

Chapter 9

Community-Based and Grassroots Programs



Mental illness, it's a bit like drugs, it doesn't give a shit who you are. And you know what's worse? The stigma doesn't give a shit who you are.—Sinead O'Connor (2017)

Community members can aid in making change in mental health awareness and improving the system of care and reentry. In fact, there appears to be substantial growth in nonprofit organizations of all sizes to affect such change, as well as the volunteer hours needed to sustain this momentum. In 2015, the Urban Institute released their annual *Nonprofit Sector in Brief*, which supports this claim (McKeever, 2015). This report reveals that the number of 501(c)(3) public charities grew 19.5% from 2003 to 2013, and 25.3% of American adults had volunteered for a nonprofit organization in 2014. While this proportion of adults who volunteer at least once per year is on a slightly downward trend, the number of total volunteer hours in any given year is at the highest ever recorded at 8.7 billion hours in 2014—valued at \$179.2 billion. This volunteerism is consistently concentrated in social service and care activities, including food preparation, cleanups, food, goods, and clothing collection and delivery, direct care and/or services, teaching, mentoring, and counseling. In the cases of local mental health-care system improvements and criminal justice reform (e.g., reentry), this momentum has been buttressed by grant opportunities through the Substance Abuse and Mental Health Services Administration, the Bureau of Justice Assistance, and other Federal government funding agencies specifically tailored to support public nonprofit collaborations. For example, the Bureau of Justice Assistance Second Chance Act Comprehensive Community-Based Adult Reentry Program is specifically geared for community-based nonprofits who engage in reentry activities such as mentoring support, treatment services, legal aid, and more. These opportunities also seem to be on the rise; however, it is uncertain how the current administration will shape this trend in the upcoming years. With momentum in Congress and local governments for justice and mental health reform, it appears that the trajectory of improvements will continue to some degree. This chapter focuses on promising nonprofit activity led by icons, world leaders, and

everyday people to give readers some orientation of the rigorous activity that is affecting changes in mental health and justice.

9.1 Know the Role

Nonprofits have embraced the challenges facing individuals with mental illness, those who are experiencing mental health crises, and those reentering society from periods of incarceration, treatment, and hospitalization. As noted earlier, episodes of each of these can be the most volatile and difficult struggles in people's lives—and they most often occur in our communities, on our city streets, and in the countryside. The risk of overdose and relapse is assuredly higher when individuals are confronted with their triggers or being close to bars and hangouts, passing the abandoned house turned into a drug den, seeing or hearing from those acquaintances or sexual partners who engage in drug use and deviance, and so on. In the case of reentry, the stress of returning home and dealing with substance use/abuse/misuse, income and work, and family relationships can be overwhelming. Family members and loved ones may not always be supportive after a person has been incarcerated. In fact, some may be full of anger, mistrust, and spite, which may require counseling in order to heal the damage done from “losing” their loved ones to the system for acts that they may feel are the fault of the person coming back into their lives after long periods of absence.

Many people involved in the nonprofit sector in the capacity of serving mentally ill and justice-involved populations have been directly or indirectly touched by problems addressed in this text. Some are parents of a daughter or son with mental illness and/or those that have served time—or other family members. Some individuals with mental illness and/or previous justice involvement become peer supports for others who become involved with the justice system. One perfect example can be found with an even-keeled, insightful, and mild-mannered Maryland man named Eddie Ellis. In the years after his release, Mr. Ellis has been speaking about his story of incarceration after serving 22 years in prison for shooting and killing a man when he was 16 years old (Ellis, 2016). Now Mr. Ellis serves as a mentor and advocate for others with shared experiences, including being held in solitary confinement for long periods of time because of his violent conviction and not due to his prison behavior. His motivation and hard work post-release has culminated in a vibrant 501(c)(3) nonprofit organization named One by 1, which Mr. Ellis serves as Chief Executive (One by 1 Inc., 2017).

