

# Alameda County Behavioral Health Care Services

---

Needs Assessment and Innovative Strategies  
to Support Isolated Adults and Older Adults  
Living with Serious Mental Illness

*Findings & Recommendations*

March 2012

by Focus Strategies and Korwin Consulting



## TABLE OF CONTENTS

Table of Contents.....	1
Project Summary .....	2
Target Population Profile .....	4
Needs of the Target Populations.....	18
Recommendations for BHCS Outreach and Engagement .....	19
Other Key Issues Identified .....	20
Appendices .....	22
Appendix A: (Removed from March 2012 "Findings and Recommendations" Report)	
Appendix B: Focus Group and Interview Summary.....	23
Appendix C: Literature Review .....	37
Appendix D: Methods .....	52
Appendix E: Summary Table of Datasets Used for Needs Assessment .....	55
Appendix F: MHSIP Results: Social Relations and Living Arrangements .....	56
Appendix G: Bibliography.....	61
Appendix H: Acknowledgments .....	65
Appendix I: About the Consultants.....	66

## PROJECT SUMMARY

Alameda County's Community Services and Supports (CS&S) Plan recognizes isolation as a critical issue for both adults and older adults with serious mental illness (SMI); for older adults it is identified as one of two top priorities. As the Mental Health Services Act has been implemented locally, many programs and efforts have improved the availability and quality of mental health services for underserved groups. However, for many of Alameda County's residents with SMI — including those living with family members, in board and care homes, or in residential hotels — their social isolation continues to be a significant barrier to services and a factor negatively impacting quality of life. Family members, in particular, have helped identify isolated consumers as an underserved population with unmet needs.

Focus Strategies and Korwin Consulting, in partnership with Abbott Consulting and Debbie Raucher Consulting, have prepared this report to help identify key characteristics and specific needs of this underserved population and to recommend learning questions and outreach strategies that may be effective with them. A variety of research methods, including focus groups with consumers and family members, key informant interviews, a literature review and analysis of population and service user data sets were used to prepare this report.

## POPULATION PROFILE

While recognized nearly universally as a critical issue, social isolation is not defined or measured consistently. It is also not a static condition, and persons with SMI may be more or less isolated at different times, based on both the severity of their mental illness and a number of personal and social factors. Due to these factors, estimating the prevalence of social isolation is challenging, however based on a number of studies using different measures of isolation, authors estimate that between 17% and 43% of persons living with a serious mental illness in Alameda County may be somewhat or extremely isolated from external social relationships and their community. Social isolation is known to be associated with other types of social barriers and forms of isolation, including economic disparities, racism and discrimination, language isolation, ageism and co-occurring disorders. Older adults, ethnic minorities, and limited English-speaking populations all experience higher rates of general social isolation.

## NEEDS

Strategies to reduce social isolation among adults with SMI should focus on the unmet needs of these individuals. Based on research for this project, key needs include:

- ▶ Opportunities for culturally/language appropriate positive social interaction and relationship building, starting in the home;
- ▶ Welcoming places to go and engage in social and recreational activities;
- ▶ Meaningful culturally/language appropriate activities in the community including skill building and opportunities to contribute through volunteering;
- ▶ Links to integrated health and behavioral health services, including mobile services for older adults and others with mobility difficulty; and
- ▶ Increased availability of quality housing and transportation.

In addition to the above, family members of isolated adults and older adults also identified specific needs for family support which include:

- ▶ Respite support, allowing caregivers to take a break from caring for their isolated family member;
- ▶ Recognition of their role and inclusion in treatment planning; and
- ▶ Assistance in planning for the future care of their family members.

## LEARNING QUESTIONS AND OTHER RECOMMENDATIONS

Isolated adults and older adults with SMI are a population about whom there is no widely accepted definition or measurement tool, limited research on best practices, and no set of consistently-employed service strategies. Well-designed Innovation projects can contribute to learning about what works to engage isolated adults within the community and in services.

Based on the information gathered, this report provides three types of recommendations and observations:

- ▶ Eight recommended learning questions are offered; each is designed to test an innovative outreach, engagement, support or training strategy that may be effective in identifying and reaching isolated persons, reducing their social isolation, improving their quality of life, and connecting them to appropriate behavioral health services.

*(NOTE: These questions have been removed from the version of this report titled “Findings & Recommendations, March 2012”)*

- ▶ Recommendations for other outreach and engagement strategies that can be incorporated into existing services and efforts to better reach the target population.
- ▶ A list of other issues and concerns identified in the course of the project that currently impact the experience of isolated adults and older adults or their family members.

Appendices provide detailed information about the sources of information used to prepare this report, including a discussion of methods used, summaries of focus groups and interview results, and a review of the literature on isolation and promising practices.

## TARGET POPULATION PROFILE

For this project the target population was defined by ACBHCS as “adults and older adults with serious mental illness (SMI), who are isolated and withdrawn, living with families or in board and care homes or hotels, and their families.” As described in the Literature Review (Appendix C), this description does not encompass a single well-recognized population group and includes people defined by a combination of characteristics including age, mental health condition, level of social engagement, and living situation.

For the purposes of this project, the defining characteristic of this population was presumed to be a profound lack of social connection and community interactions. The needs identified in this report are those of people with a serious mental illness (whether currently diagnosed or undiagnosed) who are disconnected from the community, have no or infrequent social interactions, and therefore may be referred to as “socially isolated.” Additional attention is paid to living situation, though the report recognizes that persons with SMI can be isolated in a variety of living situations.

