

United States House of Representatives
Committee on Energy and Commerce
Subcommittee on Health
"Examining H.R. 2646, the Helping Families in Mental Health Crisis Act."

Testimony of
Steve Coe, CEO, Community Access, Inc.
2 Washington Street 9fl NY, NY 10004
212.780.1400 x7711; scoe@communityaccess.org

June 16, 2015

Thank you Chairman Pitts for giving me this opportunity to appear before your committee.

Before I address the particular issues related to H.R. 2646, I'd like to take a moment to tell you a little about Community Access and why I think our experience has something to offer your committee as it deliberates the merits of this important piece of legislation.

The Community Access: Mission, Values and Programs

Community Access founded in 1974 by parents and relatives of people with mental illness who had been long-term patients in state psychiatric facilities. As our name implies, the focus of the program was, and remains, to assist people find a meaningful role in the broader society.

Our founders were mostly associated with Manhattan Psychiatric Center, a 5,000 bed facility located on an island in New York City's East River. At the time, New York, like many states, had adopted a policy of deinstitutionalization, which encouraged the discharge of long-term patients into the community, many who had never lived independently and were poorly equipped for this sudden transformation in their lives.

The outcomes from this policy, we now know, were tragic. Former patients often became homeless, or if they were fortunate, found housing in squalid rooming houses or, in the case of New York City, massive single room occupancy hotels. Without any supports or access to basic resources, the former patients became frequent users of emergency care, jails, and the newly-expanding homeless services system.

Community Access' solution was simple: to provide a safe place to call home, combined with caring supports to insure tenants had enough to eat, proper medical care, and a daily routine that promoted some semblance of a "normal" life. Because we lacked funds to hire more than two staff, the "support services" were the roles played by our friends and neighbors every day: fellow tenants helped each other out in big ways and small, from shopping and cooking, to providing leads for jobs or other community resources.

Today this model has evolved into what we call supportive housing, but at the time it was a unique and compelling social experiment, especially for a young graduate student like me. After writing a paper about Community Access as part of a research project, I offered my services as a summer intern in 1979 and became the agency's second staff member.

Our mission has remained steady for 41 years, while the scope and methods evolved over time. The original apartments in run-down tenements on Manhattan's Lower East Side have been replaced by modern apartment buildings. Our twenty projects now provide housing for over 1,100 tenants. However, the lessons learned from those early days have been incorporated into everything we do today.

First, our buildings are mostly "integrated," by including both units for formerly homeless adults with mental illness, but also families with children and others who simply need an affordable home. We encourage tenants to adopt pets and provide 24/7 front desk service. Our buildings also include amenities like free WiFi, on-site laundry facilities, computer labs, and community space for special events and meetings.

Most importantly, we rigidly separate our dual roles as landlord and service provider. Accepting or using services is not a prerequisite for living in our housing. All tenants sign leases and agree to abide by standard house rules that are common to apartment buildings in the city. Tenants pay their own rent, electric, and other bills. In short, they treated like responsible adults.

By contract, referrals for our special needs units come exclusively from the New York City's Department of Homeless Services, with a priority given to long-term shelter stayers and homeless veterans. We have a housing first philosophy, which means no referral is rejected because the person is not deemed "ready" for housing.

Community Access Staff

Support staff work in most of our buildings and tenants often seek their assistance to manage the many complicated issues in their lives. This can be related to finances, work, or follow up medical care. Who these support staff are and how they are recruited and trained is a key factor in our success.

In 1993 we made a decision to affirmatively hire individuals had a lived experience with the mental health system. We do this by affixing the following statement to all job announcements:

"Community Access is an Equal Opportunity Employer and is committed to the hiring of at least 51% consumer staff, in all of its departments and programs, and at all levels of management."

This policy has created a work environment and culture that, we believe, more is sensitive to the needs of the people we help and has led to the creation of some innovative programs, including a peer training academy, peer-run crisis services, and advocacy efforts to expand housing and reform criminal justice services.

The Howie the Harp Peer Advocacy and Training Center

The Howie the Harp Center was created by Community Access' first director of advocacy, Howard "The Harp" Geld, in 1995 to help users of mental health services become providers of

services. Howie's vision was to create a defined role for peers in the workforce and to do this through a comprehensive training and internship program. Howie died of a heart attack two weeks before the first class was to meet and the program was named in his honor.

Twenty years later, the Center has expanded from an initial class of ten students to two semesters per year with 40 students each, all of whom must have an Axis I diagnosis to be eligible. The training includes 450 hours of classroom instruction¹ followed by a three-month internship at a human service agency, which can be anything from a drop-in center, to a hospital or clinic. It is a rigorous program, but over 50% of the people who start the program graduate and find employment and a career path in the helping professions.

