

ENVISIONING A GRASSROOTS FRAMEWORK FOR COMMUNITY-BASED
MENTAL HEALTH CRISIS INTERVENTION

By

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ABSTRACT

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The mental health and well-being of both individuals and communities are going to be best served by community-based services and care completely unreliant on traditional top-down models that often include inaccessible services and/or coercive methods. This is especially prevalent in the case of mental health crisis intervention; where most state-based interventions involve coercive agents who often are not given any specific training on mental health crisis response. As mental health crisis and suicide rates continue to rise in the U.S., and even the most well-respected model of crisis intervention has done little to resolve the issues of prisons serving as short-term mental institutions, we must turn away from the State and towards theories of community organization and radical justice. By exploring the conclusions of these theories and the impact of groups that have attempted new models of community-based mental health support and crisis intervention, we can envision something new, something that might one day serve as the framework for future models of care.

Key words: mental health, crisis intervention, suicide, Crisis Intervention Teams, police, community organization, radical justice theory, mutual aid, care webs

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CHAPTER 1: INTRODUCTION

Saugus, MA

On the afternoon of Saturday, August 15th, 2021, three Saugus Police Department officers were dispatched to the home of 38-year-old Stephanie Gerardi. Gerardi had a history of mental illness, and her sisters had called on the Saugus Police Department multiple times in the past to try to get her some help. Gerardi was diagnosed with bipolar schizophrenia in her early 20's, and had been forcibly placed in mental health institutions several times prior. This was what Stephanie's sister, Stacey, was hoping would happen again when she called 9-1-1 for support. Stephanie's other sister, Deanna, opened the door for the three officers shortly after 4:30pm.

Minutes later, Stephanie would be shot three times in her kitchen, just a few feet away from Deanna. Stephanie was pronounced dead on the scene.

Conflicting reports of whether Stephanie was holding a knife or not, or whether she was threatening the officers with it or not, serve to muddy the waters of culpability. But one thing remains true: a young woman, a mother of two young children, needed mental health care in a moment of crisis. Instead, she was shot and killed. (Sweeney, 2021).

Santa Ana, CA

A little over a month later, on the other side of the country, police were dealing with a standoff that had begun with a stolen vehicle report originating in Anaheim on Tuesday, September 28th. 34-year-old Brandon Lopez had taken his girlfriend's car after a fight, which she had reported to the police as stolen. When Lopez's car had stalled out

in some gravel, he was surrounded by the Santa Ana Police Department, who would later be relieved by Anaheim SWAT.

Also arriving on the scene was Jonathan Hernandez, a Santa Ana city councilman and a cousin of Lopez. Hernandez was also a trained mental health counselor, and offered to help de-escalate the situation with information he had about his cousin's mental state. Lopez suffered from an undisclosed mental illness, and needed mental health care. Instead, Hernandez was rebuffed and ignored by the officers on the scene. He would later refer to the officers as unprofessional, aggressive, and disrespectful.

As night fell, SWAT officers deployed chemical agents to force Lopez out of the vehicle. As he did, he was shot multiple times, and was killed.

When later asked if the police department had dispatched any mental health professionals to the scene, they stated that they had a Crisis Negotiator on the scene. According to Hernandez, it appeared that it was this person's job to point a sniper rifle at Lopez's vehicle and shout threats at him.

Hernandez spoke out about the incident. "What it says to me is that police do not have adequate skills to handle a mental health crisis." Dale Galipo, an attorney hired by Lopez's family, would go on to argue the case for better response practices for mental health crises. "What's concerning," he would state, "is we're getting to the point where individuals who have loved ones in a mental health crisis are going to be afraid to call the police."

Hernandez was more direct and succinct. "A mental health crisis in the hands of the police equals death." (Mendez, 2021).

Pittsburg, CA

Police arrive on the fourth floor of the Hampton Inn on Wednesday, February 23rd, 2022. They had been called for a wellness check on Ashton Porter, who had broken out the window in his room and barricaded the door. According to family, Porter had been struggling with mental health issues, and in particular depression. Porter's family members are present, and are able to relay this to police officers.

The police call backup; in this case the department's Crisis Intervention Team, as well as the county's mental health evaluation and mobile crisis-response teams. A slew of mental health professionals, and specifically trained police officers, were now able to begin conversation and negotiation with Porter. These professionals, along with Porter's family members, spent the next few hours speaking with him and encouraging him to leave the room. Porter, for his part, refused to leave the room, denied needing help, and simply asked for "more time."

By nighttime, Porter was indicating that he wanted to "end it all", and that he was in position of a large butcher knife. The county mental health teams left, replaced by tactical team. Many hours passed as Porter continued to refuse to talk or open the door. By morning, the tactical team had deployed chemical agents in the room to get Porter to exit.

The end of this confrontation can be seen in police body cam footage.

"If at any point in time you want to tell you," an officer said, "we're going to make sure you come out and everything's safe and I can make you a lot more

comfortable.” Then, a warning. “But the longer you don’t listen to me, the worse it’s going to get for you. I’ve been nothing but honest with you.”

“I know,” Porter replies. “But I don’t feel safe.”

The officer responds: “The only safety you’ve got is listening to me.”

More chemical irritants are forced in the room. More conversations, mostly one-sided, attempting to convince Porter to exit. Finally, ultimately, Porter does open the door and step out. He’s holding a butcher knife in his hands.

Officers immediately fire non-lethal “beanbag” rounds into Porter, which do not appear to phase the man at all. He turns to a different officer and swings the knife up above his head. The officer fired his service weapon twice, striking Porter each time and causing him to fall to the ground. On-scene paramedics quickly rush to care for him.

Porter’s wounds were non life-threatening, and he was treated at the local hospital after being taken into custody. He would later be charged with five counts of assault on a public officer, misdemeanor charges that in total could bring up to five years in prison. As of this writing, Porter is currently being held on bail (six figures). There is no word on what, if any, mental health treatment he has received since the incident. (Kelly, 2022).

Lessons Learned

These are just three incidents in the thousands upon thousands of police responses to mental health crises across the county. According to the Washington Post, 1,572 people have been shot and killed by police in the middle of a mental health crisis since 2015. Stephanie Gerardi and Brandon Lopez are just two of the 147 deaths listed by their tracker for 2021. If there is a positive, it is that this annual count has decreased every year

since 2015. As of April 26th, there have been currently twenty-eight names added to this list so far for 2022, and it is perhaps fortune to thank that Ashton Porter is not counted among them (2022).

Still, there is a lot that we can learn from these three incidents. With the clarity of hindsight we can see the mistakes that were made, compassionate choices not taken, unnecessary force and unnecessarily resorting to deadly violence. Lopez was fleeing from officers due to an unrelated crime, but those responding did not seem to take Lopez's mental health condition into consideration at all. Gerardi was at home, standing in her kitchen in the middle of what should have been a routine wellness check; now she is dead. And even in the case of Ashton Porter, where specifically trained police officers and county mental health officials were sent in to facilitate communication, can we truly say that everything that could have de-escalated the situation was done? This was an incident that could be pointed to as a "success"; after all, Porter survived his injuries, and nobody else was physically hurt. Porter is alive, sure, but currently sits in prison, and may spend up to several years there as a result. Can that be counted as a "success?" And will it lead to better outcomes in Porter's future?

In this paper, I will be breaking down the state of mental health in the United States, as well as defining what a mental health crisis actually is. Then, I will explore and explain in greater detail the concept of the "Crisis Intervention Team" as mentioned briefly in Ashton Porter's incident, and limits to positive outcomes within these and other forms of coercive State interventions into mental health crises. In the following chapter, I will discuss a sample of non-State organizations and organizational models that have

attempted to address the issue of mental health crisis on a national (if not global) scale. Next, I will discuss influential works of disability justice and care webs, and how they may contribute to a better model of crisis intervention built at a community level. Taking all of these lessons to heart, I will then attempt to synthesize and envision a new model for crisis intervention. Finally, we will return to these three stories, and imagine new futures where those experiencing similar crises might receive better care from their communities.

CHAPTER 2: THE DECLINE OF MENTAL HEALTH

Introduction

There are many ways to define mental health; the World Health Organization refers to it as “a state of well-being in which the individual realizes (their) own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to (their) community.” (2014). Mental health difficulties, ranging from acute crises to chronic mental illness, represent individuals who are impaired, in some way, from contributing to their communities. Roughly one in five adults in the United States suffer from a mental illness, while over one in twenty U.S. adults suffer from what is termed a “serious” mental illness. (National Institute of Mental Health, 2022). And these statistics are trending up, not down. While not all mental illnesses, serious or otherwise, lead to a mental health crisis, and not all acute crises are the result of a mental illness, these facts would suggest that the rates of an individual crisis requiring (or seeming to require) outside intervention for the safety of either the individual in crisis or others would be relatively high, and are only likely to increase in the future.

The most likely first responders to such a crisis are typically law enforcement. As recently as 2000, the New York City Police Department reported responding to roughly 18,000 calls regarding what was then dubbed “Emotionally Disturbed Persons” or EDPs (Fyfe, 2000). This trend dates back to the 1960’s, when state governments were in a rush to close state-run psychiatric hospitals, and few if any local or community institutions sprung up to replace them. Police, prisons, and jails were all that were left. The

percentage of jail and prison inmates with mental illness skyrocketed during this time, and one survey conducted in 2010 found that nearly one in five prison inmates suffered from mental illness, the highest such rates in the United States since at least the mid-1800's (St. John, 2016). A number of high profile police killings of individuals suffering from a mental health crisis, from Elinor Bumpurs in Bronx in 1985 (Fyfe) to Joseph DeWayne Robinson in Memphis in 1987 (Connolly), led many reformers to ponder ways in which police interventions to mental health crises might be improved, or, possibly, replaced.

Defining and Exploring Mental Illness in the United States

It is difficult to define a mental health crisis without first defining mental illness. The National Institute of Mental Health defines a mental illness as any mental, behavioral, or emotional disorder, which can cause the individual either no impairment, to having a mild, moderate, or severe impact (disorders which cause a severe impact are defined by the NIMH as a Serious Mental Illness, as described in the Introduction to this essay). The NIHM's prevalence estimates include illnesses that are both recent and diagnosable as of the 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (also known as the DSM-IV). As has already been discussed, these estimates reveal roughly one in five U.S. adults suffer from a mental illness. It should also be noted that these estimates do not include developmental disorders, nor, more troublingly, do they include substance use disorders. While mental illness and substance use disorders are often considered co-occurring disorders (formerly known as dual diagnoses), substance use and abuse can be a significant contributor to a crisis requiring intervention,

and those individuals with substance use disorders but no co-occurring mental illness are not captured in these statistics (Substance Abuse and Mental Health Services Administration, 2016).