## MEASURING SOCIAL ISOLATION

Unfortunately, there is no consensus definition of “social isolation” and different studies, authors and programs have used different metrics to quantify it. A 2002 international study defined respondents as socially isolated who answered “rarely” or “never” to questions regarding frequency of contact with friends, work colleagues, and other acquaintances in places of worship and in sports and cultural associations.<sup>1</sup> In this study, Americans had a very low rate of social isolation relative to many other countries, under 4%. A 2004 national study in the United States, however, deemed persons as socially isolated if they reported that they did not have a single person in whom they could confide or talk to about important matters. In this study, 25% of respondents were reported to be socially isolated (up from 10% of respondents asked the same question 19 years earlier.)<sup>2</sup> A medical study of persons living in Manhattan which defined social isolation as a lack of friendship networks (knowing fewer than three people well enough to visit their homes) found a prevalence of social isolation of 13.5%.<sup>3</sup> Still another study defines social isolation as “the phenomenon of non-participation (of an individual or group) in a society’s mainstream institutions.”<sup>4</sup>

It is widely documented in the mental health literature and asserted by practitioners in the field that persons with a serious mental illness often have reduced *social functioning* and are more likely to be, or become, isolated than the general public. Social isolation is both a risk factor for developing mental health problems and is frequently a result of serious mental illness. “For the general population, social isolation can be a downward spiral: feelings of exclusion affect morale, and lack of contacts with other

---

<sup>1</sup> OECD, *Society at a Glance: OECD Social Indicators—2005 EDITION* (Paris: Author, 2005)

<sup>2</sup> Duke Today, “Americans have fewer friends outside the family, Duke study shows” June 23, 2006 <http://today.duke.edu/2006/06/socialisolation.html>

<sup>3</sup> C. Rodriguez, M. Elkind, L. Clemow, M. Di Tullo, R. Sacco, S. Homma, B. Boden-Albala, “Association Between Social Isolation and Left Ventricular Mass,” *American Journal of Medicine*, (February 2011) 124(2): 164-70

people may reduce both social and economic opportunities.”<sup>5</sup> For persons with mental illness, isolation is also a contributing factor to worsened mental health and morbidity.<sup>6</sup>

However, researchers and consumers both point out that social isolation and loneliness are not synonymous — a person’s own perception of their level of isolation or support is typically seen as more important than any specific measure of frequency of interactions. Consumers in focus groups talked about their “right to isolate” and not necessarily wanting someone to impose social contact on them.

Finally, social isolation is not a static condition. Persons with SMI may experience periods of greater and lesser isolation, based on their own conditions and the contributing factors around them. Nonetheless, it was widely recognized that there is a portion of the population with SMI that experience a form of *chronic isolation* and that could benefit from specifically designed strategies to draw them out and engage them in social interactions and greater connection to the community.

## FACTORS CONTRIBUTING TO SOCIAL ISOLATION FOR PERSONS WITH SMI

**SYMPTOMS OF THE ILLNESS:** Many symptoms of major mental illness can cause persons to isolate themselves from others or to become isolated from others. These may include paranoia causing persons to withdraw, fear or unwillingness to be touched by or near other people, disassociation from the environment, hallucinations, anhedonia (a lack of experiencing pleasure), and severe depression or anxiety, either as a primary condition or in addition to another mental illness. Some people cited that the “internal life” of some persons with schizophrenia is more engaging than the external world.

**STIGMA:** Stigma acts to isolate persons with mental illness both by their treatment in the broader community and internalized stigma which may make them fear to seek social interaction. Most people do not know how to interact well with a person with outward signs of mental illness, and direct avoidance and even mistreatment is not uncommon. Some consumers’ physical appearance and personal hygiene may not reflect social standards and consumers may experience negative attention or avoidance as a result.

**MEDICATION:** While medications assist some to improve their social functioning, some medications may cause persons to become more withdrawn, lethargic or sleepy. “Overmedication” and/or side effects of medication were cited frequently by interviewees and focus group respondents as a reason for isolation.

**NEGATIVE EXPERIENCES WITH THE “SYSTEM”:** Consumers who have had negative experiences with the mental health system or other public systems may isolate themselves and avoid engagement with services or support. Care systems that use a “check box” approach rather than individual engagement to assess consumers are described as alienating and in the past many consumers have felt unseen or unheard. Consumers from ethnic communities especially report feeling that the system is not designed for them.

**SUBSTANCE ABUSE:** Co-occurring substance abuse is wide-spread among those with serious mental illness, including those who are isolated. While some persons who are using alcohol or other drugs find social circles in which to engage in their use, some consumers using substances to “self-medicate” do so

---

<sup>5</sup> OECD

<sup>6</sup> A. Christensen, R. Dornink, S. Ehlers, S. Schultz, “Social Environment and Longevity in Schizophrenia,” *Psychosomatic Medicine* (1999) 61: 141-145

privately. Participation in substance abuse treatment is typically de-isolating because most treatment programs include significant peer interaction, meetings and “sponsors.” However, relapse can result in rejection from the group and renewed or increased isolation.

## SOCIO-ECONOMIC CONTRIBUTORS TO ISOLATION

In addition to conditions directly associated with mental illness, a variety of other social and economic factors can contribute to the isolation of persons with SMI, or may create social isolation which is then a catalyst for depression or other symptoms of mental illness. These factors include:

**AGE:** Age is a significant factor in isolation, both for the general population and for those with a serious mental illness. Older people have typically left the workforce and may have lost many of the members of their social circle due to illness or death. Many have limited contact with their families. As they age, they often have increasing physical disabilities and/or chronic illnesses that reduce their mobility and ability to interact comfortably in the community. In addition, due to ageism, their treatment in society as they age often isolates them as they “become invisible” or are no longer taken seriously. In addition, older persons with long histories of mental illness have had more time to be impacted by the illness and also by treatments that may reduce their ability to socialize. Older persons are typically more impacted by internalized stigma and fear of being identified as having a mental illness. Age is a predictor for depression.<sup>7</sup>