At a recent speaking event at the National Association of Drug Court Professionals, Mr. Ellis was joined by his mother to share their points of view on the effect of incarceration in their lives with justice professionals engaged in reentry work (Cherry & Ellis, 2017). Their accounts were impassioned and full of lingering signs of pain from their experiences and allowed the audience a window into the common problems returning prisoners and their families will face upon release. As the conversation progressed, Ms. Cherry voiced her concern that family members often

lack support to help them process their feelings. This point in particular began a lively question and answer session about how professionals can best aid families at a vulnerable time in their lives.

Everyday people turned onto “giving back” or to be a change agent—like Mr. Ellis and Ms. Cherry—are at the heart of the grassroots effort in American communities. Peer support specialists, for example, are becoming critical—if not mandatory—for the care of individuals with mental illness, substance use disorder, and/or who are experiencing a mental health crisis. Thus, at this point, any comprehensive solution to the broken mental health system of care and justice reform almost requires grassroots, community support. The following sections highlight some of the most innovative endeavors of recent years.

9.2 Facing the Stigma Head On: Heroin Walks Like Cancer Walks

In reducing stigma and viewing mental health like physical health, changing thought processes and views about fund-raising is also important. In regard to physical health, for example, there are many activities in the month of October for Breast Cancer Awareness in most communities across the United States each year. These activities include fund raising walks, charitable donations from major corporations (think Yoplait yogurt), and even the National Football League players wearing pink accessories while they play in a dedicated week to the cause. These activities do not only raise money for different organizations that research breast cancer in hopes of a cure; they also are critical in raising awareness of the disease and need for preventative screening and regular health checks.

In this vein, mental health-related events and campaigns happen throughout the year, with peak activity during the official “Mental Health Week” (the first full week of October as recognized by Congress; not to be confused with mental health month—May—established by NAMI and its partners). For example, the local NAMI affiliates often sponsor 5 K events each year, called NAMIWalks, which raises money for each local branch. In the most recent year (2016), there are more than 80 individual communities having a walk, raising over \$11 million in the United States.

In more recent times, this concept has been expanded to focus on current emerging issues, such as the opioid epidemic. In February 2017, the Addiction Prevention Coalition in Birmingham, Alabama hosted an “End Heroin Bham” walk, free to everyone, with the intent to bring awareness of the recent surge in opioid-related problems and deaths occurring in the greater Birmingham area and in the state of Alabama. Likewise, the Coalition utilized a broad array of media exposure of the event to aid in its message, even if locals did not end up attending the event. Awareness and social marketing campaigns seem to be one of the primary tools of the grassroots movement in terms of relevance and sustained funding.

9.3 Partners 4 Strong Minds (Strong 365) and One Mind Care Connect

Partners 4 Strong Minds (P4SM) was a nonprofit organization created as a result of founder Chantel Garrett's long advocacy of her brother's schizophrenia diagnosis. With a background in marketing for corporations, Ms. Garrett spearheaded a modern campaign of advocacy and personal storytelling to change the way everyday people think about brain health and access to care. In particular, the organization began with a focus on creating awareness regarding the first/early onset of psychosis with the notion that addressing the psychosis early on and quickly after the first onset can aid in better results for long-term success in recovery. P4SM's use of messaging from friends, families, and loved ones often was found at the core of the organization's awareness campaigns and events, many of which were concentrated on the West Coast of the United States where P4SM was founded.

The mission of P4SM aligned with an emerging science pointing to promising results of early intervention and by being proactive. In fact, mental illness disease processes seem to be more easily managed—and possibly in some cases, symptoms can be lessened—when early intervention occurs. It often allows for the individual to live a much more productive and stable life. Further, a person can learn their triggers and be more aware of symptoms and issues before they arise, thus empowering those with mental illness.