The National Institute of Mental Health (NIMH) maintains and regularly upkeeps data on mental health and illness collected from a number of measures, including the National Survey on Drug Use and Health (or NSDUH). In this preliminary data, we can already see that there is a significant gender difference in many of the measures reported. For instance, the NIHM reports that over one-in-five (21%) of adults in the U.S. report experiencing any mental illness, and one-in-twenty (5.6%) report experiencing serious mental illness, defined as “a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities” (2019). Less than half (46.2%) of all adults seek treatment for their mental illness, and even those with serious mental illness only sought treatment two-thirds (64.5%) of the time. Of those 52.9 million U.S. adults, only 46.2% received mental health treatment within the past year.

More troublingly, this trend is negatively correlated with age, as older American adults are much more likely to seek treatment than younger adults. Serious mental illness trends break down in exactly the same patterns, but with more extreme effects. The lifetime prevalence of mental illness in adolescents is even more extreme: nearly half (49.5) of U.S. adolescents aged 13-18 will have a mental illness, and nearly one in four (22.2%) will suffer a severe impairment (NIHM).

Mental Health and Mortality

Mental illness, for a number of reasons, also leads to significantly worse long-term health outcomes, as seen in mortality and morbidity rates. In 2016, suicide was the tenth leading cause of death overall in the United States; the second leading cause of death among individuals between the ages of 10 and 34, and the fourth leading cause of death among individuals between the ages of 35 and 44. In addition, in 2019 the United States saw 248% more suicides (47,511) than homicides (19,141) during the year. This problem is growing worse, not better; between 1999 and 2018, the age-adjusted suicide rate in the United States grew over 35%, from 10.5 suicides per 100,000 people to 14.2. The study also found that 5% of U.S. adults had serious thoughts of suicide (or suicidal ideation) during 2019, with those aged 18-25 experiencing suicidal ideations at more than double the rate (11.8%) of the total population. Those aged 18-25 had significantly higher rates of suicide attempts, at nearly four times (1.8%) that of the total adult population. Overall in 2019, 12.0 million adults had serious thoughts of suicide, 3.5 million adults made suicide plans, and 1.4 million adults attempted suicide (NIHM).

In 2010, the median adult life expectancy in the U.S. was 79 years. A study conducted and released in 2015 found that globally, the median reduction in life expectancy among those with illness was 10.1 years, and that our planet sees 8 million people die every year due to mental illness (Insel, 2015). This data gets even worse when looking at schizophrenia, often considered one of the most severe mental illnesses. While the adult prevalence of schizophrenia is less than 1%, their estimated median reduction in life expectancy is 28.5 years. To extrapolate, an adult in the U.S. with schizophrenia has a

median life expectancy of 50 (NIMH). That is about as low as the median life expectancy of a U.S. adult was in 1910 (Insel). Those suffering from schizophrenia are over a full century behind the average U.S. adult in terms of life expectancy.

What is a Mental Health Crisis?

There is no universal definition for a term like mental health crisis, as the terminology used varies by precinct and time period. For the purposes of this thesis, I will define a mental health crisis as an acute period of mental, emotional, and/or psychological distress experienced by an individual that, lacking proper intervention, is likely to lead to the physical harm of at least one individual, typically themselves but occasionally other people as well. This includes instances of self-harm up to and including a suicide attempt (completed or otherwise). What I seek to uncover is whether the models we will explore later mitigate or exacerbate the potential for harm within these situations, and theorize what a better model might look like.

Resources to help and support those with mental illness are dwindling, as more and more resources are devoted to bolstering police departments and the expansion of prisons and jails. Has the diversion of some of those resources to police Crisis Intervention Teams made a difference in the short-term and long-term outcomes for those suffering from mental illness?

CHAPTER 3: THE LIMITS OF STATE-BASED INTERVENTIONS

State-Based Model: Crisis Intervention Teams

The concept of the Crisis Intervention Team first originated in Memphis in the wake of the 1987 police slaying of Joseph DeWayne Robinson. This model seeks to train officers in de-escalation tactics best suited for individuals dealing with a mental health crisis, as well as connecting those officers (and teams) with local psychiatric professionals who could help not only in the field but also in making more appropriate referrals for individuals in mental health crisis than arrest and lockup (Connolly). In the intervening thirty years, the model has spread across the country and around the globe, and there have been CIT trainings in countries such as Uruguay, Greenland, Australia, and China. The reach and expansion of the CIT model is undeniable, but has it been more effective in producing better outcomes in police responses to mental health crises?

First we must answer the question: what is Crisis Intervention Training, and why is it considered a necessary supplement to traditional police training? To put it simply, CIT is specialized training to create teams, often working with local psychiatric professionals, to respond to mental health crises in a way that helps to de-escalate the situation and reduce the chances for harm to occur. Why is such specialized training necessary? There are a number of reasons, but the primary one is that traditional police methods of de-escalation, such as cornering individuals and making deliberate shows of force to intimidate subjects into the surrender, are far more likely to escalate the chances of harm when practiced on an individual experiencing a mental health crisis (Fyfe). One CIT researcher goes so far as to acknowledge that the “CIT concept is diametrically

opposed to the traditional law enforcement training” (Ellis, 2014). The “traditional law enforcement training”, then, leads to more escalations, and more situations involving harm, danger, and worst of all, death. A Washington Post study found that roughly one in four of the individuals killed by police officers in 2016 had a mental illness, and similar study in Minnesota found that between 2000 and 2016, 45% of those killed by police officers either had a history of mental illness or were experiencing a mental health crisis when they were killed (Connolly).

Perhaps the most compelling data for the success of the Crisis Intervention Team model comes from the place where it all began: Memphis, Tennessee. Memphis Police Lt. Col. Vincent Beasley speaks glowingly of the changes he’s seen in the city, where a full 15 percent of the sworn officers have completed the CIT training. Anecdotally, he has witnessed fewer negative outcomes, such as injuries to either the individual in crisis or to the officers responding to them. More quantitatively, the department received more than 18,000 CIT calls, and only three percent of those resulted in an arrest. The model also appears to be gaining the confidence and support of the community, as the number of CIT calls has steadily risen in response to greater outreach and education efforts (Connolly).

The other compelling data in support of the effectiveness of Crisis Intervention Team training relates to changing officer attitudes regarding mental illness and the mentally ill. The law enforcement field is notoriously heavily impacted by mental health stigma; police officers are more than twice as likely to die by suicide than to be killed in the line of duty (even when including traffic collision fatalities), and the culture cultivates

a feeling that admitting to a mental health issue is tantamount to ending your career (Casteel). Studies conducted by both CIT International (Connolly) and Horace A. Ellis in Miami (2014) have found significant changes in the perceptions, attitudes, knowledge, and comfort level regarding mental illness and the mentally ill as a result of CIT training. Ellis's study also found reduced arrests and incarcerations of individuals suffering from mental health crises after the implementation of CIT training at Miami's precincts. A full 100% of the officers who participated in Ellis's study admitted to having dealt with individuals with mental illness, and 80% of the participants admitted to having arrested a person with mental illness.

Other studies have painted a less rosy picture, particularly two studies performed by the team of Amy Watson, Melissa Schaefer Morabito, Jeffrey Draine, and Victor Ottati. The first study, conducted in 2008, also found strong evidence of the shift in attitudes and beliefs regarding mental illness in those officers who participated in the CIT training. However, they found no evidence that CIT training led to a significant difference in the number of arrests of people with mental illness. They also found that there was little assessment to draw from in finding which aspects of the training have the greatest impact on positive outcomes, and which aspects of the training do not produce significant results and can therefore be improved upon. Their second study, found in 2011, found results both more hopeful and more dire. This study compared the outcomes of police interventions of mental health crises by CIT trained officers in two distinct types of neighborhoods; ones with greater resources and availability of mental health services, and neighborhoods with little to no mental health resources. The study found

that in neighborhoods with greater resources, the CIT training did appear to have a positive impact on the short and long-term outcomes of police interventions in mental health crises. In neighborhoods without those resources, however, the CIT training did not have to have any significant impact on outcomes. This suggests that community mental health resources are a more significant factor in improving outcomes of mental health crisis interventions than CIT training are, or at least that CIT training is completely ineffective in areas lacking the resources needed to provide long-term care and support for those suffering from mental illness. Given the lack of local resources, even CIT-trained officers had little choice but to fall back on arresting individuals in crisis.

This is the argument put forward by a 2014 study of Crisis Intervention Teams in Philadelphia conducted by Jennifer Wood and Laura Beierschmitt. They find that the CIT training has produced a minimal but significant increase in positive short-term outcomes as a result of CIT training: fewer arrests, and more referrals to appropriate mental health care facilities. On the other hand, there has shown to be no significant impact on long-term outcomes, particularly the recidivism rates for the chronically mentally ill, whom the officers and mental health care workers interviewed by the study referred to as “regulars”. What’s worse, the researchers found that the care for these “regulars” tend to become perfunctory and routine; their mental health crises are always responded to in the same manner with the same outcomes, and there becomes little incentive to strive to find better long-term solutions for these individuals. Wood and Beierschmitt argue for “moving upstream” by building stronger relationships between municipal authorities to

create stronger and more available support systems and resources for preventative and long-term mental health care.

Furthermore, a great deal of research and theory have been conducted and crafted making the argument that members of law enforcement are necessarily a greater cause of violence within the community, not the answer or solution to violence. Much ink has been spilled regarding the proliferation of prison privatization and the enforcement of “broken windows” policing, all of which support the hegemonic, misogynistic, and racist agenda of white colonialism (Bierria, Kim, and Rojas, 2010). Andrea Ritchie’s *Invisible No More: Police Violence Against Black Women and Women of Color* (2017) documents a long and brutal history of racialized and gendered police violence that specifically targets underrepresented communities and populations. The simple fact is that some communities cannot and should not rely on the police for any kind of assistance, and particularly not in the instance of a mental health crisis. Both Elinor Bumpurs and Joseph DeWayne Robinson, victims of high profile police killings in instances of mental health crisis, were African-American, and police continue to not be held to account for their slayings of people of color across the nation. Is there another model, one which relies on the community and not the state for invention in situations which demand it?

