage of children who are not getting help. We can address this treatment gap by developing service-delivery models other than individual therapy and medication, but the effort will require more investment to drive the spread of these models.

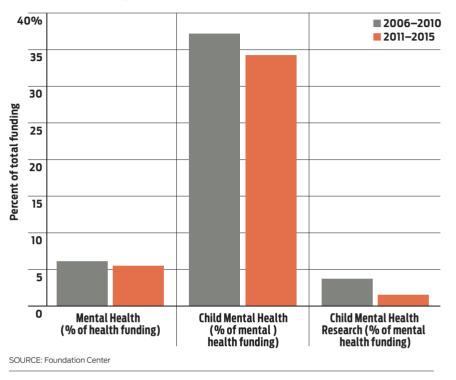
Private philanthropy is especially suited to addressing the mental health treatment gap for children. As philanthropist Laura Arrillaga-Andreessen said in an interview with *Forbes* magazine,

Philanthropy is often seen as society's risk capital. That means the onus is on philanthropists, nonprofit leaders, and social entrepreneurs to innovate. But philanthropic innovation is not just about creating something new. It also means applying new thinking to old problems, processes, and systems.<sup>19</sup>

The mental health treatment gap in children is a prototypical example of a complex problem that requires new thinking, because the current service-delivery model—individual psychotherapy and medication—is ineffective in reaching the vast majority of kids.

## Philanthropic Funding for Mental Health Has Declined

Although the total dollars devoted to mental health and to children's mental health has increased, the percentage devoted to both has fallen.



Unlike the business sector, which is accountable to shareholders; government, which is accountable to voters and special interest groups; and public charities, which are accountable to donors, private foundations need only meet their legal requirement within IRS regulations to disperse at least 5 percent of their endowments annually to tax-exempt causes. Private philanthropy is therefore in a position to take big risks. In addition, because of philanthropies' capacity to fund, they can convene a variety of important parties, such as government funders and regulators, private industry, policy-makers, and advocacy groups.<sup>20</sup> The ability to convene and the freedom to take risks places private philanthropy in an ideal position to catalyze solutions to complex, multisystem problems like this one.

In his 2018 book, *Innovations in Psychosocial Interventions and Their Delivery*, Alan Kazdin proposes eight characteristics to guide the development and implementation of mental health service-delivery models to address the treatment gap.<sup>21</sup> I have highlighted the three features that I believe are most important for funders: scalability, affordability, and acceptability. (See "Criteria to Evaluate Mental Health Service-Delivery Models" on page 39.) These characteristics offer a way for funders to weigh the impact that different servicedelivery models might have in closing the treatment gap, and to compare and contrast the relative strengths and weaknesses of different models, because closing the treatment gap will require integrating many different service-delivery models. (No one model will address all problems or all populations.) Not coincidentally, affordability and acceptability are also two of the three components of the WHO's definition of access to treatment described earlier. Ultimately, closing the treatment gap is about making mental health interventions accessible to all who need them.

Several systemic changes in health care have already begun to foster new models of delivery that may improve the accessibility of care for children struggling with mental health problems. For example, health insurers and payers, including Medicare and Medicaid, have begun moving from volume to value-from reimbursement based on fees for service (e.g., a session of individual therapy) to reimbursement based on population health outcomes. Population health emphasizes scalability at the outset of designing ways to improve children's mental health. Focusing on the mental health of entire populations fosters prevention and early intervention in children, because these practices are likely to be less expensive than waiting until mental health problems arise or become more severe.

We now have the opportunity to build on these changes by furthering the adoption of new models. Specifically, funders should consider four innovative models of delivery to reach children struggling with mental health needs. Private foundations have begun incubating all of these innovative models, yet the time is ripe for philanthropy to play a much larger role in funding these models to close the treatment gap once and for all. Let's consider them in turn.

## TASK SHIFTING

Task shifting is the process of delegating tasks, when appropriate, to less specialized health workers. Other countries have used task shifting for decades to improve access to care. In the United States, the change to value-based purchasing is driving health-care delivery systems to employ task shifting to both improve access and lower costs. Most people have become familiar with task shifting through visits to their doctor's office, where they are seen first by a medical assistant, then by a nurse or physician's assistant, and then, finally, for a few minutes by a physician.<sup>22</sup>

A particularly innovative example of task shifting is Project Echo, which trains primary-care clinicians to provide specialty services by linking these clinicians via videoconference to multidisciplinary teams of specialists in academic medical centers. Project Echo's first test of its model, with hepatitis C in rural New Mexico, was so successful that the prototype has been expanded to cover more than 100