**POVERTY:** Low income is associated with higher rates of mental illness and also with higher rates of social isolation. Lack of mobility, negative social images, and social support networks that are typically under similar pressures all contribute to greater isolation of those with low socio-economic status. Lower levels of education also are correlated with high rates of social isolation.<sup>8</sup>

**RACE AND ETHNICITY:** Racism and discrimination in the broader society contribute to the isolation of many ethnic groups and non-whites are at higher risk for social isolation than whites. Racial and ethnic minorities have less access to and availability of care, receive generally poorer services, and experience a greater disability burden from unmet mental health needs.<sup>9</sup> In addition, in some cultures, mental illness is typically not discussed, seen as shameful or not even necessarily recognized as existing, making persons with SMI isolated from members of their own culture.<sup>10</sup>

**LINGUISTIC ISOLATION /IMMIGRATION STATUS:** Mono-lingual speakers and persons with limited English often find it extremely difficult to interact in the broader community and have been demonstrated to have the greatest challenges receiving services. Repeated misunderstandings, both based on language and cultural differences, cause many limited English speakers to be isolated from community services. Persons who are undocumented may also isolate for fear of being identified and deported.

**LIVING SITUATION:** Where someone is living is a major factor in potentially being isolated. Housing situations that do not encourage social interaction (including some board and care homes and

<sup>7</sup> Does growing old increase the risk for depression? Roberts, Robert E.; Kaplan, George A.; Shema, Sarah J.; Strawbridge, William J. *The American Journal of Psychiatry*, Vol 154(10), Oct 1997, 1384-1390.

<sup>8</sup> Duke Today

<sup>9</sup> U.S. Department of Health and Human Services, *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General* (Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (2001).

<sup>10</sup> Alameda County Behavioral Health Care Services, *Revised Mental Health Services Act Community Services & Support Plan*, (January 17, 2006).

residential hotel settings) can “trap” people in their rooms or apartments. Neighborhood is also a factor as people may live in communities where they do not feel it is safe to be out of their home. This can include high crime areas but also may affect persons living in neighborhoods where they may be perceived by others as a threat (e.g. African-American men in affluent or predominately Caucasian neighborhoods.) Geography is also a factor, in that lack of access to transportation and long distances to services, supports or amenities can contribute to or exacerbate isolation.

## ESTIMATED SIZE AND DEMOGRAPHICS OF THE TARGET POPULATION<sup>11</sup>

It is very difficult to estimate precisely the size and characteristics of the target population. Despite consensus in the literature that social isolation is widespread among persons with a serious mental illness, there is little consistent information on the prevalence of those in the SMI population that may suffer from isolation. One study of people with schizophrenia indicated that 43% of study participants had no friends outside the family.<sup>12</sup>

The consultants spoke with many consumers, family members and advocates who variously approximated the size of the population at between 20% and 50% of persons with a serious mental illness. To attempt to estimate the size and characteristics of the population, the consultants used information from four sources: the 2010 Census, the American Community Survey (2005-2009), a data set generated from ACBHCS administrative billing database, and the results of the Alameda County 2009 Mental Health Statistics Improvement Program (MHSIP) survey. (See Appendix D: Methods for details on the data sets.)

In interviews with practitioners, social isolation was expected to be highest among those who have been in the mental health system longest. Based on the ACBHCS data set, 24% of those currently in the system have been enrolled for at least 20 years (enrollment is when electronic registration begins) and 51% of all those enrolled in BHCS services have been enrolled for more than 10 years.

In the 2009 MHSIP surveys, consumers were asked how often they see someone with whom they do not live. Thirty percent of adult respondents reported they saw someone either less than once a month (13%) or not at all (17%).<sup>13</sup> Consistently, between 15% and 20% of respondents who were asked a variety of questions about their quality of life responded that they felt “terrible,” “unhappy” or “mostly dissatisfied.” These included responses to questions about the frequency and quality of social interactions. This survey was given to persons engaging in mental health services; the rates of social isolation and dissatisfaction with social relations may be higher for persons who are not engaged in services (though there is no way to know this). (For more information on responses to specific questions in the MHSIP see Appendix F: *MHSIP Results—Social Relations and Living Arrangements.*)

For the remainder of this profile, a range will be used to show low and high estimates (17% and 43% respectively) of people with SMI to approximate the number of people who are likely to be socially isolated in Alameda County. The low end of the range (17%) is associated with the percent of people who indicated in the 2009 MHSIP that they never saw people they didn’t live with, and were dissatisfied

<sup>11</sup> Unless otherwise noted, demographic information on the population of Alameda County is from the U.S. Census Bureau, 2010 Census and information on the population of clients served by BHCS is from [an administrative dataset exported from the BHCS system on 10/27/11](#).

<sup>12</sup> W. Hirschberg, “Social Isolation among Schizophrenic Out-patients,” *Social Psychiatry*, (1985) 20: 171-178

<sup>13</sup> While this question was not included in the survey specifically designed for older adults, 27 older adults answered the adult survey, and 30% answered “not at all.”



with their level of social relationships and friendships. The high end of the range is the rate reported in the Frankfurt study of schizophrenic patients indicating that 43% of persons with schizophrenia had no friends outside their immediate family. Since persons with schizophrenia make up 47% of adult service users and 58% of older adult service, this figure is used as the high range estimate.<sup>14</sup> This figure also closely matches the high end of an Ohio study using combined functional assessments to create client clusters for program targeting. **Note that the use of this range still represents an educated guess and does not constitute a scientifically derived estimate.**

