# THE VOICES OF HOMELESS PEOPLE WITH MENTAL ILLNESSES



## LOCKED OUT

A REPORT BY THE
COALITION ON HOMELESSNESS, SAN FRANCISCO
SUBSTANCE ABUSE MENTAL HEALTH WORK GROUP
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A big warm thank you to all the righteous volunteers who made this study possible.

Survey Takers: Jane Kahan Bert Connell Chance Martin Allison Laurette Spanglet Pattie Yost Frank Vallecillo Ronnie Eagles Hal Garner Jack York Mike Wise Bill Hirsh Mara Raider Johnnie Durden Patricia Knox Jennifer Friedenbach Mark Williams Lionel Kelly

Writers:
Laurette Spanglet
Allison
Chance Martin
Marykate Connor
Jane Kahan
Jennifer Friedenbach

Technical Assistance:
Dr. Harvey Feldman
Tia Martinez

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#### EXECUTIVE SUMMARY

The Coalition on Homelessness, through its Substance Abuse Mental Health Work Group, interviewed 282 homeless men and women at shelters, self-help centers, food lines, drop-in centers, health clinics and welfare offices during the months of April and May in 1999. The survey was primarily conducted by volunteers who had themselves experienced mental illness and homelessness. This survey was done to gain insight on the mental health treatment system from the perspective of homeless people who have mental health issues.

#### Mentally III Homeless People Want Treatment

224 or 92% of the people who responded said that if a program was designed that met their individual needs, they would enter it.

#### One Third of Those Who Tried To Get Services Didn't Get Them

When we asked our survey respondents if they had ever tried to access mental health services in San Francisco, 152 responded 'yes' (63% of respondents). Of the 152 people who attempted to voluntarily access services, a shocking 47 or 31% never got any.

#### People Keep Trying To Get Treatment

37% (93) of those who had tried to access services, tried in the last year.

Of the 105 respondents who did manage to get mental health services, 25 or 24% of respondents received treatment for less than a month. An additional 26 or 25% of people were in treatment for 2 - 6 months. Comparatively, only 24 people or 23% received treatment for more than ten years

#### Treatment System Fails More Then It Succeeds

More then half (51%) reported a negative experience with the mental health system.

Of the people who specified a negative experience, the most common comment was that the process for entering treatment was too cumbersome and that it took too long. Other common reasons were negative interactions with staff, denied medications, denied treatment, or kicked out of treatment.

#### Mentally III Homeless People Know What They Want

Housing (179 or 63%), counseling (171 or 61%), and medication (148 or 52%) were cited as the top needs in treatment services.

Respondents were asked what would be contained in their ideal program. There were fifty seven (57) comments wanting staff that would be caring and respectful.

Fifty-seven (57) participants also wanted to have treatment available on demand. Respondents in this category said the ideal program would have easy access, would serve them right away without a wait, or without being turned away. They didn't want a bureaucratic process that prevented them from getting the help they needed.

The third category of common responses for an ideal program was those that fell under the productivity category. Thirty-five (35) respondents called for a program that included work, recreational activity or some way to give back to their community.

#### INTRODUCTION

San Francisco states in its federal HUD report that the estimate of homeless men, women, and children exceeds 14,000. About 30% of those are mentally ill, often the most visible segment of the homeless population. They are seen everywhere - pushing shopping carts, sleeping in doorways, or asking for spare change.

This survey was done by the Coalition on Homelessness Substance Abuse Mental Health Work Group to get the perspective of homeless people with mental illnesses and to create a dialogue for understanding each individual's experience within the mental health system in San Francisco. We attempted to gain insight on the ideal mental health treatment program from each person's individual perspective. We wanted to ensure the voices of homeless people who have mental health issues are heard loudly and clearly.

Mental illness itself continues to be highly stigmatized. People suffering from this condition are often ignored and misunderstood. The result for many has been homelessness, poverty and destitution.

The voices of those we interviewed were articulate, lonely, desperate, and most of all, ringing clear. While individuals had diverse and varied needs, it was apparent that each person knew exactly what they needed to get healthy and off the streets. In order for the City to succeed in assisting individuals, policy makers must stop and take the time to listen. Until the needs of people, not funding, are placed at the center of the system, the system will fail.

If the City funds and creates programs based on people's needs, then treatment will be successful and the City will not incur the higher costs associated with untreated mental illness. Untreated mental illness often leads to higher hospitalization, social service, lost productivity and unnecessary criminal justice costs.

We need a community based mental health treatment system that not only treats clients, but treats people who become clients with dignity and respect.

It's time to tear through the silence.

#### METHODOLOGY

It is important to note that these responses are not meant to represent a scientific survey, rather they are a reflection of what 282 homeless people with mental health issues want and need. There were many individuals who were not able to respond to the survey, because their psychiatric disabilities were too severe. These are the same people most often neglected by the treatment system. In addition, there are populations that are not represented here, such as Pacific Islanders, and others that are underrepresented, such as Latinos.