Crisis Alternatives and Parachute NYC

It has long been a goal of Community Access to create programs and services that would replace the standard care people receive during a psychiatric/emotional crisis. It has been our experience that this care, which usually involves the use of police officers, handcuffs, confinement in a facility, and high doses of medication, is traumatic for the individual and does not promote long-term recovery. It also extremely costly for the taxpayer, especially if the person being helped suffers a relapse and repeats the cycle, which is often the case.

After extensive research, we drafted a report and several business plans to create a crisis alternative to hospitalization program (Access to Recovery), but we were continually frustrated by the lack of public funding for what we knew would be a more cost-effective approach.

In 2011, we finally saw a funding opportunity when the Centers for Medicare & Medicaid Services announced the availability of Health Care Innovation Awards that were designed to support "...the most compelling new ideas to deliver better health, improved care and lower costs to... those with the highest health care needs."² We approached the City of New York about responding to this program and the result was a successful application³ to create Parachute NYC.

"Parachute NYC is a citywide approach to provide a "soft-landing" for individuals experiencing psychiatric crisis. This new program offers community centered options that focus on recovery, hope and a healthy future. Parachute NYC uses mobile treatment teams, crisis respite centers, and a peer operated Support Line to provide early engagement, continuity of care and combined peer and non-peer community service, thus shifting the focus of care from crisis intervention to long-term, community-integrated treatment with access to primary care, improving crisis management and reducing emergency room visits and hospital admissions."⁴

Community Access has a three-part role in the overall Parachute project: open the first peer-operated respite center in Manhattan, launch the peer-operated support line, and provide

¹ An outline of the class schedule is included as an attachment to this testimony

² <http://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/>

³ Submitted as an attachment to this testimony

⁴ <http://innovation.cms.gov/initiatives/Health-Care-Innovation-Awards/New-York.html>

enhanced training through the Howie the Harp center to expand the peer workforce.

In August 2012 we began advertising for people with a “lived experience” to work at the respite center. We had 14 respite positions, plus 5 positions for the support line, which would operate out of the respite center from 4 pm to midnight. We received 800 applications for these 19 positions. By October 2012 we were fully staffed and training began in two primary methodologies: Intentional Peer Support⁵ and Need Adapted Treatment (also known as Open Dialogue)⁶.

The Crisis Respite Center

In January 2013, we opened the Manhattan Crisis Respite Center⁷ at 315 Second Avenue. As with any new service introduced into an established system, it took a number of months before referrals from providers and families began with regularity. In the first five months of operation, there were only 13 guests and a 12% occupancy rate. However, during the most recent five-month period we had 100 guests and a 70% occupancy rate. The average length of stay is 7.5 days.

It’s important to note that the largest single source of referrals (25%) is “self-referrals,” which the majority of the time means a family member or friend has contacted us. About 45 of the 370 total guests have been repeat users, and fewer than a dozen people have come more than twice.

“Treatment” at the respite center follows the principles of Intentional Peer Support and common sense practices to ensure the guests and staff remain safe. If we don’t know prospective guests, we ask that they secure a letter from a treating professional that states they are not a danger to self or others. We do not create a treatment plan or conduct psychosocial assessments, although we maintain linkages with mobile health and mental health teams in case we suspect someone needs immediate attention. Guests bring, use, and store their own medications.

Unlike a hospital setting, guests are free to come and go, use computers and phones provided in the common area, and, in some cases, even bring their pet or service animal. A washing machine and dryer are provided and guests are expected to maintain their personal space.

The initial focus when a guest arrives is to make him or her feel safe and relaxed. This might take a day or so, but guests quickly adapt to the new routine. Morning and mid-day meals are the guests’ responsibility. We provide a well-stocked pantry, but guests may buy and store their own food. Dinner is a social event in which guests and staff work together to plan, prepare, and then eat as a group. This activity developed quite by happenstance, but has proved to be one of the most highly regarded aspects of the respite experience.

Guests understand they are only allowed to stay for only ten days, so within a day so conversations with staff naturally turn to exploring the nature of the issues that brought them to the Center and developing strategies for managing their lives when returning home.

⁵ <http://www.intentionalpeersupport.org/wp-content/uploads/2014/02/Peer-Support-What-Makes-It-Unique.pdf>

⁶ <https://www.power2u.org/downloads/OpenDialogueApproach.pdf>

⁷ <http://www.communityaccess.org/what-we-do/respite-center>

Having the opportunity for extended conversations with staff—who have been trained to carefully listen and respond with honesty—is a surprisingly powerful approach, in that the guest’s perspective is being acknowledged and not judged as being right or wrong.