## **Criteria to Evaluate Mental Health Service-Delivery Models**

| Scalability   | Is it able to reach a large<br>number of people, including<br>those most in need of help?        |
|---------------|--|
| Affordability | Is it less expensive than the current dominant model of treatment?                               |
| Acceptability | Is it suitable to the population<br>(e.g., race, ethnicity, culture) to<br>which it is targeted? |

Source: Adapted from Alan E. Kazdin, Innovations in Psychosocial Interventions and Their Delivery, New York: Oxford University Press, 2018.

diseases, including adult psychiatric and substance-use disorders. The Robert Wood Johnson Foundation has funded Project Echo to treat behavioral health problems in pediatric care.<sup>23</sup> Project Echo aims to reduce disparities in access to care, expand the workforce of behavioral health clinicians, and diffuse best practices. However, as some researchers have cautioned, more research is needed to evaluate the clinical outcomes and cost effectiveness of Project Echo for diseases besides hepatitis C.

Task shifting can also train laypersons to treat mental health needs, such as depression and anxiety, in low- and middle-income countries where few specialized providers exist.<sup>24</sup> In the United States, the professionalization of lay counselors into "peer specialists" is another example of task shifting. In March 2017, Mental Health America, in collaboration with the Florida Certification Board and Kaiser Permanente, developed the National Certified Peer Specialist Certification, which requires background checks, work experience, training, a certification test, and continuing education. In Connecticut, Beacon Health Options, the state's administrative care organization for Medicaid, has employed peer specialists to reduce psychiatric inpatient days by 57 percent for children transitioning to a different level of care.25

Wider implementation of these interventions in the United States has been hampered by state licensing departments that are designed to protect the public from fraudulent practice and by mental health professional associations that exist to promote the reputation and financial viability of their professional members. As a result, many children who could be served will continue to go without treatment. Private foundations could play a role in advocating for change within professional associations, since foundations cannot lobby for changes in legislation. Because the treatment gap is so large, professional associations can endorse the use of lay therapists without adversely affecting the livelihoods of their professional constituents.

Task shifting shows promise along Kazdin's three dimensions for new models. It makes care more affordable, by offering service considerably less expensive than the dominant model of individual psychotherapy conducted by a mental health professional. In addition, the fact that lay counselors and peer specialists have been well received by consumers suggests that their acceptability is high.<sup>26</sup> The scalability of these models is yet to be fully evaluated, but the rapid expansion of task shifting and the growth of innovative models such as Project Echo imply that the scalability of task shifting is promising.

### DIGITAL SELF-HELP TECHNOLOGY

Digital technology-computers, the Internet, mobile devices, and apps-offers considerable promise as a delivery model that sidesteps stigmas and could expand access to evidence-based mental health care.<sup>27</sup> Digital versions of a range of evidence-based psychotherapies are available, including Internet-based cognitive behavioral interventions for anxiety, depression, and post-traumatic stress disorder that focus on modifying unhealthy ways of thinking and improving behavioral coping skills.<sup>28</sup> In addition, online self-help interventions exist to prevent anxiety and depression, such as MoodGym, which was designed for people ages 15 to 25 and has helped more than one million users. MoodGym has five interactive modules with information, exercises, and quizzes that focus on feelings, thoughts, and relationships. The modules are based on cognitive behavioral therapy and interpersonal therapy, which emphasizes changing social and familial difficulties. Clinician-supported digital interventions have been found as effective as face-to-face treatment.<sup>29</sup> In addition, virtual reality treatment has proven effective for a number of child mental health conditions, including anxiety, depression, attention deficit hyperactivity disorder, eating disorders, and autism.<sup>30</sup>

In 2014, the Colorado Health Foundation made its first programrelated investment in MyStrength, an evidence-based online mental health treatment platform designed to expand access to mental health and wellness interventions for a range of clinical problems. The foundation structured its investment in this for-profit company as a \$1.5 million senior loan agreement. Private foundations can use a range of program-related investments, including equity investments, investing in intermediary funders, loans, and recoverable grants, to fund early-stage for-profit companies that are expanding access to mental health care for children. The Bill & Melinda Gates Foundation has used many of these vehicles to foster the development and spread of health-care innovation and to prevent the spread of disease.

The digital self-help model is affordable and scalable, because more than 50 percent of the world's population has Internet access, In smaller primary-care practices where it is not feasible to have on-site child psychiatrists or psychiatric advanced-practice registered nurses, more than 30 states have adopted the Massachusetts Child Psychiatry Access Program model, wherein pediatricians and other primary-care providers can talk to a team of child psychiatrists, licensed mental health clinicians, and resource coordinators for medication consultation, referral, and treatment recommendations, regardless of the client's insurance. The National Network of Child Psychiatry Access Programs is a nonprofit member organization that provides methods and consultation to support the implementation of this model throughout the United States. Further foundation funding to design and implement innovative models like this could enhance the integration of mental health and pediatric care to reach more children with mental health needs.