#### How the Survey Was Conducted

Mental health issues are highly stigmatized, and as a result this was a very difficult survey to undertake. We spent a great deal of time designing the survey in a way that we could gather the information we needed, while being deeply sensitive to the nature of this particular issue.

The survey was peer based with survey takers being people who have mental health issues themselves and who are or had been homeless. Surveyors targeted sites where people without housing congregate, although very few sites contained people who suffered exclusively from mental health issues.

Part of the survey design was to never directly ask people if they had a mental health issue prior to interviewing them. Instead, we let people know that the purpose of the survey was to gather information from homeless people about their experiences within the mental health system. At that point, many individuals self identified as not having any illnesses, whereby the interview was terminated. We then used indicator questions to determine if someone had a mental illness, and discarded those surveys in which no mental health condition was indicated. This led to the elimination of 36 additional surveys, which left us with 282 usable surveys.

#### Who was Surveyed

We completed surveys during the months of April and May, 1999. Surveys were conducted at shelters, self-help centers, food lines, drop-in centers, health clinics and welfare offices.

#### Total Sites & # of respondents at each

Mission Rock Shelter	72	(23%)	Streets	11	(3%)
Tom Waddell Health Ctr	40	(12%)	United Council Food Prg		(2.5%)
St. Anthony's Food Prg	26	(8%)	Glide Food Program	8	(2.5%)
GA Office	29	(9%)	Mission of Charity Food	7	(2%)
Central City Hosp. House	20	(6%)	St. Anthonys Women Sh	5	(1.5%)
Haight Ashbury Food Prg	24	(7%)	Public Library	5	(1.5%)
Episcopal Sanctuary Shltr	16	(5%)	Senator Res. Hotel	4	(1%)
MSC-S Shelter	14	(4%)	Spiritmenders Drop-In	4	(1%)
McMillan Drop-In Ctr	13	(4%)	Swords to Plowshares	2	
A Women's Place Shltr	13	(4%)	SFGH	1	

The age of the respondents had a wide range, from 15 years of age to 84 year old. The majority of homeless people surveyed were between the ages of 36-50 years old; this group comprised 50% of the homeless people we spoke with. The remainder were almost evenly divided into 15-30 years old (32 or 11%) and 51 and older (51 or 16%).

Age of	Respondents		
15 - 20	4	46 - 50	54
21 - 25	8	51 - 55	27
26 - 30	20	56 - 60	13
31 - 35	43	61 - 65	8
36 - 40	57	66 - 70	2
41 - 45	56	70 +	1

The ethnicity of the respondents is as follows: There were 106 Caucasians (37%), 98 (35%) African-Americans, 16 Native Americans (6%), 14 Latinos (50%), 11 Asians (4%), and 10 (3.5%) mixed ethnicity, with the remainder as unknown/unspecified.

We interviewed 172 males (61%), 91 females (32%) and 8 transgenders (3%), and 11 unknown/undecided (4%).

#### EXPERIENCES WITH THE MENTAL HEALTH SYSTEM

"I was suícidal and dídn't get any services. I could have been dead."

- 47 year old Asian Male

We asked respondents if they had ever tried to get into the mental health system and if so, what positive or negative experiences they had with the system. While the answers were quite varied, there were some clearly startling findings.

#### Difficult Access a Major Problem

Access is the essential component in the delivery of mental health services to a population which is largely characterized as 'difficult to engage', and access is the biggest barrier for poor and homeless people seeking mental health treatment.

When we asked our survey respondents if they had ever tried to access mental health services in San Francisco, 152 responded 'yes' (63% of respondents). This also indicates there is a need for engaging outreach to the pool of people who need mental health treatment but haven't tried to access it for whatever reason.

Of these 152 people who attempted to voluntarily access services, a shocking 47 or 31% never received any. Men were significantly less likely to be able to access services, as 36.7% of men never received services after trying, compared to 18.2% of women. Of the age groupings, youth were the least likely to access services.

Ever Tried to get into treatment

Yes 152 (63%)

No 128 (37%)

We also asked people when they last tried to get into treatment. Of those who responded, a surprising 93 or 63% had attempted within the last year. This indicated that people have not given up hope, and are actively trying to enter treatment. 26 (17%) had tried one to two years ago, while those remaining tried three or more years ago.

#### Last Time Tried to Get Into Treatment

Less then one year from time of survey	93	62%
1 - 2 years ago	26	17%
3 - 6 years ago	16	11%
7 - 9 years ago	4	3%
More then 9 years ago	9	6%

Centralized intake procedures can often fail to accommodate homeless people's ability or inability to keep vital mental health appointments.

"The appointment was too far away and I forgot and never went back."