Another important way the respite stay is different from a hospital is what happens after discharge. Guests are welcomed to return to the Center for meals, events, groups, and as volunteers. Some guests have been inspired to seek employment.

Also, follow-up supports using Need Adapted Treatment (a form of family psychotherapy), is used to engage family members and the guest in an ongoing dialogue around difficult issues that may have contributed to the crisis. Specially trained mobile teams under the direction of the Visiting Nurse Service provide this support.

The Support Line

A peer-operated support line is considered an essential component in a comprehensive psychiatric crisis response system.⁸ The benefits of a support or “warm” line, as opposed to a crisis line, include establishing relationships, active listening, and making sure callers are safe for the night. New York City’s crisis line, LIFENET, is responsible to responding to suicide threats or other calls that require a clinical intervention or referral. A transfer protocol between the two services was established at the outset so calls could be quickly routed to the best location.

The support line began operation about a month after the respite center opened and is staffed by the same team of respite workers. Two additional staff are dedicated to the call-in lines from 4 P.M. to 12 A.M., usually for no more than two hours at a time. This staffing arrangement reduces fatigue that crisis line workers often experience.

Since the line began operation, we have received 6,000 unique calls. Many users call more than once, sometimes every day. For some elderly or extremely isolated individuals, our staff might be the only human they speak to all day. Unless there is a queue, staff can stay on a call for as long as someone wants to talk, which is not possible on a crisis line.

Peer Training and Certified Peer Specialists

The third area of responsibility for Community Access under the Parachute project was to assist in the expansion of the peer workforce. As described above, Community Access offers a comprehensive, year-long training and employment program for people with a mental health diagnosis. Given time and resource constraints, we decided to offer an abbreviated training program that would prepare people to become certified peer specialists.

Earlier this year (2015) New York State launched the Academy of Peer Services (APS),⁹ an on-line peer training platform with thirteen modules. Peers who pass all the modules are granted a conditional peer specialist certificate and after completing 2,000 hours of work in the role of a peer specialist (equivalent to one year of full-time work), the peer becomes fully certified.

⁸ www.tacinc.org/media/13106/Crisis%20Manual.pdf

⁹ www.academyofpeerservices.org/

Knowing the many barriers peers face with on-line learning, such as access to technology and literacy issues, we decided to create an APS prep class¹⁰. Students in the class are given a Chrome netbook and training to access the Internet, set up an account on the APS website, and explore social media in general. Use of the netbooks to access the learning modules is supplemented with standard classroom training that draws from our more comprehensive peer training program. In this way, the concepts and theory behind the skills training are discussed as a group under the guidance of an expert teacher.

The first prep class was launched in April 2015 and the second class began on June 8 and is scheduled to run for 6 weeks, with three evening sessions per week.

Community Access Today

As described above, Community Access has grown substantially over the years, but has strived to main a set of core values that support the rights and dignity of the people we serve. Through our affirmative hiring practice about 1/3 of our 450 staff identify as peers, including program directors and senior managers. This culture of inclusiveness has led to the creation of unique and cost-effective programs that will serve the community and taxpayers well as the system transforms into one that is focused on outcomes and pay-for-performance contracting with managed care companies.

Taken together our work is focused on three key areas:

Housing: We expect to double our housing stock to over 2,000 units within the next five years. Future development will continue to embrace an integrated model with a 50/50 mix of affordable units for families and for formerly homeless people with special needs.

Crisis Supports: Under New York's Medicaid reform effort, we expect to see expanded funding for the development of crisis services. Through an agreement between the State and the Centers for Medicare and Medicaid Services, New York has pledged, in exchange for billions in seed capital, to reduce hospital usage by 25% over the next five years¹¹. This can only be accomplished by creating a broad array of preventive and alternative to hospital services, such as mobile crisis teams, support lines, and respite cents.

Peers in the Workforce: Integral to the system transformation described above, is the role of the peer worker. For high-cost Medicaid users, who are often socially isolated and the least likely to follow a defined treatment plan, the peer worker is often the most valuable resource. Engaging people where they live, maintaining an ongoing relationship, and providing practical support and guidance (such assisting with housing and benefits) are all the hallmarks of a skilled and trained peer specialist.

Community Access, through the use of new Medicaid-funded Home and Community Based

¹⁰ Prep class application included as attachment to this testimony

¹¹ www.health.ny.gov/health_care/medicaid/redesign/

Services¹², expects to see increased funding for peer training and adoption of affirmative hiring policies by other provider agencies, especially as managed care contracts require peers to have a significant role in the service delivery system. Optum's impressive results in transforming the crisis system of care in Tacoma, WA is a great example of this trend¹³.