METHODS FOR MEASURING SOCIAL ISOLATION AND CORRESPONDING RATES		
General Population & Subpopulation	Isolation Measure	Percent Socially Isolated
Americans	“Rarely” or “never” see friends, colleagues or other acquaintances in places of worship and in sports and cultural associations	3.1%
Manhattan Residents	Knowing fewer than 3 people well enough to visit their homes	13.5%
Americans	Having no one outside of family in whom to confide, discuss important matters	25%
Persons With SMI & Subpopulation	Isolation Measure	Percent Socially Isolated
Alameda County Behavioral Health Care Service Users	Response of “not at all” to question about frequency of contact with someone you don’t live with	17%
	Response of “terrible” “unhappy” or “mostly dissatisfied” to questions regarding feelings about social relationships and amount of friendship	15-20%
Persons with Schizophrenia, (Frankfurt)	Compound isolation score based on number of social contacts both within the family and extra-familial	35%
	Percent with no friends outside the family	43%
Adults and Older adults with SMI in Six Ohio Counties	Functional assessment including variables for level of support from family and friends, independent use of community resources and participation in leisure activities	24-44%*

\*Measure includes more than social isolation to form clusters for better program targeting

In order to measure whether efforts undertaken through MHSA Innovations or other means are successful in reducing social isolation among the target population, a measurable definition of isolation will need to be adopted or created. The literature reflects a variety of measures that have been used including measures of the size of people’s social circles, frequency of social contacts, and individuals’ feelings and perceptions about the quality of their social interactions. Since no common definition exists, it is essential that BHCS define, or ask providers to define in advance, social isolation such that interventions can determine whether the participants began as isolated and whether they are successful at achieving the outcome of reducing social isolation.

<sup>14</sup> From an administrative dataset exported from the BHCS system on 10/27/11.

## ADULTS

All adults between the ages of 18-59 (referred to as “adults” for the remainder of this profile) make up 61% of the total county population. Adults with SMI using Behavioral Health Care Services account for about 1% of the total county adult population. The median age of adults receiving BHCS services is 43, although the mode (the most frequent age) is 50.

**Table 1: Adults by Geography**

Adults (18-59)	North	Central	South	East	Last address (out of county)	Total
County Population	389,629	217,514	194,793	121,114	N/A	923,050
Percent	42.2%	23.6%	21.1%	13.1%	N/A	100.0%
BHCS Adult Services Population with SMI	4,476	2,414	1,028	411	701	9,030
Percent	49.6%	26.7%	11.4%	4.6%	7.8%	100.0%

Sources: U.S. Census Bureau, 2010 Census and Alameda Co. BHCS administrative data 10/27/11

A larger percentage of adults receiving BHCS services are from north County, relative to County population, while a smaller relative percentage comes from south and east County. This disparity is largely based on the distribution of low income households in the County. Not surprisingly, representation in the mental health system by geography is closely associated with income. The 9,000 adults with SMI within the mental health system account for 2.4% of the population below 200% of poverty, but less than one percent of the overall County population.

**Table 2: Adults by Geography, 200% of Poverty**

Below 200% Poverty Level	North	Central	South	East	Last address (out of county)	Total
County Population	214,618	92,294	52,183	23,004	N/A	382,099
Percent	56.2%	24.2%	13.0%	6.0%	N/A	100.0%
BHCS Adult Services Population	4,476	2,414	1,028	411	701	9,030
Percent	49.6%	26.7%	11.4%	4.6%	7.8%	100.0%

Sources: U.S. Census Bureau, 2010 Census and Alameda Co. BHCS Administrative data 10/27/11

The Mental Health Services Act estimates that five to seven percent of the general population has a serious mental illness. We have estimated here that between 17% and 43% of these persons may also be socially isolated. Using the entire adult County population, more than 55,000 persons county-wide are likely to suffer from SMI, and at least 9,000 but possibly as many as 24,000 of them may be socially isolated.

**Table 3: Prevalence Projection: All Adults**

Adults 18-59	North		Central		South		East		Total	
Population	389,629		217,514		194,793		121,114		923,050	
Mid-point of Estimated Population with SMI (6%)	23,378		13,051		11,688		7,267		55,383	
Estimated range of SMI population experiencing social isolation (17% - 43%)	Low:	High:	Low:	High:	Low:	High:	Low:	High:	Low:	High:
	3,974	10,052	2,219	5,612	1,987	5,026	1,235	3,125	9,415	23,815

Source: Estimate based on U.S. Census Bureau, 2010 Census, MHSA and this report.

Looking specifically at the low income population that typically receive BHCS services, (below 200% of poverty), the total population of adults with a serious mental illness is estimated at nearly 13,000, while those who are also socially isolated is estimated to be between 2,000 and 5,400.

**Table 4: Prevalence Projection: Adults Below 200% Poverty**

Adults 18-59	North		Central		South		East		Total	
Population	124,101		48,342		26,957		11,560		210,959	
Mid-point of Estimated Population with SMI (6%)	7,446		2,901		1,617		694		12,658	
Estimated range of SMI population experiencing social isolation (17%-43%)	Low:	High:	Low:	High:	Low:	High:	Low:	High:	Low:	High:
	1,266	3,202	493	1,247	275	695	118	298	2,152	5,443

Source: Estimate based on U.S. Census Bureau, 2010 Census, MHSA and this report.

## RACE, ETHNICITY AND GENDER

As has been pointed out in many other reports, the ethnic breakdown of the BHCS adult population is significantly different from that of the County adult population overall.

