



The plight of a forgotten cause

By Lauren Foster

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One Sunday morning six years ago, Peter Paetsch and a close friend hopped on their bikes and cycled nearly 100 miles from Chicago, Illinois, to Waterford, Wisconsin. It was mid-September and they sensed the changing season as they rode through farmlands strewn with hay bales.

Paetsch had celebrated his birthday the week before and the cycling trip was a gift to himself. But it was more than a scenic tour through rural north-east Illinois and south-east Wisconsin with a buddy. Paetsch's brother, a successful student and athlete throughout his high school years, had been diagnosed with schizoaffective disorder when he was in his early 20s. The goal that day was to raise funds for a local chapter of the National Alliance on Mental Illness (NAMI), a national advocacy group.

At the end of the ride, which raised about \$3,000, the friends shook hands and declared the first annual NAMI Ride. "Bike and Hike" is now an annual event that recently drew 150 participants and raised just over \$20,000. What may seem like a meagre sum is actually about 25 per cent of NAMI-Racine's operating budget.

Unlike other medical charities that benefit from big-time celebrity endorsements – think the Lance Armstrong Foundation for cancer – non-profit organisations dedicated to helping people with mental illness are neglected. Even though mental illness is more prevalent than cancer or diabetes, non-profit organisations that aim to serve people with mental illness and family members who support them remain hand-to-mouth organisations.

Paetsch, a project manager at Blue Cross Blue Shield, decided to get on his bike for his brother because he wanted to increase awareness of mental illness and, in the process, raise funds for NAMI-Racine. The grassroots organisation had provided his family with support and useful information on mental illness and he felt a fundraising bike ride was the embodiment of a "grassroots" effort.

"It's important to continuously educate and promote mental health awareness – privately and publicly. It's an issue that affects not only the person battling the disease, but also their family members and close friends," says Paetsch. "I am in the business world and an athlete. The combination of the two was my calling."

NAMI and its fellow non-profit organisations are among the orphans of philanthropy. Just as the manifestations of some mental illnesses can turn away onlookers, many philanthropists and foundations have avoided funding mental health in favour of more socially palatable causes, making funding scarce.

According to Foundation Center, which tracks philanthropy trends, foundation giving for mental health was \$225m in 2005 – about 6.6 per cent of total health giving.

While mental health giving grew in the 1990s, an article published in Health Affairs (September/October 2003) found the rate of growth was far below that for total foundation giving or giving for health.

Four years hence, the outlook is bleak. Robert Bernstein, executive director of the Judge David L. Bazelon Center for Mental Health Law, whose mission is to protect the rights of children and adults with mental disabilities, says funding has become “far worse” and the mental health system is in “a shambles”.

The toll of a broken system is high: it strains the social welfare network, in particular juvenile and criminal justice systems. “In this time of disappearing social services, prisons become the asylum of last resort,” says David Fathi director of the US programme of Human Rights Watch.

There is also an economic impact: mental illness is a treatable medical disease, yet many people do not seek treatment or have access to services. It is estimated untreated mental illness costs the US tens of billions of dollars in lost productivity each year.

The human cost is high too. A 2005 national study found that about one in four adult Americans suffer from a diagnosable mental disorder in a given year. But the main burden of illness is concentrated in a much smaller proportion: about 6 per cent of adult Americans, 1 in 17, suffer from a serious mental disorder, such as schizophrenia, bipolar disorder or severe depression.

“If there were any other epidemic affecting as many people as those with mental illness there would be a public outrage,” says Joel Corcoran, executive director of the International Center for Clubhouse Development, a global resource for communities creating opportunities for people with mental illness.

Mental health remains a low priority for many foundations and philanthropists. It is one thing to put your name on an opera house, a hospital wing, even an alcohol rehabilitation centre, but it is a different matter to be associated with severe mental illness.

“One of the main barriers to support for mental health and mental illness is the fact that it isn’t sexy and is taboo within our families, our communities and foundations. It remains a fringe issue,” says Casey Rogers, a senior programme officer at the Conrad N. Hilton Foundation where she oversees the Housing for the Mentally Ill Homeless initiative.

While mental illness is a tough sell, a small group of individual donors and philanthropic foundations are funding this area – and making a difference.