Deinstitutionalization and the Rise of Prisons as Mental Health Institutions

The history of the mental health institution in the United States began in the early days of the 19th century, beginning with private hospitals instituting treatments and culminating in the first full institution specifically built for the purpose in 1814. These institutions adopted what was known at the time as “moral treatments”, where harsh

methods of restraint and isolation were replaced with gentler, more humane treatment. At the time, though, these treatments were only available in privately run institutions, often available only to those with the means to afford them. By the middle of the century, however, activists began advocating for state-run institutions using the same model to be made available to all those suffering from mental illness. By the 1870's, nearly every state in the Union had at least one such tax-funded asylum (D'Antonio, date unknown).

It was not long, however, for these state-run institutions to come under attack. They were quickly overfull and ultimately underfunded, and the "moral treatments" that had previously proven so effective on wealthy patients with milder symptoms proved largely ineffective in treating more serious chronic illnesses, such as dementia or schizophrenia. By the 1930's, the Great Depression meant the tightening of state budgets, and by the 1950's the psychiatric asylum began to diminish, to be ultimately replaced by private practices focused more on preventative care than in treatment of serious mental health illnesses and crises. But these private practices ultimately turned out to be nearly as economically inaccessible as the original system in the early 1800's. Throughout the remainder of the 20th century, and well into the 21st, those without access to care or treatment were faced with constantly dwindling state-sponsored supports, culminating in a massive increase in those with serious mental illnesses ending up in the only other state institutions that they had access to: jails and prisons (Treatment Advocacy Center, 2010).

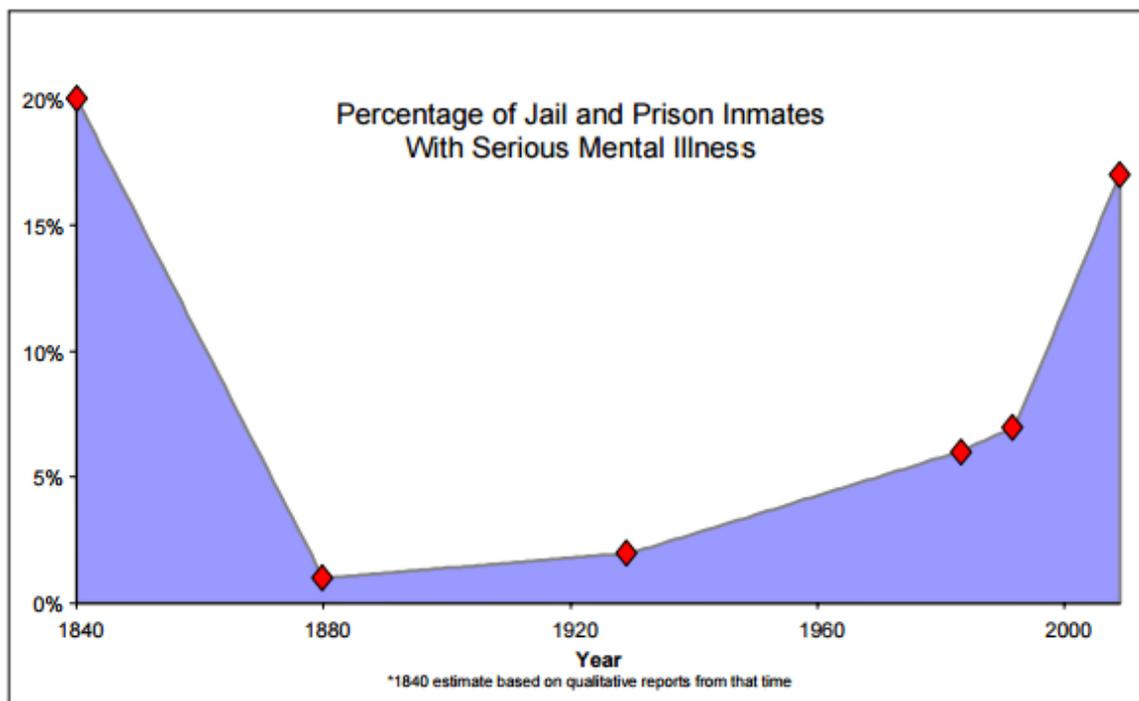


Figure 1. Percentage of Jail and Prison Inmates With Serious Mental Illness

This process, often referred to as “deinstitutionalization”, has led to demonstrably worse outcomes for individuals with serious mental illnesses, as well as demonstrable increases in the number of seriously mentally ill patients ending up within jails and prisons. As early as the late 90’s, psychiatrists and psychologists were noting the troubling trend:

“We have taken away from mentally ill persons the asylum from the pressures of the world and the care and treatment, however imperfect, that they received in state hospitals... The fact that a significant proportion of this minority are not receiving sufficient care but are instead living in jails, on the streets... is evidence that adequate community care has not been provided for some of the most severely ill persons” (Lamb & Bachrach, 2001).

By 2015, public-sector budgets for mental health support had cratered. In spite of both several federal laws demanding parity between physical and mental health insurance passed between the 1990's and 2010's, a noticeable gap remains. "Private insurance reimbursement for mental health treatment," writes E.N. Cromwel, "is still so poor that it discourages provider participation in plans and reduces consumer access to care," (2015).

In 1998, Dr. E. Fuller Torrey founded the Treatment Advocacy Center to research the criminalization of mental illness, the rise in the prison population of those with serious mental illness, and to advocate for changes within the law. This process has been complicated by the fact that there is no federal system or law pertaining to these issues. "We are effectively running 50 different experiments," states the organization's most recent report on "Grading the States" (Dalley, et. al, 2020). Yet despite their advocacy efforts, these problems have not only persisted, but in many ways been exacerbated by the passage of time. "The majority of states do not provide adequate support... for individuals with serious mental illness who have committed major crimes," states a 2017 report from the organization, leading to high rates of recidivism and re-incarceration. "Data indicate the magnitude of the problem is getting worse," the report concludes (Torrey, et. al.) Ultimately, there are now as much as three times as many seriously mentally ill persons in jails and prisons than in hospitals. As one TAC survey of the states succinctly concluded: "It is thus fact, not hyperbole, that America's jails and prisons have become our new mental hospitals" (Torrey et. al, 2010).

There are a number of factors, beyond de-institutionalization, behind this troubling trend. Nearly two-thirds of those arrested and sent to federal and state prisons

who had previously been on, and still required, psychiatric medication, were off of their medication at the time of their arrest. The numbers are worse for local jails, where 39% of inmates were off of their medication at the time of arrest, and only 46% remained or returned to medication after incarceration. This does not represent a small majority of the total prison population, either. Nearly 40% of the over two million US inmates (roughly 800,000 individuals) suffered from some measure of chronic mental health condition (Wilper et al, 2009). A 2018 study found that a number of common factors of incarceration, including overcrowding, punitiveness, lack of work assignments, lack of televisions, and significant difference from homes and/or families, were all factors in exacerbating the mental health of their inmates (Edgemon and Clay-Warner).

And yet, even if our prisons and jails could be reformed and repurposed into institutions deliberately engaged in producing positive mental health care (which is already a far cry from our current institutions), there is evidence to suggest that they still would not be particularly effective at that goal. Research into the efficacy of coercion-based treatment is rare, particularly in contrast to other methods of autonomous treatment. Many focus specifically on treatment of drug addiction, which, while sharing significant comorbidity with other serious mental health issues, is its own complex issue where many factors may not be shared by the two. For what shared factors do exist, one study did find that legal coercion has been linked with “poorer cognitive engagement in treatment”, lower meaningful participation, and lower attendance in non-coerced sessions (Urbanoski, 2010). With regards to specific mental health services, coercive treatment has also been linked with lowered self-assessments of treatment efficacy by the

individuals so coerced (Alan and McAlpine, 2018). While this issue does bear more intensive study, signs currently point to state-based coercion as a less-than-effective means of mental health treatment.

Conclusion

Compared to “traditional” police de-escalation training, Crisis Interventions Teams appear to provide clear evidence of a massive step in the right direction, leading to better beliefs and attitudes, fewer stigmas, and generally more referrals to appropriate resources. Unfortunately, not everyone has true access to these resources, especially in the case of those who need consistent long-term care in order to avoid future crises. Furthermore, without a greater commitment to expanding access to those resources, CIT training does not appear to have any significant impact on short-term or long-term outcomes. While preferable to police interventions that only serve to worsen existing crises, this training, at best, appears to limit instances of immediate harm, but does little to address the underlying issues that contribute to mental health crises. In addition, there is a significant amount of research and theory to suggest that in a number of communities, particularly within marginalized communities, police interactions are more likely to result in negative outcomes such as incarceration, injury, assault, or death; and as a violent wing of a violent state, law enforcement should not be trusted to protect against violence within these communities.

The fact remains that the true quantitative data is fairly scarce in regards to the effectiveness of Crisis Intervention Teams and essentially nonexistent. Even advocates for CITs describe the model as a “best practice,” but not “evidence-based yet”

(Connolly). And even if it was proven that CITs create better outcomes than previous interactions between police and individuals in mental health crises, does that mean that they are the best possible model, or simply one that is better, if only marginally? Or is it possible that such a model, no matter how well-intentioned and well-designed, will pale in comparison to the better short-term and long-term outcomes possible within a system that eschews the coercion of State entities entirely, and instead relies only on community resources?

CHAPTER 4: COMMUNITY CARE AND ALTERNATIVE MODELS

Introduction

Fortunately, not every group relies upon State funding (and are thus beholden to state coercion). Private groups, from the most radical collectives to groups of embattled professionals, have moved away from the models prescribed most often by the State and/or traditional psychology and psychiatry. In this chapter, we will discuss one of many models of collaborative community agreements, and explore several examples of activists and professionals working outside traditional models of knowledge regarding mental health in order to better serve people who are in need.

We will explore several models of community organizations and care in relationship to how they might improve mental health crisis outcomes. We will begin with a look at the organizational principle known as “Mutual Aid”, and move on to specific organizations, notably the *It Gets Better Project* and *The Fireweed Collective*. Finally, we will take a look into organizations that moved to make more traditional mental health inventions more easily and readily accessible through the use of phone and internet hotlines.

Mutual Aid

While there are many, many models for community organization, we will begin by looking at one of the most popular models: Mutual Aid. While often thought of as an organization in and of itself, Mutual Aid is instead an organizational *principle*, with smaller, local groups focused on their own communities, while still staying connected through the internet to other groups across the nation and world. First and foremost,

Mutual Aid describes a community system that supports itself and its members through solidarity rather than charity. To quote one toolkit:

It means we recognize that our well-being, health and dignity are all bound up in each other. It means that we understand our survival depends on cooperation, not competition... Rather than disengage and feel powerless, mutual aid allows us to plug in where we can make the most impact — locally (Ocasio-Cortez & Rama, 2020).