**Table 5a: Alameda County Adult Population by Race**

African American	American Indian/ Alaskan Native	Asian/ Pacific Islander	Caucasian	Other race (or two or more races)	Total
194,135	8,002	383,322	709,450	215,362	1,510,271
12.9%	0.5%	25.4%	47.0%	14.3%	100.0%

Source: U.S. Census Bureau, 2010 Census

**Table 5b: Count Hispanic population**

Hispanic	339,889
Percent	22.5%

Source: U.S. Census Bureau, 2010 Census

**Table 6: BHCS Adult Services Population by Race/Ethnicity**

African American	Asian/Pacific Islander	Caucasian	Latino	Native American	Other/Unknown	Total
3,214	1,091	2,375	2,019	40	544	9,283
34.6%	11.8%	25.6%	21.7%	0.4%	5.9%	100.0%

Source: ACBHCS Administrative data, 10/27/11

African-Americans are vastly overrepresented among the services population in Alameda County; making up nearly 35% of the BHCS services population though only 13% of the County population. In contrast, Caucasians and Asian/Pacific Islanders are underrepresented. Native Americans and Latinos are represented in the services population at similar rates to their rate in the overall population.

Because social isolation has been strongly shown to be linked to poverty, race/ethnicity, and language factors, it can be assumed that the rate of social isolation among non-Caucasian ethnic groups and limited English speakers with SMI is higher than among Caucasians and English speakers. Disparities in treatment based on race and ethnicity are clearly documented. The Alameda County Community Services & Supports Plan notes specifically that Asian/Pacific Islanders and Latinos have high rates of linguistically isolated households (25% and 22% respectively). In the MHSIP survey, African-Americans most frequently responded “not at all” to the question of how often they visit with someone they do not live with (21.5%), followed by Asian/Pacific Islanders and Caucasians (both 16.1%), and Latinos (13.3%).

## GENDER

Females make up a slightly larger relative portion of the adult population in BHCS services than of the adult population.

**Table 7: County and BHCS Adult Population by Gender**

	Female	Male
Adults in the County Population	448,736	447,769
Percent	50.1%	49.9%
Adults in BHCS System	4,946	4,298
Percent	53.3%	46.3%

Sources: U.S. Census 2010 and Alameda County BHCS Administrative data

Responses to the MHSIP questions regarding dissatisfaction with social relationships did not vary greatly by gender, and gender and social isolation are more likely to be associated with older adults than adults. (See Living Situation section below.)

## LIVING SITUATION

For this project, certain living situations were considered to be part of the conditions that may isolate persons with SMI. Living situation information is collected in the BHCS Administrative database but is not always completed or updated. It also does not track specifically whether service users live alone, with family, or with others.

Most adult service users live in a house or apartment (46%) either alone or with others without “supervision.” The next largest group of service users (19%) lives in a house or apartment with support or supervision. This category may include both those who live with family caregivers and those who live in boarding facilities that are unlicensed. Just over 9% of adult service users with SMI live in a licensed facility including a board and care, or social rehabilitation. This category also includes facilities intended to be temporary. 12.4% were last reported as homeless or in temporary housing, and 12.1% are in a criminal justice related setting.

**Table 8: Living Situation—Adults**

Last Reported Living Situation for BHCS Adults							
0. Other	1. Justice Related	2. Homeless	6. Board&Care, SNF/ICF/IMD, Res/Social Rehab	7. House or Apt. with Support/ Supervision, Group Quarters	8. House or Apt.	10. Temporary/ Treatment Housing	Total
74	738	423	561	1,160	2,821	339	6,116
1.2%	12.1%	6.9%	9.2%	19.0%	46.1%	5.5%	100.0%

Source: ACBHCS Administrative data, 10/27/11

According to the MHSIP survey, approximately 17% of adult respondents were dissatisfied with their living arrangements, including 10% who responded “terrible” or “unhappy.” Close to one-quarter (23.1%) of adults were dissatisfied with the prospect of living in their current place for a long time.

Dissatisfaction by race and ethnicity ranged from 14.5% of API who were dissatisfied with their living situation up to 17% of Latinos, with Caucasians and African-Americans both reporting approximately 16%. Geographically, people living in North County were the most dissatisfied with their living situation (20.2%) while people living in East County were the least dissatisfied (12.2%). Central and South County respondents both reported 17.3% dissatisfaction.

Living alone is associated with greater social isolation (though it is not the same.) In terms of living with a partner, only 10% of adults in the BHCS system are married or living with a partner while 58% have never been married, and 16% are divorced, separated or widowed. In the general population, 46% of households are married couples and only 28% of households are people living alone.

**Table 9: Marital Status**

Marital Status of BHCS Adults with SMI						
Divorced or Dissolved	Married or Living Together	Never Married	Separated	Unknown	Widowed	Total
909	984	5,345	451	1,440	124	9,253
9.8%	10.6%	57.8%	4.9%	15.6%	1.3%	100.0%

Source: ACBHCS Administrative data, 10/27/11

## OLDER ADULTS

Adults age 60 and over (referred to as “older adults” for the remainder of this profile) make up 12.2% of the total county population. Older adults with SMI in the Behavioral Health Care system account for about 0.7% of the total county older adult population. The median age of an older adult in the BHCS system is 64.

**Table 10: Older Adults by Geography**

Older Adults (60+)	North	Central	South	East	Last address (out of county)	Total
County Population	105,805	60,974	49,769	30,052	N/A	246,600
Percent	42.9%	24.7%	20.2%	12.2%	N/A	100.0%
BHCS Older Adult Services Population	876	516	192	56	69	1709
Percent	51.3%	30.2%	11.2%	3.3%	4.0%	100.0%

Sources: U.S. Census Bureau, 2010 Census and Alameda Co. BHCS administrative data 10/27/11

As with the adult population, a larger percentage of older adults receiving BHCS services are from north county, relative to County population, while a smaller relative percentage come from south and east county. This disparity reflects the distribution of low-income households in the County.