Finally, giving service recipients the opportunity to purchase services through programs known as Self-Directed Care¹⁴ can lead to transformative shifts, as we have seen in the Netherlands, where the Howie the Harp program is being replicated on a large scale through tuition paid by peers to acquire these skills¹⁵.

¹² www.omh.ny.gov/omhweb/News/2014/hcbs-manual.pdf

¹³ www.optum.com/content/dam/optum/resources/whitePapers/BSPUB0119S003JV_PierceCty-WR.pdf

¹⁴ www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html

¹⁵ www.howietheharp.nl/

Comments on H.R. 2646: “A Bill to make available needed psychiatric, psychological, and supportive services for individuals with mental illness and families in mental health crisis, and for other purposes.”

Section 103. Reports

A. Peer-Specialist Programs Training and Certification

Comment: We are wholeheartedly endorse this initiative!

B. State of the States Mental Health and Substance Use Treatment

Comment:

The term “emergency room boarding” is used several times in H.R.2646 to describe the situation of people in a mental health crisis waiting in ERs until an inpatient bed is available. The implication seems to be that there are not an adequate number of inpatient beds and government should invest resources to expand this service.

We believe the solution for emergency room boarding is not to create more inpatient beds, but to expand the array of crisis services so that people can avoid going to the emergency room in the first place. A fully functioning crisis response system would include several elements, all of which exist today, but rarely all in the same community.

- Mobile crisis response
- 24/7 crisis phone/text services
- 24/7 support line
- 24/7 urgent care centers
- 24/7 Respite
- Low threshold short-term housing
- 911 diversion (first responder crisis intervention training)

Also, even when the same program exists on paper, its effectiveness care vary widely. For example, a mobile crisis team in New York City may respond within 48 hours; in Pierce County, Washington it’s less than 48 MINUTES.

While some communities may feel the need for more hospital beds, New York State is going in the opposite direction. In an agreement with the Centers for Medicare & Medicaid Services, hospital usage is planned to decrease by 25% for high-cost, high-need Medicaid users.¹⁶

¹⁶ www.health.ny.gov/health_care/medicaid/redesign/dsrip/

Section 201. Mental Health Policy Laboratory (NMHPL)

Comment: There is a lack of research or evaluation on the long-term use of psychotropic medications.

Purpose: To evaluate and disseminate to such evidence-based practices and services delivery models using the best available science shown to be cost-effective while enhancing the quality of care furnished to individual

Section 202. Innovation Grants

Comment: The proposed duration period (less than 2 years) seems too short, given that most programs require a start-up period and then additional time to test and adjust new approaches.

Section 203. Demonstration Grants

Comment: Funding is restricted to “evidence-based” programs or projects. An independent and transparent review method should be added so “emerging best-practices” could be included. Many approaches have been documented in peer-reviewed journals, but fall short of the standards required for inclusion as a best practice.

Section 205. Extension of Assisted Outpatient Treatment Grant Program for Individuals with Serious Mental Illness

Comments:

A. Evidenced-Based Practice

The National Registry of Evidenced-Based Practices and Programs¹⁷ lists 94 interventions for mental health treatment recognized as evidence-based practice, including AOT. Of these, there are 52 interventions that promote employment, reduce homelessness, and improve quality of life, including:

The Compeer Model pairs trained volunteers with adults (including veterans and the elderly) and youth (including children with an incarcerated parent), to reduce social isolation and to increase community reintegration.

Critical Time Intervention (CTI) is a time-limited case management model that is designed to support continuity of care and community integration for persons with severe mental illness who are transitioning from institutional settings (e.g., shelters, hospitals, jails) to community care and are at risk of homelessness.

¹⁷ www.nrepp.samhsa.gov

The ICCD (International Center for Clubhouse Development) Clubhouse Model is a day treatment program for rehabilitating adults diagnosed with a mental health problem.

Housing First, a program developed by Pathways to Housing, Inc., is designed to end homelessness and support recovery for individuals who are homeless and have severe psychiatric disabilities and co-occurring substance use disorders.

The Psychiatric Rehabilitation Process Model is a process guiding the interaction between a practitioner and an individual with severe mental illness. Manual driven, the model is a client-centered, strengths-based intervention designed to build clients' positive social relationships, encourage self-determination of goals, connect clients to needed human service supports, and provide direct skills training to maximize independence.

Wellness Recovery Action Plan (WRAP) is an intervention for adults with mental illness. WRAP guides participants through the process of identifying and understanding their personal wellness resources ("wellness tools") and then helps them develop an individualized plan to use these resources on a daily basis to manage their mental illness.