How Mutual Aid works, typically, is that it begins with a small group, usually no more than twenty people, who make a commitment to materially support one another when they are in need. Resources and skills of the individuals within the community are shared by the group as a whole. What it is definitively *not* is charity; Mutual Aid is not set up so that those with a lot can share their resources with those who are most in need. Every member of a Mutual Aid community pitches in to support the group as a whole.

In addition to charity, one other aspect that Mutual Aid communities try to avoid is the appearance of *quid pro quo*. While every member commits to helping each other through their own abilities, there is no demand for every member to carry an equal share of the support. While this may seem to be a distinction without a difference, where the difference lies is in *intent*. Farmer Ted is not sharing his crops with Jane because he expects Jane to help him fix his tractor later. He's also not sharing his crops with her because he has food and she doesn't. He's sharing his crops with Jane because that is what bolsters and

strengthens their community as a whole. There is no *expectation*. There is simply aid. Support. Solidarity. (Spade 2020).

This difference is critical, because it recognizes the value and worth of every individual member of the community. In Mutual Aid organization, every member of the community is crucial, and so every member receives the support and aid they need. Those lacking material resources, or the physical or mental capacity required to “work” within a capitalist framework, are still treated as having value to add to the community. Knowledge and skills that the capitalist project has not found a way to create profit from might be incredibly valuable within a community dedicated to solidarity.

This is best seen in the organizational work of Leah Lakshmi Piepzna-Samarasinha and her network of fellow disability activists with Creating Collective Access in 2010. Tired of the many anxieties regarding available access at conferences suffered through in private moments by her and those she had been connected to, she sought to create a Mutual Aid organization centered on the accessibility needs of her fellow conference attendees. She connected with folks with varying levels of ability and accessibility needed to work out what were termed “pockets of planned accessibility”; those who could drive offered rides to those who couldn’t; those who could read provided aid and direction to those who couldn’t. The project was a success, and was repeated several years at the same conference, though it ultimately grew too large to successfully manage and organize without large structural supports that just were not there. An attempt to create a similar group in the Bay Area ran into struggles, due to “realizing that people with chronic pain and fatigue can have a hard time providing for the care needs of

physically disabled folks.” However, in the lessons learned from these struggles, Piepznasamarasinha hit upon exactly how disability justice intersects with Mutual Aid: “...just because we can't always physically provide for each other's needs or know intrinsically what they are doesn't mean we can't support or be in solidarity with each other” (Piepznasamarasinha 2020). We will spend more time unpacking the ideas of Piepznasamarashinha in the following chapters.

For now, it appears that Mutual Aid presents a possible framework for a community care model of mental health. But we need to dive deeper into theory to really explore how this theoretical model might work, or possibly be improved upon, especially in response to mental health crises. For now, we will explore a small collection of alternative models of mental health care and support.

Spotlight on the Non-Profit Industrial Complex: The Fireweed Collective

The history of the *Fireweed Collective* begins not with its founding, but the foundation of an entirely different organization known as the *Icarus Project*. The *Icarus Project* itself was a radical mental health advocacy group that originated in the Bay Area in 2002. While many people were critical in the institution's creation, perhaps its most central co-founder was Sascha Altman DuBrul (DuBrul, 2014). A musician who had written an article about his own bipolar disorder, he soon found common cause with many others whose beliefs were counter to the traditional narratives around mental illness and psychiatry.

The Icarus Project eschewed traditional psychiatric models of mental health and “illness” and sought to redefine such experiences in much the same way as radical

disability and neurodivergent activists have. It defined itself as a “support network and education project by and for people who experience the world in ways that are often diagnosed as mental illness.” Their Vision statement more strongly defines their stance:

The Icarus Project seeks to overcome the limitations of a world determined to label, categorize, and sort human behavior. We envision a new culture that allows the space and freedom for exploring different states of being, and recognizes that breakdown can be the entrance to breakthrough. We aim to create a language that is so vast and rich that it expresses the infinite diversity of human experiences. We demand more options in understanding and navigating emotional distress and we want everyone to have access to these options, regardless of status, ability, or identity.

The Icarus Project helps us overcome alienation and tap into the true potential that lies between brilliance and madness. We are members of a group that has been misunderstood and persecuted throughout history, but has also been responsible for some of the world’s most extraordinary creations. Sensitivities, visions, and inspirations are not necessarily symptoms of illness, they are gifts needing cultivation and care. When honored and nurtured, these gifts can lay the foundation for a wiser and more compassionate society. As a mutual aid community, we intertwine threads of madness and creativity to inspire hope and transformation in an oppressive and damaged world.

As all long-standing institutions do, the *Icarus Project* began to grow, both across the United States and also, eventually, internationally. And as institutions do, it began to grow more hierarchical, and as it grew more hierarchical, it became more internally oppressive. According to the History page of the *Fireweed Collective*:

“Past leadership included many white cisgender men that didn’t fully understand how deeply mental health struggles are interlocked with many forms of oppression. The result was an oppressive organizational culture that harmed people of color, women and femmes, LGBTQIA+ and other marginalized folks. White cis men, particularly those affiliated with *The Icarus Project*’s New York City chapter, were the folks most often named in these grievances...”

Attempts at accountability were met with retaliation and stubborn refusal to make necessary changes. “It became clear,” they continue, “that in order to stop and heal these harms, we had to transition away from white cis men leadership.”

Thus, the *Icarus Project* and its various local chapters ultimately disbanded, and in its place rose the *Fireweed Collective*. Smaller, more nimble, and more committed to intersectional analyses. Contrast their new mission and vision statements to the above:

Mission

Fireweed Collective offers mental health education and mutual aid through a Healing Justice lens. We help support the emotional wellness of all people, and center the needs of those most marginalized by our society. Our work seeks to disrupt the harm of systems of abuse and oppression, often reproduced by the mental health system.

Vision

We strive to cultivate a culture of care, free of violence, where the ultimate goal is not just to survive, but to thrive as individuals and as communities. We envision a world in which all communities get to self-determine the source of their care, medicine, and wellness.

With the *Fireweed Collective* we see a much more consistent view of justice and anti-violence, and an opposition to “systems of abuse and oppression”.

Their new name was meant to embrace a different kind of metaphor. *Fireweed*, they explain, is one of the first things to bloom after a forest fire. A plant that “flourishes in scorched earth”, it nevertheless “[readies] the ground for new life to thrive.” While the dissolution of the *Icarus Project* definitely appeared to be acrimonious, and quite a bit destructive to the institutional supports that the organization could once depend on, it is their belief that their new institution is going to lay the groundwork for something new, something better. “We have decided,” they conclude, “it is time to put our wings away and direct our fire towards tearing down the walls of oppression.”

Rather than an organizational structure, they have a group of individuals that serve as “staff” that run the logistics of the organization. The staff is made up almost entirely of an “Education Team” that leads the drive to provide the kinds of education and resources that the *Icarus Project* was primarily known for. They also feature a single person in charge of “operations”, as well as a single person in the role of “Development and Partnerships”, whose focus is to “increase the capacity and scope of grassroots organizations, non-profits, and collective organizations”, which appears to be a signal that this new *Fireweed Collective* is intended to rebuild its network, this time through primarily grassroots justice organizations.

The *Fireweed Collective* sees itself as a vessel for social justice and a model for educating each other and the world about the incredible range of human experiences felt and embodied by those traditionally labeled as mentally ill.

Rather than treat such experiences as “illness”, they seek to re-imagine them as simply another form of human diversity and divergence. At the same time, they are welcoming and supportive of all manners of experiencing and dealing with what would normally be defined as mental health issues; this includes individuals who still refer to and believe in medical and psychiatric diagnoses, up to and including those who take psychiatric drugs and medicines. What they do not advocate for is allowing mental emotional distress to dominate or ruin lives: their main mission is, after all, “emotional wellness for all people.”

They are also realistic about the potential dangers and harms that come about when individuals find themselves in moments of crisis. To that end they have developed what they refer to as “The Crisis Toolkit”, a series of articles offering advice on how to prepare for a potential crisis you may later experience, how to prepare others to help you through that crisis, as well as advice on how to help others through crisis. Their most significant resource is a two-page pamphlet simply titled “Navigating Crisis”. This resource provides a wealth of extremely useful advice both for preparing for a crisis of your own or helping someone else work through their crisis.

The first section of the pamphlet refers to creating an Advance Directive. While not always respected as a legal document, this directive can help guide the responses of your friends and loved ones as they seek to help an individual through a mental health crisis. This includes sections helping to describe to others what it looks like when a person is in a crisis; which medications, treatments, and/or treatment facilities are preferred or unacceptable, and the reasons why those are; and instructions on how to

respond if the individual becomes a danger to themselves or others. This directive can become a powerful tool in a community's toolkit should the need arise for them to intervene in a mental health crisis without needing to rely on the "proper authorities", such as the police or a hospital.

The pamphlet also contains eight helpful suggestions, listed in a handy "Quick List" on the front page and explained in greater detail throughout the document. The first suggestion is to work in teams, and support one another through crisis care and invention. The second is try not to panic; rather than mirror the extreme emotional states of an individual in crisis, instead try to present a calmer and relaxed attitude. Third: be real and honest about what is happening; do not overreact, but also do not underreact either. Fourth: listen without judgment; people in crises can feel like they are not being heard or trusted to accurately explain their own experiences, which can contribute to a feeling of a loss of control, which in turn can exacerbate a crisis. Fifth: encourage the individual to get some sleep; a lack of sleep can exacerbate a crisis, and a restful sleep is often enough to bring an individual out of crisis. Sixth: consider that the crisis might be related to drugs and/or medication; this could mean starting a new medication, quitting a medication cold turkey, skipping or forgetting doses, or mixing prescription medications with non-prescription medications or illicit drugs to extreme effect. Seventh: create a sanctuary; a place where the individual feels safe and secure and is able to have their basic needs (food, water, cleanliness, shelter, rest, connection) met easily and quickly. Eighth: do not automatically call the police or hospital. This last point is interesting in that it echoes comments from earlier in the article that police are often ill-suited to respond to mental

health crises and may only make the situation worse, or create more opportunities for harm or danger. Still, the pamphlet encourages the reader to “[be] realistic, however, when your community has exhausted its capacity to help and there is a risk of real danger. The alternative support networks we need do not exist everywhere people are in crisis.”