**Table 11: Older Adults by Geography, 200% of Poverty**

Below 200% Poverty Level	North	Central	South	East	Last address (out of county)	Total
County Population*	36,123	15,446	12,394	4,744	N/A	68,707
Percent	52.6%	22.5%	18.0%	6.9%	N/A	100.0%
BHCS Older Adult Services Population	876	516	192	56	69	1709
Percent	51.3%	30.2%	11.2%	3.3%	4.0%	100.0%

Source: U.S. Census Bureau, 2010 Census

\*Note: the Poverty figures reflect the age category used by the U.S. Census Bureau, ages 65+, whereas BHCS defines older adults as age 60+.

Using the entire older adult county population, nearly 15,000 persons county-wide are likely to suffer from SMI, and at least 2,500 but possibly as many as 6,400 of them may be socially isolated.

**Table 12: Prevalence Projection: All Older Adults**

Older Adults 60+	North		Central		South		East		Total	
Population	105,805		60,974		49,769		30,052		246,600	
Mid-point of Estimated Population with SMI (6%)	6,348		3,658		2,986		1,803		14,796	
Estimated range of SMI population experiencing social isolation (17%-43%)	Low:	High:	Low:	High:	Low:	High:	Low:	High:	Low:	High:
	1,079	2,730	622	1,573	508	1,284	307	775	2,515	6,362

Source: Estimate based on U.S. Census Bureau, 2010 Census, MHSa and this report.

Looking specifically at the low income population that typically receive BHCS services, (below 200% of poverty), the total population of older adults with a serious mental illness is estimated at over 4,000, while those who are also socially isolated is estimated to be between 700 and 1,800.

**Table 13: Prevalence Projection: Older Adults Below 200% Poverty**

Adults 65+	North		Central		South		East		Total	
Population	36,123		15,446		12,394		4,744		68,707	
Mid-point of Estimated Population with SMI (6%)	2,167		927		744		285		4,122	
Estimated range of SMI population experiencing social isolation (17%-43%)	Low:	High:	Low:	High:	Low:	High:	Low:	High:	Low:	High:
	368	932	158	398	126	320	48	122	701	1,773

Source: Estimate based on U.S. Census Bureau, 2010 Census, MHSa and this report.

Again it is important to note that the Poverty figures reflect the age category used by the U.S. Census Bureau, ages 65+, whereas BHCS defines older adults as age 60+. It is also important to note that social isolation is likely to be even higher among older adults than adults, but no method for estimating the differential was found for this report.

## RACE, ETHNICITY AND GENDER

As with adults, the ethnic breakdown of the County is significantly different from that of the County older adult population.

**Table 14a: Alameda County Older Adult Population by Race**

Caucasian	African American	American Indian/ Alaskan Native	Asian/ Pacific Islander	Other race (or two or more races)	Total
143,678	32,845	1,049	55,453	13,575	246,600
58.3%	13.3%	0.4%	22.5%	5.5%	100.0%

Source: U.S. Census Bureau, 2010 Census

**Table 14b: Alameda County Older Adult Hispanic population**

Hispanic	17,174
Percent	10.6%

Source: U.S. Census Bureau, 2010 Census

As with adults, African American older adults are overrepresented among the services population, but not as significantly as adults; 28.5% of the BHCS older adult services population are African Americans though they are only 13% of the County older adult population. Asian/Pacific Islander older adults are significantly lower than the percentage of Asian/Pacific Islanders in the total older adult population. Older adult Native Americans and Latinos are represented in the services population at similar rates to their rate in the overall older adult population.

**Table 15: BHCS Older Adult Services Population by Race/Ethnicity**

African American	Asian/ Pacific Islander	Caucasian	Latino	Native American	Other/ Unknown	Total
495	267	601	233	8	132	1,736
28.5%	15.4%	34.6%	13.4%	0.5%	7.6%	100.0%

## GENDER

Females make up a larger percentage of the older adult population, as women typically live longer than men. Females make up a larger relative portion of the older adult population in BHCS services than of the older adult population overall, and this difference is much more significant than the difference among adults.



**Table 16: County and BHCS Adult Population by Gender**

	Female	Male
Adults in the County Population	138,595	108,005
Percent	56.2%	43.8%
Adults in BHCS System	1030	694
Percent	59.3%	40.0%

Sources: U.S. Census 2010 and Alameda County BHCS Administrative data

Responses to the MHSIP regarding satisfaction with quality of life were markedly different between older adult males and older adult females. For example, when asked about the amount of friendship in their lives, 11.3% of older adult females responded “terrible” or “unhappy” compared to only 2.1% of older adult males.

## LIVING SITUATION

For this project, certain living situations were considered to be part of the conditions that may isolate persons with SMI. Living situation is collected in the BHCS Administrative data base but is not always filled in or updated. It also does not track specifically whether persons live alone or with family or others.

Like adults, most older adults live in a house or apartment (49%) either alone or with others without “supervision.” However, just under 25% of older adults live in a licensed facility including a board and care, Skilled Nursing facility, Institute for Mental Disease or other licensed or medical facility. The next largest group (16%) lives in a house or apartment with support or supervision. This category may include both those who live with family caregivers and those who live in boarding facilities that are unlicensed. 6.6% were last reported as homeless or in temporary housing and 2.7% are in a criminal justice related setting.

**Table 17: Living Situation Older Adults**

Last Reported Living Situation for BHCS Older Adults							
0. Other	1. Justice Related	2. Homeless	6. Board&Care, SNF/ICF/IMD, Res/Social Rehab	7. House or Apt. with Support/ Supervision, Group Quarters	8. House or Apt.	10. Temporary/ Treatment Housing	Total
9	31	49	288	188	574	28	1,167
0.8%	2.7%	4.2%	24.7%	16.1%	49.2%	2.4%	100.0%

Source: BHCS Administrative data, 10/27/11

According to the MHSIP survey, older adults are less likely to be dissatisfied with their living situation than their adult counterparts. Overall, 23.1% of adults were dissatisfied in contrast with 13.6% of older adults. However, this was very different by gender: 17.2% of older adult females were dissatisfied with their living arrangements as compared to only 9.6% of older adult males.