- 41 year old African American female

"I was not able to get an appointment, as the person referring me stayed unavailable and eventually I got disgusted."

- 36 year old African American male

Access to an adequate range of mental health services is an obstacle for those who are involuntarily committed as well, reflecting the critical burden on San Francisco's overcrowded psychiatric emergency services.

"I was arrested and taken to the psyche ward and turned loose the next day with no referral for continued care."

- 34 year old white female

#### Inadequate Treatment

Of the 105 respondents who did manage to get mental health services, 25 (24%) respondents received treatment for less than a month. After navigating the difficult process to receive treatment, and then to only receive it for a month is neither beneficial to the individual, nor to the health of the City at large. An additional 26 people (25%) were in treatment for 2 - 6 months. This indicates participants are not receiving the long term treatment necessary to address their mental health issues on a continuous basis.

The remaining respondents received treatment from 7 months to nine years, with 24 (23%) people having received treatment for more then ten years.

How Long Were Yo	u in Tre	atment?
Never Got In	47	30%
A month or less	25	16%
2 to 6 months	26	16.5%
7 - 12 months	13	8%
1 to 3 years	10	6%
3 - 6 years	10	6%
7 - 9 years	2	1%
10 years or more	24	15%

#### More Than Half of Respondents Had Negative Experiences

We asked people what their experience was with the mental health system. Sadly, more then half (51%) reported a negative experience with the mental health system. This is clearly an unacceptable level of dissatisfaction with a badly needed city service. There were dozens of reasons why people said they had either a positive or negative experience with the mental health system, which indicates we need diverse and effective treatment services to meet the varied needs of today's San Francisco.

#### Positive vs. Negative Experiences

Negative Experiences	104*	51%
Positive Experiences	99*	49%

<sup>\*</sup>Please note respondents could have multiple experiences and both positive and negative experiences

"The Psychiatrist broke confidentiality and damaged my credibility to get my children back"

44 year old African American female

Of the people who specified a negative experience, the most common comments were that it was too cumbersome of a process to access services, and that it took too long.

"I was trying to get back on medication and they gave me the runaround, and I wound up back in prison"

- 44 year old African American male

Of those who specified how the experience was negative, the second most common reasons were that they had bad interactions with staff, were denied medications, denied treatment, or were kicked out of treatment.

"I was asked to leave because the Psychiatrist said I was a trouble maker. I was trying to let people know what their rights were."

- 47 year old African American male

"The City Clinic treated me like a criminal for seeking mental health services"

- 37 year old white male

Most	Common	Reasons	For	Negative	Experiences
Denied	Meds/Trea	atment		9	
Bureau	cratic Proc	ess		8	
Bad Exp	perience w	ith Staff		6	
Kicked	Out of Tre	atment		5	

#### Less then Half of Respondents Had a Positive Experience

People had positive experiences with the mental health system as well. Staff/client relationships also played a large role in survey respondent's positive experiences. Of those who specifically described the positive experience, the most common response was that they liked the talk therapy (7). Also, numerous people mentioned programs that got them off the streets where they were able to deal with issues, and it was a safe and comfortable environment. This leads us to believe, that if done right, treatment does work.

"Treatment made me a better person, better outlook on life by helping me to deal with people in a more positive and progressive way."

- White male of unknown age

Most	Common	Reasons	For	Positive	Experiences
Talk Tl	herapy			6	
Safe a	nd Comfort	able Envir	onme	ent 4	
Empat	hetic Staff			3	
Able to	o Deal with	Issues		3	
Medica	ation			3	

### UNTREATED MENTALLY ILL HOMELESS PEOPLE WANT TREATMENT

Clearly, homeless people in San Francisco have diverse needs, as demonstrated by respondents describing what they felt an ideal mental health treatment program would be like. The results from this section of the survey indicate that people know exactly what kind of treatment works, what services they need, and how exactly they need to improve their health and exit homelessness. Listening to individual voices and building a system around the ideas and visions of homeless mentally ill people themselves is critical if we are to truly provide effective treatment.

Homeless people are often shunned and ignored by society at large. When we add to that the portion of homeless people who are mentally ill, we have one of the most vocally despised groups in our society at large. People with mental illnesses often have their opinions disregarded as "crazy", and are not perceived as being able to know what is best for themselves. The following results dispel that notion. Mentally ill homeless people know exactly what they need and what works.

#### Ideal Program

Homeless mentally ill people were asked what their ideal mental health program would be like. The responses were nothing short of stunning, and obvious in the face of the need.

"An ideal program would have people who don't treat you like crap because you're a drug addict"

- 41 year old white female.