Similarly, Shari and Garen Staglin's experiences of advocating for their son Brandon and his schizophrenia diagnosis drove them to organize and develop the One Mind Institute. Since 1995, the Staglins focused their efforts on grantsmaking in the domain of brain health research. In 2014, Ms. Garrett and the Staglins joined forces to create the One Mind Care Connect initiative: "the combined effort expands P4SM's nationwide advocacy and personal storytelling platform under the One Mind Institute brand, and complements its grassroots approach with translational research that will help us learn more about how to best evolve and scale early psychosis treatment in the United States" (One Mind Institute, 2017). One of the current programs of One Mind Care Connect is Strong 365. Strong 365 has many facets to help families in their search for help with psychosis, specifically the early stages. A treatment tracker is maintained on the Strong 365 website, which lists programs throughout the country that provide treatment after a first episode of psychosis. The information on the website makes clear that the early intervention treatment, medication management, counseling (including the whole family), brain training, and other activities are shown to aid in recovery.

9.4 Heads Together

Often, on health-related topics, a "champion" is discussed when having a celebrity or spokesperson for a campaign. As mental health emerges as a mainstream topic (again), celebrities are (re-)emerging to bring the conversation of mental health

awareness to the forefront. Further, with social media, these messages are easily able to quickly reach large audiences. Some celebrities are also opening up to discuss their own personal struggles with mental illness or substance abuse (particularly with the latter). For example, Sinead O'Connor recently shared her raw feelings regarding her own mental health and suicidal thoughts with a self-shot video on her Facebook account. In her emotional 12-min clip, O'Connor explains: "I hope that this video is somehow helpful. Not to me, but the fact that I know that I am only one of millions and millions and millions of people who are just like me, actually, that don't necessarily have the resources that I have in my heart and in my purse." Often, positive messages about mental illness and treatment are used to open conversation to happen to affect change, particularly when these messages are associated with nonprofit organizations. Having these "champions" can begin to help overcome stigma and obstacles to ensure everyone receives the treatment needed.

One example of champion-led messaging comes with the Royal Foundation of the Duke and Duchess of Cambridge and Prince Harry and its project entitled Heads Together. In particular, the Heads Together project adjoins the Royal Foundation "in partnership with inspiring charities that are tackling stigma, raising awareness, and providing vital help for people with mental health challenges" (Royal Foundation, 2017). Having world leaders, such as Prince William, Duchess Kate, and Prince Harry, speak on mental health is providing legitimacy to the cause. It can further bring hope to all affected. As such, the Heads Together program is a potent awareness campaign that unites existing organizations and elevates their cause through celebrity power—partners including Best Beginnings, the Campaign Against Living Miserably, Contact (mental health coalition for the military), Mind, Place2Be, The Mix, YoungMinds, and the Anna Freud Centre. It also includes star power from across the pond in the United States with Born This Way.

9.5 Born This Way

The Born This Way Foundation founded by musician, Lady Gaga, with its slogan "empowering youth and inspiring bravery." The Foundation features different programming and advice based on research as well as tips and direct links for seeking help when needed. Lady Gaga uses her own personal experience with post-traumatic stress disorder to dispel the concept of stigma and promote a positive community.

I have wrestled for some time about when, how and if I should reveal my diagnosis of Post-Traumatic Stress Disorder (PTSD). After five years of searching for the answers to my chronic pain and the change I have felt in my brain, I am finally well enough to tell you. There is a lot of shame attached to mental illness, but it's important that you know that there is hope and a chance for recovery. (Born This Way Foundation, 2017)

Her organization provides user-friendly information in a manner geared toward youth and helping them to create "kind communities and enhance mental wellness." Areas on the website currently focus on topics such as kindness, positive environments, mental wellness, and research and resources and further feature a Born Brave blog featuring voices and stories from across the country.

The website includes a section entitled Hack Harassment which works to combat online harassment for youth. Hack Harassment assembles its partners—Intel, Vox Media, and Recode—to work behind the scenes to find innovative ways to help keep online spaces free of harassment. Hack Harassment also includes section for users featuring an anti-harassment pledge and an application for college-aged students to become campus ambassadors at their college or university. The idea of a campus ambassador is nothing new and has used by many different organizations to promote education and information within the college campus community. Yet, the star power of Lady Gaga can further elevate campus messaging and give help to its legitimacy.

