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CaIMHSA Program Partner Spotlight: Disability Rights California and Community Clinics Initiative

At age 23, Alice Washington received a diagnosis she was told was “dismal.” The diagnosis sparked a long road to recovery for Alice and decades later she says her schizoaffective disorder is “in remission.” But the trauma and pain she experienced as a result of misinformed attitudes about mental illness still linger.

Fear of being labeled with a mental illness – and the resulting discrimination in housing, employment, education and healthcare is a primary reason many with mental health challenges do not seek help.

For Alice, a graduate from Stanford University, misperceptions about mental illness resulted in unemployment, lack of housing and incarceration. Decades later, she has full-time employment and is living in recovery.

Combating the attitudes and behaviors that stem from misconceptions about mental health and mental health challenges is the drive behind CaIMHSA’s stigma and discrimination reduction initiatives.

Mental health stigma prevents individuals from seeking care and establishes barriers to employment, education, healthcare and housing for millions of Americans living with a mental illness. CaIMHSA program partners, Disability Rights California and the Community Clinics Initiative are leveraging their expertise and breadth of knowledge to combat mental health stigma and discrimination to improve lives and lower health care costs.

Disability Rights California

For over 35 years, Disability Rights California (DRC) has worked to fight injustices against Californians with disabilities. DRC began its advocacy for people with developmental disabilities in 1978, and began to work on issues for people with

There are three major categories of mental health related stigma: **Public Stigma, Institutional Stigma, and Self-Stigma.**

“**Public Stigma**” refers to the attitudes and beliefs of the general public towards persons with mental health challenges or their family members. For example, the public may assume that people with psychiatric conditions are violent and dangerous.

“**Institutional Stigma**” refers to an organization’s policies or culture of negative attitudes and beliefs. For example, stigma is often reflected in the use of clinical terms, such as a “schizophrenic.” It is preferable to use “people first” language, such as “a person experiencing schizophrenia.”

“**Self-Stigma**” occurs when an individual buys into society’s misconceptions about mental health. By internalizing negative beliefs, individuals or groups may experience feelings of shame, anger, hopelessness, or despair that keep them from seeking social support, employment, or treatment for their mental health conditions.

From the Disability Rights CA Fact Sheet on Stigma
<http://www.disabilityrightsca.org/pubs/CMO401.pdf>



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mental health disabilities in 1986. Since then, the organization has fought tirelessly to combat mental health stigma and discrimination in the State of California.

“Based on our work in the community through legal representation, self advocacy, training and outreach, we know mental health stigma presents significant barriers to the rights of millions of Americans living with a mental health disability,” said Margaret Johnson, Disability Rights California Advocacy Director. “As an advocacy organization, it is our greatest concern to advance and protect the rights of people with disabilities and ensure all people with disabilities enjoy the power of equal rights and opportunities, dignity, choice, independence and freedom from abuse, neglect and discrimination.”

Many examples of mental health discrimination exist; some neighborhood groups have organized to block housing for people with mental health challenges (Not In My Backyard or NIMBYism) and almost a quarter of U.S. employers reported in 1995 that they would dismiss someone who had not disclosed a mental health disability.

Working with CalMHSA, Disability Rights California is implementing a threefold information campaign that combats misinformation with facts. Through their CalMHSA partnership, DRC is developing a series of [fact sheets](#), [trainings](#) and public policy papers. A peer [advisory group](#) consisting of community members and mental health stakeholders informs their work. The fact sheets and Power Point presentations of some trainings are available on the [DRC website](#).

Disability Rights California’s three-year contract with CalMHSA addresses stigma and discrimination by:

- Examining laws and policies and developing related fact sheets
- Providing training to the public about legal rights of Californians with disabilities
- Recommending needed changes to discriminatory laws and policies
- Distributing culturally relevant and age appropriate fact sheets and training materials

DRC will also build capacity to continue the work after the funding term.