The most common responses centered around the kind of staff the program would employ. After all, programs are made up of people, and programs are only as good as the people who work there. There were fifty seven (57) comments about the kind of staff that would be in their ideal program. In their own words, people wanted staff who are "dedicated, friendly, supportive, sympathetic, caring, patient, loving, non-judgmental, calm, and serious." There were calls for staff who had good time management skills, who knew what the respondents needed, who are at the "same mind level" and who would take the time to develop relationships with their clients.

"The ideal facility would have counselors that are caring and sympathetic, less apathetic"

#### - 47 year old African-American woman

For 57 participants, the ideal program would have treatment available on demand. Respondents in this category said the ideal program would have easy access, would serve them right away without a wait, or without being turned away. They didn't want a bureaucratic process that prevented them from getting the help they needed. These responses demonstrated that people in crisis should not be turned away and told to wait.

The third category of common responses for an ideal program was those that fell under the productivity category. Thirty-five (35) respondents called for a program that included work, recreational activity or some way to give back to their community.

"An ideal program would enable people to work and become independent. It is one which would not treat patients as dependent and helpless"

- 50 year old Native American woman.

Thirty-three (33) people said they wanted programs that were attached to a integrated set of services, such as hospital services, substance use treatment, dental care, follow-up and assessment. Twenty (20) people said the ideal program would include self-help or peer support, which consumer advocates have been urging for years. These included comments around self-government, and how beneficial it is to receive help and then return that help to people in similar circumstances. People wanted to develop support systems and friendships. Homeless people with mental illnesses would like to see their peers when they come for services -- it's reassuring and empowering.

Thirteen people (13) said they wanted a comfortable, safe environment for services to take place in. These individuals emphasized both ambiance and feelings of safety within programs.

Many respondents (12) wanted targeted services. They would like to see programs that target particular communities, such as women, seniors and youth. Significantly

more women targeted services, as 14% of women requested this, compared to only 3.7% of men.

"Give us a place to live, clothing, and food and therapy"

- 50 year old African-American woman.

#### Most Common Responses to Ideal Program Dedicated and Friendly Staff 57 On-demand/Easy Access & No Turnaway 57 Work and Recreation 35 Integrated Services 33 Subsistence Services 21 Peer Support/Self-Rule 20 Comfortable and Safe Environment 13 Individualized Services 13 Targeted Services 12

#### Mentally III Homeless People Know What Services They Need

Respondents were asked what services they would want in an ideal program. Almost all wanted comprehensive services, so that their needs would be met in a holistic manner. They felt the other needs in their lives were intimately connected to their mental health; in other words, they felt that a stable living situation was a prerequisite to managing their psychiatric issues.

"Don't put us in shelters, give us housing."

- 52 year old African American female

The number one item requested was for housing. One hundred seventy-nine people (179 or 63%) requested this. Many people saw housing as integral to their overall mental health and ability to become productive.

"Without housing people can't find work. This is the most serious problem. And without money, people can't find housing because of the high rents"

- 37 year old Asian male.

The second highest request was for one-on-one counseling. One hundred seventy-one (171 or 61%) respondents said the ideal program would offer this service. An additional one hundred forty (140 or 52%) people said the ideal system would offer group counseling. This was a theme throughout the responses - people want someone to take the time to listen to them, and assist them in addressing their issues.

The third highest request was for medication, with one hundred forty-eight (148) people saying the ideal system would offer medication. And one hundred thirty-eight (138) individuals said the ideal program would offer therapy. In summary, housing, counseling, and medication are the top needs for services in the ideal mental health system.

Top Services Mentally III	Homeless	People Want
Housing	179	63%
One on One Counseling	171	61%
Medication	148	52%
Group Counseling	140	50%
Therapy	138	49%
Diet and nutrition	137	49%
Job training and Placement	128	45%
Health Care	125	44%
Substance use Treatment	120	43%
SSI Advocacy	114	40%
24-hour services	110	39%

#### Mentally III Homeless People Want Help

Perhaps the most important finding of our survey is that mentally ill homeless people want treatment. This is an especially compelling finding given that the dominant message we hear in the media and from certain politicians is that homeless people with mental illnesses simply don't want any assistance. 92% of the people who responded said that if a program was designed that met their needs, they would enter it. Many gave reasons why they would enter it, including that they needed the help, that they felt they could help others in their ideal program, and that it would be beneficial overall. For the small number of people who would not enter an ideal program, they said they didn't need mental health treatment at this time, or they were already in treatment.

#### CONCLUSION

This survey provides us with an extraordinary wealth of information. The findings are revealing, informative and at times shocking. We must no longer ignore the needs of people suffering from mental health issues - it is high time to both expand and reform the mental health treatment system. The voices that come through in this report are calling for action, and as a community it is our obligation to respond. We cannot afford to wait.

The Coalition On Homelessness Substance (Ab)Use Mental Health Work Group (SAMH) will be looking to this survey to direct our advocacy efforts. We will continue to urge responsibility on the part of policy makers who in the position to create real change for mentally ill homeless people.