Making the promotion of AOT a priority for government funding purposes, among all the possible evidenced-based approaches, is not supported by research or other logical explanation. Requiring states to adopt AOT as a legal mandate to secure funding for other programs seems inconsistent with other aspects of H.R. 2646 that promote research-based solutions and transparent analysis.

B. AOT Models

Research has shown that AOT programs vary greatly, as do the outcomes¹⁸. In New York City, for instance, an AOT-assigned individual is given priority for supportive housing, which greatly improves community stability. In other places supportive housing barely exists and the “treatment” offered is an intensive case manager who might be working with 50 or 60 other clients. In these cases, support can be little more than a requirement to take medication.

Further, while AOT may have achieved the status of an evidenced-base intervention, the services offered under an individual AOT program itself are often NOT evidence-based. For example, requiring individuals to take psychotropic medications is not on National Registry of Evidenced-Based Practices and Programs. Neither would the requirement to attend a day treatment program or any number of interventions that a state or locale might deem helpful, but have no evidence to support their use.

This lack of standards creates a concern for rights advocates who fear states will adopt AOT legislation to meet the requirements of the law, then “race to the bottom” to deploy a service that ignores the aspirational vision outlined in Section 223 of H.R. 2646, which promotes demonstration programs for Community Behavioral Health Clinics that include:

¹⁸ www.onlinelibrary.wiley.com/doi/10.1037/0002-9432.77.3.350/abstract

- Crisis mental health services, including 24-hour mobile crisis teams, emergency crisis intervention services, and crisis stabilization.
- Screening, assessment, and diagnosis, including risk assessment.
- Patient-centered treatment planning or similar processes, including risk assessment and crisis planning.
- Outpatient mental health and substance use services.
- Outpatient clinic primary care screening and monitoring of key health indicators and health risk.
- Targeted case management.
- Psychiatric rehabilitation services.
- Peer support and counselor services and family supports.
- Intensive, community-based mental health care for members of the Armed Forces and veterans

AOT should mean guaranteed access to this array services, and a home.

“There needs to be an array of services, with case management, integrated mental health and substance abuse, housing, supports. People have to navigate a maze in order to get access to the services they need.” Ronald S. Honberg, national director for policy and legal affairs at the National Alliance on Mental Illness.

“We do not believe that AOT is the solution to the problems of the mental health system, to the sad reality that there are so many people who are falling through the cracks,” concludes NAMI’s Honberg. “On the other hand, as a last resort, we do think it can be helpful with certain individuals.”¹⁹

C. Social Justice

AOT is disproportionately applied to black citizens.²⁰ This is justified by the fact that blacks are more likely than whites to be in the public mental health system. If we accept this rationale, then it’s acknowledged that AOT is a service for primarily low income and minority users of the public health system, i.e., not a service that impacts all citizens equally.

Section 597. Fellowships

Crisis Intervention Grants for Police Officers and First Responders

Comment: We applaud this recommendation. Community Access has been a leader in promoting CIT programs in New York City. Our successful advocacy efforts have led to the launch of New York City’s first training program, which began on June 1.

¹⁹ www.behavioral.net/article/aot-cost-effectiveness-study-stirs-national-debate?page=2

²⁰ <http://content.healthaffairs.org/content/28/3/816.full>

Section 301. Interagency Serious Mental Illness Coordinating Committee

Comment: We applaud the measures described below, in particular, employment and educational attainment.

Measurement of: (A) reduced rates of suicide, suicide attempts, substance abuse, overdose, overdose deaths, emergency hospitalizations, emergency room boarding, incarceration, crime, arrest, victimization, homelessness, and joblessness; (B) increased rates of employment and enrollment in educational and vocational programs. (p 106)

Section 501. Enhanced Medicaid Coverage

Comment: While we have concerns about loosening the Medicaid Institutions for Mental Diseases (IMD) exclusions, we believe a range of possible interventions need to be explored. Limiting the time a person may be confined to a facility seems to be a much more critical factor in preventing institutional care than the total numbers of beds in that same facility.

Inpatient psychiatric care: short-term, acute inpatient psychiatric hospital care means care that is provided in either an acute-care psychiatric unit with an average annual length of stay of fewer than 30 days that is operated within a psychiatric hospital operated by a State; or a psychiatric hospital with an average annual length of stay of fewer than 30 days. (p 126)

Section 233. Demonstration Programs to Improve Community Mental Health Services

Comment: We enthusiastically support the study and expansion of programs that promote health, recovery, and community integration.