Finally, the pamphlet makes the distinction that mental illness does not necessarily coincide with crisis, and neither necessarily coincide with suicide. They take great pains to caution against romanticizing extreme mental or emotional states and madness to the extent that the warning signs of suicide are missed. This section provides a few brief pieces of advice and words of encouragement for those who might be feeling suicidal or attempting to intervene on the behalf of another individual’s suicidal thoughts or behaviors. First, it reminds us that feeling suicidal does not mean giving up on life, but instead represents a desire and desperation for a change that seems impossible to obtain in any other method. Second, it reminds us that people who are suicidal are often socially isolated, and may just need to reach out and make a strong connection to someone, or to just have someone who can listen to them. Third, it reminds us that people experiencing suicidal desires often need to hear things that may seem obvious, simple words of encouragement and praise that can remind the person not only that they can be the person they hope to be, but that in many ways they already are. Finally, it reminds us that suicidal individuals are often under the sway of a critical belief or voice that lies to them about themselves. This voice may come in many forms, either external or internal, but it is often a highly critical voice that is not fully connected to reality.

Ultimately, this model consists of forming a sort of community-based Crisis Intervention Team, but with several key benefits over the police model. First, the team is built within the community and consists of friends and loved ones, not strangers. These teams know the individual intimately, and have a greater understanding not only of the person's history, but also their desires and wishes, whether through experience or through an Advance Directive. Second, by not being tied to any state, there is no risk of negative consequences associated with coercive state interventions of mental health crises, such as incarceration or involuntary hospitalization. Third, one does not need to face the risk of whether or not the first responder has received any kind of appropriate training for handling mental health crises, or whether they will instead rely on tactics and training that have been proven to exacerbate crises and lead to potentially greater risk of physical harm, injury, or death. Finally, by building such a community team this group is building and strengthening the relationships within the community that can set the stage for responding to greater threats of violence within and without the community, all without having to rely on state intervention and the significant possibility of introducing state violence and criminal "justice" to an already volatile or harmful situation.

Spotlight on the Non-Profit Industrial Complex: The It Gets Better Project

The *It Gets Better Project* would describe itself, first and foremost, as a LGBTQ+ advocacy organization, as it begins in its mission statement: "The *It Gets Better Project* fulfills its mission **to uplift, empower, and connect lesbian, gay, transgender, and queer (LGBTQ+) youth around the globe.**" (emphasis theirs). In fact, the terms mental health, depression, suicide, and bullying are nowhere to be found in either the

organization's vision or mission statements. The organization's roots, however, are absolutely steeped in the problems of queer teen suicide and youth gay bullying. The *Fireweed Collective*, on the other hand, is up front about its focus on both mental health and on advocacy, but it is a particularly radical group, having splintered from, and grown out of, a previous radical mental advocacy group. The mention of "health" within "mental health" is likely a paean made to the way such issues are talked about exclusively, and often reframe the issue as much as they are able to counter and deny the medical industry's role in a person's mental and emotional wellness. The *It Gets Better Project*, on the other hand, is about as mainstream as mainstream gets. Two of its most popular videos (its primary format for outreach) feature Ke\$ha and then-President Barack Obama. Its co-founder, Dan Savage, became practically a household name in the wake of the project's overnight success.

The *It Gets Better Project's* website boasts that over 630,000 people have pledged to support their mission. Their public Facebook page has nearly half-a-million followers, and their Twitter account nearly 200,000. Contrast this to the *Fireweed Collective*, whose website hosts no membership or pledge numbers to count. Their primary means of outreach and support, their private Facebook group, hosts only a little over 10,000 members, and its twitter account boasts just over 5,500 followers. When I refer to the *It Gets Better Project* as mainstream and the *Fireweed Collective* as radical, I mean more than just each organization's politics, but also their effective reach. The *It Gets Better Project's* most watched video has nearly 2.5 million views on YouTube. The *Fireweed Collective's* handful of half-a-year-old YouTube videos barely muster double-digit views.

The *It Gets Better Project* is a 501(c)3 nonprofit organization. It might bill itself as, more broadly, a LGBTQ+ rights and advocacy organization, but this is not its history. Its history begins not with an organization, a call to action, or even any kind of movement. It began with a single video made by two gay men: media personality Dan Savage and his husband Terry Miller. Their video rose in response to the high-profile suicide of Austin Aaberg, a 15-year-old openly-gay teen who suffered anti-gay bullying at his high school. Savage's initial thought upon hearing the news was "I wish I could've told him it gets better." And so, he and his husband made a grainy, eight-and-a-half-minute long video titled "It Gets Better: Dan and Terry", in which the two men describe their experiences with bullying growing up, and how their lives changed significantly for the better after leaving high school. The video was posted to YouTube on September 21, 2010. By the end of the month, Savage and Miller were inundated with hundreds of videos from other LGBTQ+ adults sharing their own stories and urging young queer students to stick it out, that it gets better. Bullied LGBTQ+ teens and their parents sent videos of their own stories. Before too long, it was no longer a video, it was a *Project*. By October 7th, Savage had created the *It Gets Better Project* website, with a call to action. The mission could not be more clear: "This site," Savage posted on its welcome post, "is a place where LGBT adults can share the stories of their lives with LGBT youth. It's a place where you people who are gay, lesbian, bi, or trans can see with their own eyes that love and happiness and reconciliation with their families are possibilities for them, too." Their motivations were also quite clear: "We despaired as we read about gay teens taking

their own lives, and didn't know how to reach out to these kids" (Savage and Mills, 2011).

The initial *It Gets Better Project*, then, was explicitly a repository of videos offering messages of support and hope to suffering LGBT kids in mental health crisis in an effort to address and reduce instances of queer youth suicide. But Savage's vision for the future of these videos extended beyond mere messages of hope, but also practical tips for surviving queer youth, as well as serving as role models and mentors. I think this is reflected in what the *It Gets Better Project* has become: "a major, multimedia platform capable of reaching millions of young people every year through inspiring media programming, a growing network of international affiliates, and access to an arsenal of community-based service providers." Its mission is now split between two primary methods, the first being the "Storytelling" from which the project got its start, and the second being "Building community" by "engaging with young LGBTQ+ people both on and offline, and... connecting them to local community service providers." The *It Gets Better Project* is not a direct action organization, and the throughline goal seems clear: to connect queer youth to stories of hope and to each other, in order combat the feelings of despair and potential suicidality that can be found in bullied LGBTQ+ teens. While the website's current depiction of itself, its vision, or mission do lack references to depression or suicide, it still mentioned in the introduction of the organization's 2019 Annual Report (Wenke & Levy, 2020).

It is important to note that the problem being addressed was more than just media sensationalism of a few photogenic white gay youth. Suicide has been a major issue

among young people; as of 2010, it was the 2nd leading cause of death in people aged 10 to 24. LGB youth (transgender and other queer identities were excluded from this dataset) were three times as likely to contemplate suicide and five times more likely to attempt suicide than their straight peers. A separate study of trans adults found that 40% of trans people had attempted suicide, and 92% of those had made their first attempts before the age of 25. Bullied queer teens were at even greater risk; those that faced rejecting families attempted suicide at eight-and-a-half times the rate of their LGB peers with accepting families, and *each* instance of bullying, violence, or abuse faced by LGB teens increased their odds of attempting suicide by two-and-a-half times, on average (Trevor Project). The *It Gets Better Project* leaves out actual data on youth LGBTQ+ suicide from its annual report, which one might expect to be included as a significant measure on the success of the project. The report instead focuses on its event and engagement numbers, which as we've seen are quite impressive. Equally impressive in the organization's most recent annual report is their financials; they reported nearly 150% growth in their revenue and support between 2018 and 2019, increasing from just over \$900,000 to \$2.2 million (Wenke & Levy, 2020). And while these are indeed measurable outcomes and impressive benchmarks, their report again leaves out the data on the key point of the institution: has queer youth suicide decreased?

Turns out, the answer is no. In fact, from 2009 to 2018, the U.S. suicide rate continued to climb year after year. 2019 actually has marked the first time in a decade that the U.S. suicide rate has dropped (Trevor Project, 2020). The picture is bleaker for youth. More than a third of all students and nearly half of female students reported

feelings of overwhelming sadness and hopelessness in 2019, a rate that had climbed steadily since 2009. Serious suicidal thoughts, make a suicidal plan, and actual suicidal attempts all also increased in youth from 2009. Though there was a significant (and hopeful) drop in 2017, that backwards trend reversed itself in 2019, with their highest numbers in a decade. While this study did not disaggregate data by sexuality or non-binary gender identities, there was evidence that students with marginalized identities were seeing their suicide rates increase at even larger rates. Female and black students saw their suicide rates increase, particularly since 2017, at much greater rates than males and students of other ethnicities (Center for Disease Control, 2020). Separate studies sponsored by the Trevor Project, who are critical of the CDC's lack of data on LGBTQ+ youth, do show that marginalized youth, and especially trans youth, have seen their rates of suicidality and suicide attempts increase as well (Trevor Project, 2021).

Can we say that the *It Gets Better Project* has been a phenomenal failure? Sadly, it is not that simple. Barring access to alternate dimensions, we have no control sample from which to judge whether the increase in suicidality and suicide attempt rates in queer youth would have been much worse had the *It Gets Better Project* never existed. It is probably fair to say that the *It Gets Better Project* has provided hope for some queer youth, and it is likely not a stretch to say that the project may have saved quite a few young peoples' lives. It would be hard to argue, then, that we would be better off without the *It Gets Better Project*. What can, and has, been argued thoroughly, is that queer youth would have been much better served by a *better* project. No matter Savage and Miller's best-selling book, and the scores upon scores of celebrities, gay and straight, all the way

up to the leader of the free world, were lining up to share their own videos of support and hope, it was still not particularly difficult to find criticism of the project, from multiple avenues. These range from calls to listen to queer youth and help them feel seen, rather than speaking at them; recognizing that not all queer people have happy and successful adult lives; the recognition that the passive voice “It Gets Better” name encourages privileged would-be allies not to help because it doesn’t seem like it needs it; the fact that queer communities face their own issues with discrimination and bullying, whether from a stance of racism or transphobia; and much more. Articles came out with headlines like “Let’s Not Pretend the Gay Community Has No Rifts” or the Psychology Today’s “It Won’t Get Better By Itself” (Eichler, 2010). A rival organization with a more active name and goal “Make it Better” rose and then briefly petered out and died, leaving little trace on the internet save a single introductory post made on October 8th (one day after *It Gets Better* went from a video to a *Project*). Sadly, none of these critiques really seemed to reach the mainstream. By the end October, President Obama had shared his own video with the project, permanently cementing the air of gravitas around it.