In 2017, Lady Gaga and Prince William open up to one another about their experiences with mental illness via a FaceTime call shared with the world with the hashtag #okaytosay (a Heads Together awareness tool). For Prince William, he shared personal details about his brother Harry's need to seek counseling to help with his struggles after the death of his mother.

Lady Gaga: ...The beautiful videos of the Heads Together campaign...told beautiful stories and it reminded me how much my mental health changing changed my life.

Prince William: [Most of our charitable work] seemed to stand back to mental health issues, and you know, I read your open letter you wrote the other day and I thought it was incredibly moving and very brave of you to write down such personal feelings. I wanted to ask you very much how you found speaking out and how it made you feel?

Lady Gaga: It made me very nervous at first. For me, waking up everyday and feeling sad and going on stage, is something that is something very hard to describe. There's a lot of shame attached to mental illness. You feel like something's wrong with you. And, in my life, I go "oh my goodness look at all this beautiful, wonderful things that I have. And I should be so happy." But you can't help it that if in the morning when you wake up, you are so tired, you are so sad, you are so full of anxiety and the shakes that you can barely think. But, it was like saying, this was a part of me and it was okay.

Prince William: ...for me, the little bits that I have learned about mental health so far is that it's okay to have this conversation. It's really important to have this conversation, you won't be judged. It's so important to break open that fear and taboo which is only going to lead to more problems down the line.

Lady Gaga: Yes, it can make a huge difference. I feel like we are not hiding anymore; we're starting to talk and that's what we need to do really.

Prince William: Absolutely. It's time that everyone speaks up and feels very normal about mental health. It's the same as physical. Everyone has mental health and that we shouldn't be ashamed of it. Just having a conversation with a friend or family member can make such a difference.

Lady Gaga: Even though it was hard, it was the best thing that could come out of my mental illness – was to share it with other people and let our generation as well as other generations know that if you are feeling not well in your mind, that you are not alone. And that people that you think would never have a problem do.

This collaboration will pick up again in October when Prince William plans to meet up with Lady Gaga to take the next steps in this conversation and create some action out of it. Along with this example, there are many other celebrity champions who have surfaced in recent years to bring to light issues related to mental health.

9.6 Wear Your Label

Wear Your Label is a Canadian-based clothing company created by two friends “to spark conversations about mental health” (Wear Your Label, 2017). Both of the co-founders have suffered from mental illness and wanted to let others know that “it’s okay not to be okay,” and the importance of self-care. Their shirts feature sayings like “stigma free” and “i am enough” and come in unisex sizing to be inclusive to all gender and gender fluid individuals. Wear Your Label has now expanding to also include jewelry with a bracelet series that not only provides awareness for different mental health diagnoses but also includes information on those disorders and where to seek help if needed.

This is one example of how individuals turn statements about mental health into mainstream society. Importantly, the success of Wear Your Label is occurring in simultaneously with other clothing labels that may have antithetical messages (e.g., cliqueish, thin-is-in, and so on). The effort of the company to advocate for mental health awareness is also echoed on its website, which includes a blog regarding mental health issues. This is one of many examples of marketing innovation that serves mental health advocacy.

9.7 Active Minds

Active Minds was created by a woman named Alison Malmon following the suicide of her older brother, Brian. As both were college students at the time, Ms. Malmon was struck by the dearth of discussion of mental health issues on her campus. After a few years of activism, she incorporated the Active Minds nonprofit in late 2003; the organization works as a student-led group on college campuses across the United States to bring awareness to mental health issues at these campuses. In almost 15 years, Active Minds has grown to over 400 chapters with thousands of student members at universities across the nation. Additionally, there is now a national conference where members of different groups can come together annually at a forum to help growth, understanding, and awareness. The organization offers many different, turnkey-style programs that can run independently at each campus (e.g., individual-led efforts) as well as group-based efforts such as Active Minds’ signature Send Silence Packing® event (Active Minds, 2017).