Vincent Mai, chairman of AEA Investors, a global private equity firm, is a philanthropist who has supported the work of Fountain House, an organisation that provides services to the mentally ill to help them function as independently as possible.

“There is a paucity of good programmes serving people with mental illness,” he says.

“Both government funding and private philanthropy should focus on programmes that support helping people ‘get a life’ instead of assuming they are always necessarily dependent.”

Funding from foundations and individuals has helped fight the stigma that usually accompanies a diagnosis of severe mental illness, brought about improvements in health services and policies, and, along with government dollars, provided vital support for research.

For example, Theodore “Ted” Stanley, chairman of consumer products company MBI, has donated tens of millions of dollars toward research into severe mental illnesses. One of the institutions he funds is the Stanley Medical Research Institute, a big source of support for research into schizophrenia and bipolar disorder. (As is NARSAD, a public charity.)

Jane Isaacs Lowe, a senior programme officer at the Robert Wood Johnson Foundation, the largest US healthcare philanthropy, says mental health “pervades” many issues that foundations are concerned about. “The role of philanthropy is to jump-start ideas, test models and advocate for social change,” she says.

These ideas range from funding research or specific programmes to improve access to services, especially among disadvantaged populations, to advocacy and mental health policy.

The California Endowment, one of the leading givers in mental health, stands out for its work on reducing stigma as a barrier to care and for its efforts to find ways to integrate mental health services into non-traditional settings.

The Annie E. Casey Foundation focuses on vulnerable children and families. “How can we begin to accomplish what we want to do if we don’t address what got children into foster care or juvenile detention in the first place – and part of that is their mental health needs. Children with mental health problems are at an increased risk of being placed in foster care or the juvenile justice system,” says Abel Ortiz, senior associate and manager of the foundation’s portfolio on mental health grant-making. “Their mental healthcare needs need to be addressed while they are in care and when they return home.”

Some of the most important work in mental health takes place in the realm of advocacy and public policy. The van Ameringen Foundation, for example, helped fund Disability Advocates, a legal advocacy group in Albany, that brought a lawsuit against New York State’s prisons and the NYS Office of Mental Health.

The suit challenged the failure to provide adequate mental health care for seriously mentally ill prisoners and the practise of consigning inmates with severe psychiatric illnesses to solitary confinement. In April the two sides reached an agreement that significantly improved the lives of mentally ill prisoners.

Small local foundations – including van Ameringen, Saint Luke’s Foundation of Cleveland, and the Hogg Foundation for Mental Health – have had success at the regional level. But there is a gaping hole nationally.

The John D. and Catherine T. MacArthur Foundation, a leading funder, is leaving the field after nearly 30 years of grantmaking and investments in mental health policy and research.

“We now are interested in mental health issues as they arise in other mainstream policy areas such as juvenile justice and housing,” says Laurie Garduque, director for research in the programme on human and community development at the MacArthur Foundation.

“We had done a great deal of work in mental health and it was time for new leadership and vision. We are challenging others to build on the momentum in the field and to articulate a strategy for continuing to move forward.”

Bernstein of the Bazelon Center is not optimistic others will rise to the challenge.

“MacArthur has made an enormous contribution to the mental health field – its departure leaves an enormous vacuum and no other foundation has stepped up to take its place,” he says. “If there’s a door and a doorknocker, we have knocked on it.”

For the near term, it is going to take a lot of legwork to raise awareness and dollars.

Organisations working in mental health

The National Alliance on Mental Illness. A non-profit, self-help, support and advocacy organisation of consumers, families and friends of persons living with mental illness.

Judge David L Bazelon Center for Mental Health Law. Based in Washington, DC, the centre's mission is to protect and advance the rights of adults and children who have mental disabilities.

Fountain House. An alternative model for psychiatric rehabilitation created in 1948 in Manhattan by former patients on the premise that "members" could work productively and have socially satisfying lives.

International Center for Clubhouse Development. Based in New York City, ICCD is a global resource for communities creating opportunities for people with mental illness.

Mental Health Advocacy Coalition. Based in Cleveland, Ohio, MHAC works to increase awareness of mental health and policy issues relating to it.

Mental Health America is a non-profit group aiming to help everyone live a mentally healthier life.

NARSAD. A national, not-for-profit organisation that raises and distributes funds for mental health research.

This is the first article in an occasional series on orphans of philanthropy. Next: the juvenile justice system

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