It was clear then that the *It Gets Better Project* was here to stay. It was popular because it was safe. It didn’t challenge anyone’s preconceived notions of the struggles of marginalization beyond the types of schoolyard bullying everyone could easily picture. There was no nuance, no racialized contexts; there was very little communication with actual mental health professionals, and finally and perhaps most important, there was no *call to action*. You can tell a child “it gets better” from your couch. Most importantly, you don’t have to do anything yourself to actually *make* it better for them.

Ironically, Dan Savage himself was aware of these shortcomings. In his introductory October 7th post, he explains:

“These videos on this site do not solve the problem of anti-gay bullying. We need to work on getting safe schools legislation passed in every state; we need to push for anti-bullying programs; we need to hold negligent school administrators accountable; and we need to confront the bigots and demagogues who inject hate into the national conversation about LGBT people and give straight children license to abuse and bully LGBT kids. All of that will take years of dedicated activism.”

Conclusion

We have seen how the State has failed to produce positive outcomes through its crisis intervention. By looking at larger non-State organizations that have attempted to address mental health crises, we can see their successes and pitfalls and take the lessons learned into the work of envisioning something new. We can see that it takes both direct action and mindful preparation in order to ensure greater positive outcomes. Smaller community-based models are able to more directly meet the needs of their members. While there can be no one-size-fits-all solution, we can still build a sample framework; one that provides flexibility while building on best practices developed by these organizations.

But the lack of truly successful large-scale institutions means that we cannot rely solely on the methods practiced by these smaller scale organizations, which have produced little in the way of truly measured results. Instead we must turn to theory to fill in the gaps in our evidence to envision something new.

CHAPTER 5: CARE WORK & DISABILITY JUSTICE THEORY

What is Disability Justice?

To begin this discussion we must first define what is meant by “Disability Justice”. It is easy to conclude that such a movement begins and ends at the most common and visible attempts at accommodating individuals with physical disabilities, in particular mobility issues. Some might think of accommodations for the hard of hearing, such as sign language interpreters. The key word here is “accommodation” and conflating efforts at expanding accommodations with disability justice would be a mistake. These are instead the hallmarks of the Disability Rights Movement, a movement that led to, among other things, the creation of the Americans with Disabilities Act. The relationship between the Disability Rights Movement and a movement for disability justice are complex and only occasionally in alignment. Primarily, the Disability Rights Movement established civil rights for people with disabilities. This meant protections against discrimination based on disability, as well as the ability to demand accommodations within public spaces. These were (and are) important steps in the process towards improving the lives of those living with disabilities. The downside comes from those who have been most invisibilized and left behind by these civil rights efforts.

To answer the question of what disability justice is and what sets it apart from its civil rights-focused counterpart, we turn to Sins Invalid, a collective of disabled performance artists working towards what it describes as disability justice. As to the question itself, they have no simple answer, no straightforward definition.

Foundationally, they look to the work of advocate and activist Aurora Levins Morales: “There is no neutral body from which our bodies deviate... What our bodies require in order to thrive, is what the world requires.” They provide four key aspects of a disability justice framework:

- All bodies are unique and essential
- All bodies have strengths and needs that must be met
- We are powerful, not despite the complexities of our bodies, but because of them
- All bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them

Tracing the history of the disability justice movement brings us to individuals, many of them disabled queer women of color, who found themselves disillusioned by disability rights activism that centered on primarily white experiences, to the exclusion and erasure of intersectionality and less common and/or invisible disabilities.

Furthermore, mainstream progressive and radical movements for social and racial justice often ignored disability or simply failed to address the oppressive nature of ableism within their activism. A “second wave” of disability rights was needed, and leaders stepped up within their communities to address this new foundation of disability justice.

Historically, such leadership found themselves local and ephemeral, isolated from like-minded peers in physical space, if not digital space. It is this ephemeral quality in particular that we will see multiple times as we discuss the activism of Leah Lakshmi Piepzna-Samarasinha and the formation of care webs. To quote Sins Invalid: “These

groups and organizing structures often come into being, fall apart and regroup with different names and configurations over time.” Larger, broader networks have been largely scarce, though we shall also examine one such network later this chapter.

Central to disability justice is the concept of intersectionality; the idea that able-bodied supremacy operates in relation to other systems of oppression, and cannot be addressed through single-policy politics. The language and perspectives of white supremacy are steeped in ableism, in the creation of “others” that are deemed “lesser” due to their perceived deficiencies. Such language also suffuses the heteropatriarchy, in particular pointing to queer and gender non-binary bodies as “deviant” and thus again lesser; less worthy, less able, less capable. This can be seen through the infantilism of imperialism, and through the domination of capitalism and the diminishment of the “have-nots”, particularly those who are deemed valueless (such as the houseless). All of these must be addressed simultaneously to achieve justice for all, including those with disabilities. Or as Sins Invalid puts it: “There is no way to stop a single gear in motion – we must dismantle this machine.” (2020).

Care Work & Care Webs

Leah Lakshmi Piepzna-Samarasinha is a queer woman of color and disability justice advocate, frequent contributor to Sins Invalid, and is the author of *Care Work: Dreaming Disability Justice*, a critical book in the intersection of disability justice theory and practice. In particular I want to highlight Piepzna-Samarasinha’s discussions of the community groups she had been a part of, several of these ephemeral groups that she refers to as “Care Webs”. She begins her essay on Care Webs as follows:

This is an essay about care—about the ways sick and disabled people attempt to get the care and support we need, on our own terms, with autonomy and dignity. It’s specifically an essay about some experiments that have taken place over the past decade by sick and disabled predominantly Black and brown queer people to create networks of care by us and for us. It’s about our attempts to get what we need to love and live, interdependently, in the world and in our homes, without primarily relying on the state or, often, our biological families—the two sources disabled and sick people have most often been forced to rely on for care, sometimes, well, often, with abuse and lack of control. (2018, 33).

Piepzna-Samarasinha discusses the activist and community spaces that she has found herself a part of over the years, without sugar-coating or papering over the difficulties and disputes, the “contradictions and the cracks”. She is quick to point out that “‘community’ is not a magic unicorn”. Her mission is to share the stories of QTBIPOC (queer and/or trans Black, Indigenous, and people of color) dealing with disabilities and trying to find their way both on their own and within their communities; where they’ve succeeded, and more importantly where they have failed in creating sustainable webs of care. She tells of webs both deliberately structured as well as organic; on care webs she says “sometimes we call them... collectives, sometimes we call them ‘my friend that helps me out sometimes,’ sometimes we don’t call them anything at all—care webs are just life...”

She continues to describe multiple models of care, developed in part on the foundations built by Loree Erickson and her model of a “Care Collective”. Erickson’s

model is itself based upon the concepts of Mutual Aid, and defines itself as broad network of friends and acquaintances that make themselves available to care for one another as they need. While a solid first step, a “deep possibility model,” as Piepzna-Samarasinha describes it, she is quick to point out that it is not a one-size-fits-all model. Not everyone has access to such a tight knit social circle, and in fact in many cases disabilities can exacerbate social isolation. Still others feel uncomfortable with the idea of relying on friends or acquaintances; those whose care might be seen as dependent on how well liked they are. As one friend of Piepzna-Samarasinha’s states: “I don’t ever want to depend on being liked or loved by the community for the right to shit in my toilet when I want to” (44-47.)

Other experiments discussed include Creating Collective Access, which began as a pop-up call for care and accessibility for those attending a conference in Detroit in the Summer of 2010 and grew into something stronger. It was “one of the first places [Piepzna-Samarasinha] ran into... cross-disability solidarity... the reality of our different disabilities not being a liability, that there could be was we supposed each other.” She describes one individual using “poor, cute cripple skills” in order to talk their way into the use of a communal kitchen, while another neurodivergent member without mobility issues hiked a mile and back to provide food for those who could not make the walk.

Contradictions of Care

Similar organizations, including a CCA founded in the Bay Area, grew and flourished and flamed out in equal measure. Problems would often arise in the form of interdependence, on expectations and ability, of guilt and disappointment. What did it

mean to be an acceptable member of such a community? An example is one of a member with physical disabilities asking for help moving; what of those unable to physically help due to their disability? What if they cannot afford to bring food as a means of support? What about those unable to help due to chronic fatigue, or illness, or simply cannot get out of bed, so as to even provide moral support? Piepzna-Samarasinha characterizes the issue, also discussed by Loree:

What happens when chronically ill folks—who often have fatigue, lack of physical strength, and a need to shift and cancel schedules as we get sick—try to assist physically disabled folks, who often need folks to be able to lift heavy things, and who may have pretty scheduled lives? ...We weren't always great at sitting with those contradictions with kindness and curiosity... Often, instead, we experienced the places where interdependence didn't just magically work out as betrayal, letting each other down (58.)

The result is breakdown after breakdown of once strong communities, as those so used to betrayal and being let down by those outside their community they never considered for a moment they would be let down by someone from *within*. With the value of hindsight, Piepzna-Samarasinha stresses the need for building towards resilience, an understanding that these questions will come up and that these struggles and setbacks will occur, and that compassion, understanding, and even humility play a huge role in creating sustainable communities. One example she gives of care webs not built for resilience are what she calls “emergency response care webs,” which she describes as often being built for when a formerly able-bodied individual experiences an acute disability; say a car-

accident or long-term illness. The result are able-bodied friends coming together to schedule whatever they can do to help. Potlucks, fundraisers, errand running! These care-webs largely begin with an unsustainable burst of energy and urgency, which begins to taper off before too long, regardless (or especially) if the individual's emergency disability becomes more of a long-term nature. Bitterness and frustration are likely to follow. These care-webs point not just to the unsustainability of urgent emergency systems of care, but of the need for able-bodied activists to truly begin to understand that the work they struggled through for their formerly able-bodied friend is the lived reality for many people with long-term and permanent disabilities. Most importantly, there needs to be an acknowledgement that like other forms of oppression, these issues are not individual but systemic, and that dismantling ableist systems is a necessary step on the path to justice.

World Wide Care Webs: SDQ

SDQ, or Sick and Disabled Queers, was a Facebook group launched in 2010 that attempted to take this model of care web nationally, if not globally, through a shared internet space. As Piepzna-Samarasinha describes it, it was mostly, for its time, a roaring success. The members of this group shared many things, both digitally and in many cases physically, through mailing extra medication and adaptive equipment, to running crowdsourced campaigns to pay for any number of needs, from replacement equipment to rehab to simple living expenses.