Living alone is associated with greater social isolation (though it is not the same.) In terms of living with a partner, only 12.8% of adults in the BHCS system are married while 36% have never been married, and 33% are divorced, separated or widowed. In the general population, 46% of households are married couples and only 28% of households are people living alone

**Table 18: Marital Status of Older Adults**

Marital Status of BHCS Adults with SMI						
Divorced or Dissolved	Married or Living Together	Never Married	Separated	Unknown	Widowed	Total
375	221	623	78	316	119	1732
21.7%	12.8%	36.0%	4.5%	18.2%	6.9%	100.0%

Source: BHCS Administrative data, 10/27/11

## NEEDS OF THE TARGET POPULATIONS

A complete summary of the needs expressed in interviews and focus groups, and in the literature are included in Appendices B and C. The following list summarizes the most frequently identified needs, which were also used to develop the learning questions and other recommendations in this report.

**OPPORTUNITIES FOR POSITIVE SOCIAL INTERACTION:** The greatest need identified by all respondents was the need for positive social interactions that treat the person respectfully and help them connect with others through their own interests and strengths. One-on-one interactions were particularly important. Words that were used in focus groups and interviews to describe desired interactions include:

- ▶ Listening
- ▶ Understanding
- ▶ Acceptance
- ▶ Validation
- ▶ Honesty
- ▶ Source of hope

Interactions, both formal and informal, not only need to be supportive, they also need to be consistent and predictable, culturally and linguistically appropriate and in close proximity to consumers' homes.

**WELCOMING PLACES:** Places to go that are safe, comfortable and provide for basic needs such as food, warmth and company, as well as social and recreational opportunities, and the opportunity to engage in meaningful activities.

**MEANINGFUL ACTIVITIES:** This group of consumers needs the opportunity to engage in meaningful activities with others; not necessarily with the intent of leading to another specific outcome (such as employment) but for the social and self-esteem building value of the activity itself. These include:

- ▶ Social and recreational activities aligned with consumers interests
- ▶ Volunteer opportunities
- ▶ Skill training and development

**ACCESSIBLE AND INTEGRATED HEALTH AND BEHAVIORAL HEALTH SERVICES:** Isolated persons are more likely to use services if access is easy to navigate and physical and behavioral health services are coordinated and complimentary. Especially important for many isolated persons is the inclusion of mobile programs for those who cannot leave their homes, especially older adults.

**ECONOMIC SUPPORT:** Unsafe and low-quality housing, lack of transportation and mobility, and other economic conditions lead to greater isolation. This population has significant needs for financial or material supports including income, transportation, and housing supports.

## NEEDS OF FAMILY MEMBERS

For this project, the target population includes a subset of consumers who live with their families. Family members in these situations often act as a caregiver and may be the only source of regular social interaction for the consumer. This is a challenging role, and family caregivers expressed need for specific support:

- ▶ Respite support, allowing family caregivers to take a break from caregiving without worrying about their family members' safety.
- ▶ Recognition of their role in support of their family member and inclusion in treatment planning.
- ▶ Increased knowledge of resources and access to information assistance in planning for the future care of their family members.

## RECOMMENDATIONS FOR BHCS OUTREACH AND ENGAGEMENT

While many of the recommendations gleaned from a review of the literature and from the focus groups respondents and interviewees are innovative and would benefit from additional learning through an Innovations grant, many suggestions were made for practices or efforts that could be incorporated immediately or with limited additional resources or planning into the existing workings of Behavioral Health Care Services and/or its subcontractors. These include:

- 1. COUNTY-SUPPORTED PEER ENGAGERS:** The County currently supports peer volunteerism in the Pool of Consumer Champions. Training and deploying some peers to identify or follow-up with the most isolated/withdrawn consumers and build relationships was suggested as a way to use the existing peer resources to reach out in the community.
- 2. BUILD IN FOLLOW-UP:** Many consumers participate in community programs or see individual providers for medication or other purposes. When they fail to make appointments or attend their programs, in many cases there is no follow-up. For those who don't have an assigned case manager, have a tickler system where either the provider or an appointed peer or volunteer is made aware of the person missing appointments or failing to make appointments, and can check on them.
- 3. INVOLVE FAMILY MEMBERS IN CARE PLANNING AND TREATMENT:** Many family members comment that psychiatrists do not engage with family members when assessing the needs of a consumer, even when the family member is present, which can lead the professional to be unaware of increased isolation. Although confidentiality provisions limit certain aspects of interaction between the provider and family, there are ways that psychiatrists and other health care providers can include the input of the family without violating confidentiality if trained to do so.
- 4. ASSESSMENT OF HOUSING AND TRANSPORTATION NEEDS AND REFERRALS TO SUPPORT:** Isolation is increased by lack of transportation options and by marginal or inappropriate housing. All practitioners should incorporate into their regular contact with consumers a review of their transportation and housing resources and assist them as much as possible to secure these resources. The BHCS Housing Services Office has resources to assist consumers to move if needed. Transportation resources are extremely scarce but in order to improve outreach and engagement the lack of transportation resources has to be addressed.
- 5. INCREASE INFORMATION AT TIME OF CRISIS AND AFTER:** Increase availability of information about support and programs available to consumers and family members at the time of crisis including ensuring all consumers and family members leave hospitals or crisis settings with information about continuing community-based services, and a follow-up call.
- 6. INCREASE AWARENESS:** Broaden dissemination about the services available from the County including greater outreach to community agencies, faith-based communities, ethnic-based organizations and community centers and improvement of the BHCS website to assist anyone in the county seeking mental health services for themselves or their family member to find appropriate resources.