Send Silence Packing® gives passersby a visual representation of suicide among college-aged students. To do so, a traveling tour of donated backpacks is brought to each site to be laid out in a high-traffic area on campus, like outside of the student union or main campus “quads.” As a visual representation, the backpacks symbolize the number of college students who take their lives each year; signage is placed near the backpacks with statistics, ways to seek help, and other helpful information. In 2017, the Send Since Packing® campaign has reached over 15 campuses, including

the University of North Alabama, Alcorn State University, the University of North Texas, The University of Denver, Colorado State University, Mt. San Jacinto College, and Occidental College.

9.8 SLIDDE, University of Louisiana at Lafayette

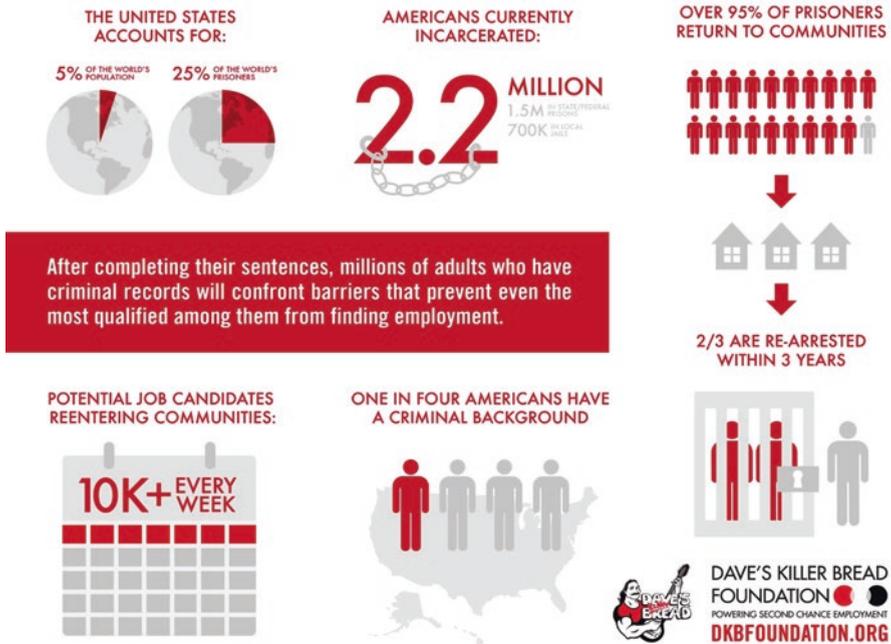
Further, on a direct community level, universities themselves have taken the awareness efforts on their own. One great example of programming is at the University of Louisiana at Lafayette. There, a student organization called SLIDDE, School Leaders Involved in Drinking and Drug Education, has been created. The program was started within the Counseling and Testing Center to provide education, awareness, and prevention on campus for drinking and drug use. It has now grown to be an official student-led organization and is involved in many different activities on campus throughout the academic year, such as an annual 5 K run that occurs in spring. These events are often coordinated with popular campus events to ensure wide visibility and maximum exposure. In fact, most modern colleges and universities offer such programming through a division or office of student health. Therefore, it should not be surprising to see mental health programming becoming more prominent in such messaging in some capacity. For the time being, grassroots organizations such as Active Minds are filling the voids on campuses across the country, as are campus-based NAMI organizations. Much more activity is expected in the upcoming years in this arena (University of Louisiana Counseling and Testing Center, 2017).

9.8.1 *Dave's Killer Bread*

Created in 2005 as part of a family bakery, Dave's Killer Bread has grown to become *the* top rated organic bread in the United States. The story of the Dahl brothers, Dave and Glenn, is a testament to community partnerships working to help solve some of the nation's struggles. Dave served 15 years in prison and was given a job by his brother to work in their family bakery after his release. Their dream was to create bread that was both organic and non-GMO, and they succeeded. Now, the company has more than 300 employees with distribution in all 50 US states and Canada (thanks to the distribution power of Flowers Foods who acquired Dave's Killer Bread; products currently reach 85% of Americans). Even further, one in three of their employees at the original bakery has a criminal background. As a company, they are working to reduce the struggles of stigma and recidivism in the United States.