At its height, [SDQ] was everything good that social media made possible—instant connection with a million people with shared identities

and interests, who could listen to you when you were in crisis or answer a disability question that no one near you knew the answer to. It was a structure that broke two of the biggest barriers most disabled people face— isolation and shame. (61).

Critically, SDQ was a space free of the “activist stardom” that had plagued past community efforts Piepzna-Samarasinha had previously been a part of. Instead, it was a truly broad and crowdsourced network not just for care, but for sharing art, poetry, theory, and activism. Most importantly, its size made it sustainable over a long period of time; no one person was so depended upon that a member could lack capacity for care or response without shame or consequence; with so many to step up that no one would be let down or feel betrayed.

Sadly, Piepzna-Samarasinha does not elaborate on why the organization no longer exists, at least in its current form. There is little information to be found in cursory search as well. Instead, there are but a handful of much smaller SDQ groups that have risen in its place, located primarily in larger metropolitan areas, such as the Bay Area. Without insight on the dissolution of this space, there is little we can do to speculate as to why this amazingly sustainable group ultimately failed to sustain itself.

Lessons Learned

Piepzna-Samarasinha closes out her chapter with a short section of tools and pitfalls for those looking to replicate the types of care work she is describing. While she describes multiple pitfalls, they boil down to three key points. The first is in finding ways to avoid burnout. This is the most important aspect of sustaining a great network. She

recommends recruiting able-bodied folks who actually “get it”, “it” being the roadblocks of structural ableism and respecting the needs and abilities of all, as well as spreading the administrative load, such that one person is not handling all of the logistics of the web.

Second is checking assumptions at the door. When one lives their life as a sick or disabled person and has done care work or activism it becomes easy to assume one can be an “expert” in every specific need or aspect of care required within the group; this is patently false. Listening, believing, and respecting should always trump assumptions when it comes time to provide for others within the group. Finally, one must always keep an eye out for other dynamics of oppression to exert themselves within the web. This can often take the form of feminine individuals doing much more of the care work than masculine individuals; the same often goes for people of color doing more care work than white people. She recommends having a proactive plan for “checking in and making sure funky dynamics aren’t creeping [in]...” not just for these identity-based dynamics but also any feelings that can create tension and isolation within the group, such as expressions of pity, guilt, or martyrdom. Making sure boundaries are being consistently respected through care work is also essential. Any of these issues can evolve from slight interpersonal tension to massive, group-shattering conflicts that can become a bridge too far in keeping the care web intact and afloat.

CHAPTER 6: ENVISIONING THE MADNESS WEB

Prevention is the Best Intervention: Care Webs

One cannot have a complete discussion of mental health crisis intervention without addressing the role that preventative care plays. Professional mental health care can be inaccessible for any number of reasons, from cost to timing to philosophical differences. State intervention in crises can lead to coercive care, which limits individuals' autonomy and agency over their own care and progress, which can often have a deleterious effect on those dealing with severe mental health issues. Models of community care, on the other, allow individuals to maintain their own agency while still providing options for care and support in times of need, if not outright crisis.

Care Webs, as presented by Leah Lakshmi Piepzna-Samarasinha in *Care Work: Dreaming Disability Justice* provide a great blueprint to build off of. While envisioned by Piepzna-Samarasinha for creating groups of care and support for and by people with disabilities, it is not too far a leap to include those struggling with mental health issues within that framework. Alternatively, one could build a separate network dedicated to those who are mentally ill or “mad” can reach out to provide care and support for and to each other. Such a “Madness Web” would reach out to and recruit those most often left behind, exploited, or damaged by traditional and professional models of mental health “care.” As was often the case in the Care Webs described by Piepzna-Samarasinha, those mostly likely to fall into that category are, presumably, those already outcast or shunned by traditional society: queer, trans, Black and indigenous people of color (QTBIPOC), from those struggling to survive to leaders in activist spaces throughout their many

communities. The Madness Web would adopt the same Mutual Aid framework that Care Webs do; to each according to their need, from each according to their ability.

The structure of the Madness Web would be similar to that of the Care Webs described earlier. A membership primarily made up of those who struggle, whether routinely or intermittently, with mental health issues; as Piepzna-Samarasinha recommends recruiting a few able-bodied individuals who “get it” to participate in Care Webs, those who deal with only minor mental health issues, if at all, would also potentially be extremely helpful members of the community, for as much of themselves as they are willing to give of themselves. The Mutual Aid model means that care offered is never transactional, and care must be made to make sure that this key aspect of the web remains intact.

Care could take many forms, several of which cross over with work done by previous Care Webs, such as the sharing or mailing of needed but unavailable or inaccessible medications, ride sharing, and access to free resources that might be more in demand than for the general population, such as legal advice. In a lot of cases, however, especially for those suffering from severe depression or anxiety, mere presence can make a huge difference. Whether this is in the form of regular support groups, to someone who just really needs to not be alone; simply being there for a person dealing with mental health distress can go a long way towards preventing a potential crisis.

Sustainable Madness Webs - Building Community to Last

One notable trait shared by all of the Care Webs discussed by Piepzna-Samarasinha is that they all, eventually, went defunct. Even the nationwide Sick and

Disabled Queers (SDQ) Facebook group, to which she lauded for their longevity and sustainability, eventually ceased to function in its broader shape. While there is still no clear reason why SDQ broke up, we can perhaps turn to the lessons learned by the Icarus Project's dissolution. In many ways, the Icarus Project shares a lot of the same basic shape as the "Madness Web" I am envisioning in this chapter; an intersectional and nationwide community of support for those dealing with mental illness and madness. And its breakup mirrors many of the warnings Piepzna-Samarasinha gave regarding building for sustainability. As we know from the Fireweed Collective, the group that rose from the Icarus Project's ashes, the Icarus Project dissolved because leadership had turned a blind eye to the systems of racism, homophobia, and transphobia that were negatively impacting the Icarus Project's QTBIPOC membership. After refusing to address harassment and abusers from within, these members essentially imploded the Icarus Project. The resulting Fireweed Collective has been extraordinarily slow to rebuild, as much of the wind has been taken out of its sails, and many of the resources they relied upon were no longer available. Thus, it is important that, much like in our past example Care Webs, QTBIPOC activist leaders lend an intersectional approach to the work performed by the web, and monitor proceedings so that systems of oppression are not perpetuated within the group itself, and address issues when and where they may creep in before they fester.

A Madness Web might work well in conjunction with the Fireweed Collective, but the latter organization has spread itself thin, and has begun to dedicate much of its remaining resources towards education and activism. Important topics, to be sure, but

work that must be kept separate from a Madness Web in order to protect its members and its benefits from the types of burnout that can come with working with one foot in both spheres. A Madness Web must focus itself on caring for and supporting the members of its community, a mission that is both too significant and too fragile to entrust to those also doing the hard work of education and advocacy. Clearly, such individuals would still be welcomed into a Madness Web; activists and educators are going to be regularly in need of mental health care and support themselves, more often than not. But the work must remain separate; members of Madness Web should not be counted upon to provide work on the educational and advocacy tasks produced by the Fireweed Collective. This is a surefire path towards eliciting feelings of shame and guilt for those “not doing enough for the community”. Shame, guilt, and pity are common enough features of living life in the margins with a severe mental health issue; great care must be taken by the membership (or leadership) of such a Madness Web to mitigate any source of these deleterious emotions creeping in.

Local or Global?

While the national SDQ group no longer exists, I was at least able to find somewhat active SDQ groups with a local focus. Perhaps this is the fate of all national or global activist organizations; even the Icarus Project grew and thrived when it remained nearly exclusively within the Bay Area. Ideological divides are perhaps inevitable, and no activist or support space is immune from being infiltrated by bad actors and abusers who seek to take advantage of their status within the group. A smaller local group is ironically

better equipped to unite and deal with such divisiveness, whether through restorative justice or other means, in order to keep the group working well and with each.

But then, Piepzna-Samarasinha also described multiple local-based Care Webs that also ended up dissolving, and none of them lasted nearly so long as the wide-scale version of SDQ did. What are the lessons we can learn from that?

In my estimation, the best Madness Web is one that is global in nature, but assists its members in building local care webs of their own. The world is constantly shrinking, and between freely and widely available voice and video chat, the only thing missing from global presence is physical touch. A global web has all of the virtues that Piepzna-Samarasinha ascribes to the old SDQ; with so many members, there is always going to be someone who is (a) available and (b) able and willing to provide comfort, care, or support.

On the other hand, having access to a local, or even personal, care web is also essential to the wellbeing of every member of the Madness Web. Such a web can serve a different but no less important role in the health and safety of any mad individual, and will prove critical in the actual act of crisis intervention.

Preparing for the Worst - Advance Directives

The late Icarus Project has provided us with a lasting and living tool for dealing with mental health crises: the Navigating Crisis pamphlet we have previously discussed. While there are a lot of great tips for how to help someone through a crisis, many of which we will incorporate in our Madness Web's framework for crisis response, while we are still discussing prevention we have one last key element to discuss: the Advance

Directive. The Advance Directive is each person's best chance at making sure they retain as much agency as they can *during* a crisis. In this case, an Advance Directive is a guideline or series of instructions for you to determine before a crisis to help anyone who might be helping you during one. Provided examples include "Take me out into the woods," "Help me sleep with these herbs or those pills," "Make sure I can see my pets as soon as possible." The list can include a list of people to contact (or conversely, whom to not contact); a list of acceptable and non-acceptable medications, treatments, hospitals, doctors, etc. By providing as much of your own autonomy as possible in writing before a crisis ever occurs, you can give yourself the best chance to control the circumstances of your intervention even when you are no longer in control of yourself. As a result, writing an Advance Directive is a key necessity to provide for your personal Madness Web if you worry that you might suffer from a mental health crisis.

Personal Webs - Keeping Everyone Safe

Your personal web is composed of the members of the larger Madness Web that you most trust, and are most likely to be able to support you during a crisis. Having at least one or two local members, friends or loved ones, even if they aren't part of the broader Madness Web, can play an essential role in keeping everyone as safe and secure as possible. Your personal web, equipped with your Advance Directive, should have all of the tools necessary to react to your crisis with respect to your own autonomy, and without needing intervention by any State actors. It is critical that the personal web be a team, and a team that are comfortable working with and supporting each other. De-escalating and de-dramatizing a crisis is one of the best ways to end a crisis, and

overreacting, panicking, or bringing in any outside drama will only exacerbate the situation.