#### ACCOUNTABLE COMMUNITIES FOR HEALTH

Value-based purchasing has spurred public and private health-care payers' interest in the social determinants of health (SDOH). They increasingly recognize that improving the health of entire populations requires addressing the social determinants, within the com-

# Estimates of new philanthropic funding becoming available are sizable. But funding for children's mental health is trending downward.

but the acceptability of these treatments needs further evaluation. Translation of digital interventions into different languages and cultures is an area for further study and funding.

## INTEGRATION OF BEHAVIORAL HEALTH AND PRIMARY CARE

Another market force influencing the development of new delivery models is the Affordable Care Act (ACA), which then-president Barack Obama signed into law in 2010. The ACA provided incentives for practices to adopt a patient-centered medical home, an integrated-care delivery model with the physician at the center of a team that included behavioral health specialists. ACA funding has also encouraged the further integration of medical and behavioral health care.

Federally Qualified Health Centers (FQHCs) are perhaps the most widespread example of integrated care. Many FQHCs provide fully integrated medical, dental, and behavioral health care for children and adults, facilitating "one-stop shopping" where entire families can get treatment for multiple needs at the same site at the same time. Research has found that primary care providers, rather than specialists, treat roughly three-quarters of children's mental health needs, so integrating care makes sense.<sup>31</sup> In addition, it can decrease stigmas surrounding mental health needs, because a "warm handoff" from a pediatrician to a mental health provider can reinforce the principle that "mental health is health."<sup>32</sup>

munities where people live, work, and raise their children, believed to account for as much as 60 percent of the factors responsible for premature death.<sup>33</sup> Addressing the SDOH calls for collaboration among multiple service systems, including health care, housing, public health, social services, and job training.

Accountable Communities for Health (ACHs) are communitybased partnerships that bring together these systems to address the SDOH. In 2016, the US Department of Health and Human Services funded a five-year, \$157 million program to develop the ACH model in 31 communities throughout the United States. A number of private funders, including the Robert Wood Johnson Foundation, the Kresge Foundation, the W. K. Kellogg Foundation, and the California Endowment, have also embraced this model for improving health. The California Endowment is one of several private foundations invested in the California Accountable Communities for Health Initiative, a public-private partnership to develop ACHs in 15 California communities. At the national level, these foundations have joined with public funders, including the Center for Medicare and Medicaid Innovation, the Centers for Disease Control and Prevention, and the Health Resources and Services Administration in the Funders Forum on Accountable Health, a vehicle sponsored by George Washington University's Milken Institute School of Public Health, to share ideas and develop ways to assess the impact of ACHs.

The National Academy of Medicine recently proposed the concept of an ACH focused on children and families.<sup>34</sup> ACHs offer considerable promise in using prevention and early intervention to improve children's mental health and reduce the economic and psychological burden of mental illness. In a recent blog post for Health Affairs, Benjamin F. Miller, chief strategy officer of Well Being Trust, and Anne De Biasi, director of policy development at Trust for America's Health, highlighted the need for foundations to fund policy initiatives that close the "prevention gap" in mental health, which emerges prior to the first symptom of a mental health condition.<sup>35</sup> All three of the new delivery models we have discussed-task shifting, digital self-help technology, and the integration of behavioral health and primary care—could be integrated within an ACH to prevent and treat the emergence of mental health conditions. Although it is too early in the development of ACHs to evaluate their long-term effectiveness, their potential to improve the SDOH makes them a promising model in the quest to close the mental health treatment gap.

## AN OPPORTUNE TIME

Estimates of new philanthropic funding becoming available in the next decade are sizable. According to a recent analysis by LOCUS Impact Investing and the Center for Rural Entrepreneurship, "If only 5 percent of the \$9 trillion in assets projected to pass from Americans' estates over the next decade were captured by philanthropy, it would create the equivalent of 10 Gates Foundations" and would generate an additional \$22.5 billion in grantmaking annually.<sup>36</sup> In spite of this anticipated increase, funding for children's mental health is trending downward. This is unacceptable.

There has never been a better time for private foundations to invest in solutions to close the mental health treatment gap for children and adolescents. They have the capital, and there are many ideas worth funding. New delivery models that are scalable, affordable, and acceptable to the children and families they serve and that address the social determinants of health will require collaboration among many parties, including government funders and regulators, private industry, policymakers, and advocacy groups. Private philanthropy is in an ideal position to convene them to help drive the further development and spread of these delivery models.

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