Two examples of DRC’s work include development of a filter to analyze proposed legislation to determine if the legislation tends to discriminate against people with mental health disabilities or tends to reduce stigma and discrimination, and a policy paper identifying best practices in first responder training.

The filter is a series of questions to help a legislator or their staff analyze the discriminatory impact of legislation on people with mental health disabilities, in hopes that they will oppose discriminatory legislation and support legislation that reduces stigma and discrimination. The filter is currently in development and is expected in 2013. The tool is believed to be the first of



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its kind to specifically address mental health issues. “This filter is an objective tool to examine legislation and determine if there are any biases in the proposed bill,” said Margaret.

DRC project staff are also developing a policy paper that will examine first responder training related to people with mental health disabilities and will make policy recommendations based on the information gleaned. The paper is expected by 2014.

Further, Disability Rights California is collaborating with CalMHSAs program partner, Community Clinics Initiative, to disseminate information about mental health discrimination in health care provider settings. Community Clinics Initiative is combating mental health stigma and discrimination in the health care provider setting through the [Integrated Behavioral Health Project](#). The IBHP is an initiative to accelerate the integration of behavioral health services and primary care in California. The goal is to identify and elevate program elements, strategies, and treatment approaches leading to successful integration of mental and physical care.

Community Clinics Initiative- Integrated Behavioral Health Project

On average, people with serious mental health conditions are dying 25 years earlier than the general population and medical outcome studies reveal that depression results in more functional impairment than chronic diseases such as diabetes, arthritis and angina. (*Wells et al., 1989*)

But the stigma of being labeled a “mental patient” still exists and prevents many people from seeking help in specialty mental health services. A national survey found that 32% of undiagnosed, asymptomatic adults would likely turn to their primary care physician to help with mental health issues; only 4% would approach a mental health professional. (*National Mental Health Association, 2000*)

These astonishing statistics shed light on the urgent need for an integrated health delivery system in which primary care clinics, mental health agencies and substance abuse programs work together to coordinate the detection, treatment, and follow-up of both mental and physical conditions for individuals.

“We know from interviews and the literature that primary care physicians typically are not trained in the diagnosis and treatment of mental health issues and, therefore, are not prepared or are uncomfortable treating people with these issues. Similarly, mental health and substance use professionals are not trained to screen for and address physical health issues,” said Karen W. Linkins, PhD and Director of the Integrated Care Project. “Integrated care approaches emphasize the need for increased understanding of the mind-body connection, and training among primary care, mental health, and substance use providers in screening, identification, treatment, and referral approaches to improve access and quality of care.”

Integrated care has a long history of support by national and peer-reviewed research and was endorsed by the National Institute on Medicine. “The integrated care model is the optimal way



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to provide health care services because it produces better outcomes and promotes greater access and quality care.”

“We know integrated care works,” said Karen. “The challenge is re-shaping the health care system to deliver care that works for those with mental health challenges.”

To facilitate this shift, the IBHP completed a needs assessment, developed a [toolkit](#) and [website](#), and continues to collaborate with health and behavioral health care providers and conduct trainings. Over one million people have visited the website and the toolkit continues to receive favorable reviews. The kit provides practical, operational advice through forms, strategies, prototypes and best practices for an integrated model. Tailored to counties, the toolkit can be adapted to other locales and will be updated to meet the needs determined in the initial survey.

“The integrated care model saves money,” said Karen. “By matching an individual with the appropriately trained provider, we are creating efficiencies in the system.”

California’s health care system will not dramatically change over night. It will take dedicated time and perseverance from organizations like IBHP to transform our health delivery system to one that considers mental health and substance use on par with physical health. This approach is proven to reduce the mental health stigma that prevents millions of Americans struggling with mental illness from receiving care.

Twenty years after her diagnosis, Alice has a rewarding career, is an active mental health advocate, and effectively manages her mental illness. “They gave me a dismal diagnosis and over the years I proved them wrong,” said Alice. “It’s important to note not just that we *can* recover, but we *do* recover.”