By maintaining a personal web, you can be physically supported by just a handful of your most trusted loved ones, while your broader personal web can provide additional advice and moral support to those physically supporting you. With this tiered process, you are able to keep a large enough team that you will be more likely to have someone to count on in any given moment of crisis, without also being physically overwhelmed by there being too many people in your presence. In the absence of anyone local being a part of a personal web, care can be made to allow those most trusted individuals to reach out through voice and video chat, though the lack of a physical presence can increase the danger of the arrival of coercive State agents.

The immediate goal of a mental health crisis is to end the crisis, and this can only happen in situations where the individual in crisis can be made comfortable. Creating a sanctuary for the individual, and ensuring that they are still being listened to with respect and without judgment, are some of the most important ways to help bring somebody down from a crisis. Failing that, sleep often works wonders, and many Advance Directives can benefit from providing a preferred method of toxicological sleep, either through pharmaceutical or herbal methods. Agency and autonomy throughout the process are still key, however. An Advance Directive is not a license to shove a Benadryl down a person's unwilling throat. Advance Directives allow the person directly responding to make the case that these were their own wishes, while remaining empathetic and calm in response to crisis. The terms agency and autonomy have been repeated frequently

through this chapter, and with good reason. You cannot de-escalate a crisis through force or coercion. This is largely the reason why police responders so often fail at de-escalating mental health crises.

Network Response - Debrief and Recovery

The crisis past, the role of neither the personal web nor the Madness Web are complete. For the personal web, the debrief is an important step in improving any potential crisis response in the future. With the virtue of clarity and hindsight, the individual themselves can discuss how they were made to feel throughout the incident; missteps, particularly endearing moments, etc. There is no such thing as a perfect crisis response, and it is the goal of the personal web to always do better by the individual they are in their web with.

A global debrief is also a significant step towards improving the crisis response of every member within the Madness Web, both in person and digitally. While privacy always is and should be the number one, there are ways to anonymize incidents, changing or providing false details to make it so nobody can “figure out” who it was (not that that should be of interest to anyone participating in a Madness Web in the first place!). While the final determination should always be on the person who lived through the crisis, every story told and debriefed improves the shared understanding of everyone involved. An assumption of perfect understanding, and a refusal to admit an inability to understand others in different situations, was one of the key downfalls of many of the groups discussed by Piepzna-Samarasinha. Every member of the Madness Web must set aside

their assumptions on what is universally best, and learn from each individual what is best for them.

CHAPTER 7: CONCLUSION

One Future of Crisis Intervention

The past cannot be changed. We cannot turn back the clock to create the support networks that Stephanie Gerardi, Brandon Lopez, and Ashton Porter needed to make it through their respective crises unharmed. All we can do is imagine a brighter future. Speculative fiction allows us to explore what a potential future might look like for individuals in similar situations, but with the benefit of being members of a large and widespread Madness Web.

Ripton, MA

Connie was worried.

Mandy had gone in and out of her bedroom several times, back and forth, for no obvious reason. But Connie knew the reason; her sister had been struggling with depression for years, and this manic pacing was how her suicidality manifested itself.

Connie took a moment to compose herself. She would be of no use to anybody panicking. Their youngest sister, Irma, was in the living room watching the television. Mandy's two young children were playing on the floor. "Irma," Connie said, trying to suppress the quiver in her voice, "why don't you take the kids to the park? It's a nice day outside."

Irma turned to Connie, her angry scowl making it clear she had no intention of leaving the couch. When Connie motioned her head down the hallway, however, Irma understood what was happening. Within moments, the tv was off and Irma was on her feet. "I'll text the others," she told her older sister, referring to the others who had come

together at the behest of Mandy to take care of her and keep her safe when her worst moods struck. It was a team that was created for just this type of occasion. They all knew that Mandy had no desire to return to any type of institution any time soon, and they promised they would work together to ensure she never would.

After they had all left, Connie made her way back down the hallway. “You doing okay, hon?”

“Yeah,” came Mandy’s broken voice, this time from the kitchen. It was clear she had been crying. Connie made her way down the hall and into the kitchen, where Mandy sat at the dining table. She was holding a steak knife.

“What’re you up to?” Connie asked, trying to remain as casual and conversational as she could.

“Hungry,” Mandy replied. She was twirling the tip of the knife along the edge of her finger. “We don’t have anything though.”

“What do you want? I’ve got some DoorEats credits we can use. C’mon, whatever you want.” That was a lie, of course, and DoorEats was probably going to be too expensive, but Connie knew that Sam or Charlie would be good to pick up and drop something off if it were necessary. She silently cursed herself for the deception though. She knew she ought to be honest and respectful. Something to think about next time.

Mandy only shook her head. “No, I’m not actually hungry.” Connie knew better than to call her out on the contradiction.

“How’s about we put the knife away, then?” Connie asked. She was nervous to point it out, hoping that it wouldn’t escalate the situation. To her surprise, it didn’t.

“Sounds good,” Mandy said. She stood, pushing her chair back in and walking to the knife drawer. She opened it with a grunt; it often stuck; and gently placed the knife back in. She did not, however, close it. Instead, she kept her gaze locked on the contents of the drawer; knives of varying shapes and sizes, cobbled together from however many gift sets and thrift stores they had assembled them from.

“What’cha doing, hon?”

“Just looking at the knives.”

Connie gave herself permission to scrunch her face in consternation, as her sister had her back to her. Connie struggled for what to say, something she could do to get her sister out of the kitchen.

That was when “Frontstreet Back” began blaring from Mandy’s room. She had set the boy band anthem as her ringtone as a joke after a particularly rowdy night of karaoke. Connie blushed from embarrassment, but steeled herself as best as she could. “You gonna get that?”

“Probably just spam,” Mandy said in a dry monotone. She had not moved an inch, her gaze still transfixed on the open drawer. They sat in awkward silence as the song played out for a moment before stopping. Only a few moments later, another embarrassing song began to fill the kitchen, this time from Connie’s own phone. As soon as she saw who was calling, she answered immediately.

“Hugh, how are you?”

This got Mandy’s attention. Rattled from her stupor, she closed the drawer with a slam. “Why is Hugh calling?”

“Here, let me put it on video.” Connie fiddled with the buttons on her phone, and soon Hugh’s giant toothy grin filled the screen. “Where’s my favorite girl?” he asked in that thick Brooklyn accent. Hugh was one of Mandy’s best friends, another member of that FaceSpace group, as well as a member of Mandy’s support team. She couldn’t admit to understanding what made them such great friends, but she couldn’t deny that he was a great influence on her. If anyone could bring her sister down, it was Hugh.

Mandy’s face was fairly overcast, but the call had definitely had an effect, and she quickly grabbed Connie’s phone to speak with her friend. Connie decided it was best to give her some space, and went into Mandy’s room. The room was a mess; Mandy had probably trashed it earlier. The least she could do was help tidy up; give Mandy a clean and comfortable space to rest in. After several minutes of cleaning, another noise wrested Connie from her own stupor; Mandy’s loud, infectious laugh traveling down the hallway. She poked her head out to check in on her sister. Tears still rolled down her face, but she was smiling now. The worst was over.

She picked up Mandy’s phone, cleared the missed call notification, and opened the texting app. “Everything’s fine,” she typed, sending the text off to Irma. After a few minutes, the phone dinged, a text from her younger sister. “Kids are having a blast, will be home soon. Charlie wants to know if he should stop by with some burgers.”

Connie’s stomach rumbled. She responded in an instant: “YES!”

What We Can Learn

The Madness Web is an idea that requires a strong social and community bond, both in physical local space and digital online space. The realities of mental illness, of

“madness”, can make building these structures, or committing to the needs of the structure, all the more difficult. From LGBTQ+ individuals who have been disowned and abandoned by their families, to those financially struggling so hard with food and shelter and other necessities that having access to online spaces on a regular basis, even the most open and welcoming Madness Webs can be inaccessible. In our story above, Mandy had many privileges that might otherwise elude the chronically mad; a home, a close-knit family, a cell phone. And each of these privileges was critical to her successful intervention. Regular access to a Madness Web might be considered a luxury by many whose economic realities force them to focus on direct survival. And yet, each year in the United States tens of thousands do not survive their mental health crises, and even state-sanctioned interventions still lead to hundreds of preventable deaths.

The Madness Web cannot simply be one person’s individual connections. It must be welcome to all those who identify as mad, who struggle with mental health crises, and in doing so build a new community, of friends, family, and strangers alike. Its members must reach out to those most vulnerable, to envelop them within the web, to understand their realities do the work to shore up those vulnerabilities. It is hard, social work, but it is work that must be undertaken if we wish to see our suicide rates drop and our interventions in general providing better outcomes for all those who need them.

Further Consideration

Several topics ended up outside the scope of this paper, but will need to be explored in greater depth in the future if the Madness Web is to be built upon the strongest possible foundation. The most critical issues to undertake are the

professionalization of mental health care and the establishment of non-professional mental health care and treatment. In order to grow beyond crisis intervention to crisis prevention, a Madness Web must work to dismantle the idea that only professionals with years of expensive education and training can provide mental health treatment, and only those who can afford upwards of hundreds of dollars a session ought to be able to access it. Long before we had clinical therapists, we had communities, and we can build those again.

Another source for future study is in the sustainability of large-scale organizations of care. Neither the Icarus Project nor the Sick & Disabled Queers groups survived long term without fading into smaller, less accessible groups. Perhaps this cycle, from small-scale to large-scale back to small-scale again, is an inevitable part of community organization. Perhaps there are ways to make a larger organization more sustainable in the long run. A more comprehensive study of these and other groups might hold the key to unlocking greater resilience within large-scale efforts of community in action.

Finally, while we have touched on the idea of a post-crisis debriefing as an aspect of the Madness Web that can help lead to healthier and safer outcomes for the chronically mad, this is also a topic that demands further study and consideration. It is not enough to save a life in the moment; building better outcomes for the future must be an essential part of the web's work.

In Conclusion

Our current structures of mental health care and crisis intervention are failing hundreds daily, killing some and leaving many, many others in worse situations than they

originally were. A Madness Web, a Care Web specifically designed for mental health crisis prevention and intervention, is our best bet at creating a new structure for crisis intervention that allows for the agency of the individual and places their humanity first, while also setting them up for greater successes and better outcomes in the future.

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