Additionally, Dave's Killer Bread Foundation has been created to aid in education and implementation of Second Chance Employment. The Foundation has created a Second Chance Playbook which features all topics related to understanding how and why hiring individuals and providing them with a "second chance" is ben-

eficial to the community and their organization. Organizations can join the community and have access to the Playbook and even attend the Second Chance Summits held across the country. The Second Chance Playbook not only provides guides but also video modules covering topics such as “risk mitigation and insurance, legal compliance and the use of criminal background checks, financial incentives for hiring Second Chance candidates, organizational culture and values, the hiring and staffing process, successful onboarding and orientation, and more” (Dave’s Killer Bread Foundation, 2017).



9.9 Conclusion

Many of these organizations mentioned above both reduce stigma and raise awareness about mental health and the criminal justice system. More importantly, their efforts are part of the steps in making a change for their communities and society as a whole. Support and positivity can manage to spark change in many ways. Persons suffering from mental illness that have a criminal background can also find solace in partnering with these, and many other, organizations to tell their stories. Education to the public is an essential component in success for all involved.

Part of the importance of the awareness campaigns mentioned in this chapter is to aid students and professionals to understand the normality of mental health

issues in our society. If we can begin educating students and arm them with the information in these campaigns, this can drastically impact the careers of these individuals or professionals already working in these careers—which can thus have an impact on justice-involved individuals and those with mental health concerns (most likely, both).

References

- Active Minds. (2017). *About us*. Retrieved October 30, 2017, from <http://www.activeminds.org/about>
- Born This Way Foundation. (2017). *Born this way*. Retrieved October 30, 2017, from <https://born-thisway.foundation/>
- Cherry, S., & Ellis, E. (2017). *Speaking at the national association of drug court professionals*. Washington, DC: NADCP.
- Dave's Killer Bread Foundation. (2017). *About us*. Retrieved October 30, 2017, from <https://www.dkbfoundation.org/about/>
- Ellis, E. (2016). *I am one of the success stories from D.C.'s second-chance law for young offenders*. Retrieved October 30, 2017, from https://www.washingtonpost.com/opinions/i-am-one-of-the-success-stories-from-dcs-second-chance-law-for-young-offenders/2016/12/16/f1f2c9a4-c211-11e6-8422-eac61c0ef74d_story.html?utm_term=.ae7c13f61e28
- McKeever, B. (2015). *The nonprofit sector in brief 2015: Public charities, giving, and volunteering*. Retrieved October 30, 2017, from <https://www.urban.org/research/publication/nonprofit-sector-brief-2015-public-charities-giving-and-volunteering>
- O'Connor, Sinead. (2017). *Personal Facebook post*. Retrieved September 1, 2017, from <https://www.facebook.com/Sin%C3%A9ad-OConnor-151509961629721/>
- One by 1 Inc. (2017). *Welcome to one by 1*. Retrieved October 30, 2017, from <http://www.oneby-1inc.org/>
- One Mind Institute. (2017). *About one mind institute*. Retrieved October 30, 2017, from <https://www.onemindinstitute.org/about-one-mind-institute>
- Royal Foundation. (2017). *About our foundation*. Retrieved October 30, 2017, from <http://www.royalfoundation.com/about-our-foundation/>
- University of Louisiana Counseling and Testing Center. (2017). *School leaders involved in drinking and drug education (SLIDDE)*. Retrieved October 30, 2017, from <https://counselingandtesting.louisiana.edu/content/slidde/school-leaders-involved-drinking-and-drug-education-slidde>
- Wear Your Label. (2017). *Wear your label*. Retrieved October 30, 2017, from <https://wearyourlabel.com/>