## OTHER KEY ISSUES IDENTIFIED

In addition to ideas for Innovations and for improved Agency outreach, respondents in focus groups and interviews raised several other issues that made it difficult for them, their consumers or family members to receive services or to reduce their own isolation. These included (in no particular order):

- 1. NEED FOR DAY PROGRAMMING:** The conversion of Creative Living Centers to Community Wellness Centers reduced the number of days a week that drop-in services and place-based programming is available, and in some cases removed the service from persons who were using them. The need for places to go where people can get basic needs met (food, socialization, recreation) was cited repeatedly as a significant gap in Alameda County. The Clubhouse model in other communities was cited as an example of the kind of programming needed.
- 2. LACK OF HOUSING CHOICES:** Consumers, family members and provider interviewees repeatedly expressed that housing is a huge issue for consumers that leads to isolation and lower quality of life and that housing resources are inadequate. Support for the creation of more housing where people can have their own rooms with support on-site as an alternative to Board and Care was strongly supported.
- 3. BOARD AND CARE IMPROVEMENT AND TRAINING:** Board and care homes house a significant number of seriously mentally ill persons. Some operators are recognized as doing an outstanding job and providing strong support for their residents, but many lack the skills to provide proper support and in most the demands of the work and financial considerations limit their ability to do so. The need for training, support and a higher level of scrutiny of Board and Care homes was a common theme. Some people suggested a *train the trainers* model for Board and Care staff that could improve their skills.
- 4. TRANSPORTATION:** The lack of transportation resources was raised repeatedly as a big barrier for service access and a major contributor to isolation. East county family members in particular cited both the lack of transportation and dearth of services in their area. Respondents recognized the challenge of addressing transportation needs but saw it as critical to reducing isolation.
- 5. FAMILY RESPITE:** As with the lack of day programming, family caregivers frequently mentioned the need for some kind of respite support, either as places that their family members could go so that the caregiver could have a break, or someone who can come in and provide them with respite coverage.
- 6. DE-TRAUMATIZING THE 5150 PROCESS:** The 5150 process was described as both too traumatic and too difficult. Respondents indicated that the role of law enforcement in the 5150 process is traumatizing for consumers and makes people around them less likely to use the process. Particularly in cultures that do not trust law enforcement, the requirement that they be involved makes the process more problematic. People wanted the 5150 process to be handled by Crisis Response.
- 7. TRANSITION PLANNING:** Family members who have been caring for their son or daughter are extremely concerned about what will happen to their adult child when they die or are unable to care for them. Support for creating transition plans from the FERC or other County entity would be invaluable.

8. **RESOURCES FOR THOSE WITH PRIVATE INSURANCE PROVIDERS:**

Many family members spoke about the dilemma created by the fact that their family member has access to private insurance thereby disqualifying them from county services. Most private insurance

plans do not provide ongoing mental health support beyond medication management, such as case management or other support programs, and as a result these individuals do not have any access to such support.

## APPENDICES

- ▶ APPENDIX A: *Removed from Findings and Recommendations, March 2012*
- ▶ APPENDIX B: **Focus Group and Interview Summary**
- ▶ APPENDIX C: **Literature Review**
- ▶ APPENDIX D: **Methods**
- ▶ APPENDIX E: **Summary Table of Datasets Used for Needs Assessment**
- ▶ APPENDIX F: **MHSIP Results—Social Relations and Living Arrangements**
- ▶ APPENDIX G: **Bibliography**
- ▶ APPENDIX H: **Acknowledgments**
- ▶ APPENDIX I: **About the Consultants**

## APPENDIX B: FOCUS GROUP AND INTERVIEW SUMMARY

### STAKEHOLDER INPUT OVERVIEW

The project consultants were contracted to gather information about the behavioral health needs of seriously mentally ill and isolated adults, older adults, and their families in Alameda County. Emphasis was placed on gathering data from the target populations within each supervisorial district of Alameda County using the following participatory research methods:

#### A. FOCUS GROUPS:

- ▶ Five focus groups targeted the geographic location of residents (adults, older adults, and family members) who reside across all five of the Alameda County Board of Supervisorial districts.
- ▶ Five focus groups, as identified by the demographic data, targeted underserved language and ethnic populations, and inappropriately served populations.

#### B. INDIVIDUAL AND GROUP INTERVIEWS:

- ▶ Individual interviews for more in-depth information addressing the specific needs of target population.

**FOCUS GROUPS:** Ten focus groups with consumers and family members were held throughout the county between October 27 and November 15, 2011. Each focus group followed a similar protocol and had both a facilitator and a recorder present. Eighty-eight consumers and 33 family members participated. Consumers were given \$15 Safeway vouchers as stipends. The following chart summarizes the focus groups held, their locations, supervisorial districts, primary target populations, and attendance.

**Focus Groups: Location, Supervisorial District, Target Population, and Attendance**

Date	Location	Super-visorial District	Primary Target Population	Attendance
10/27/11	Oakland Family Education & Resource Center (FERC)	4	Family members	7
11/5/11	Tri-Valley National Alliance on Mental Illness (NAMI)	1	Family members	9
11/8/11	BACS Hedco House	2	Adults and Older Adults	9
11/10/11	Afghan Coalition	1	Afghani Adults/Older Adults	9
11/12/11	Alameda Co. & East Bay NAMI	4	Family members	17
11/14/11	Berkeley Drop-in Center	5	African American Adults/Older Adults	18
11/14/11	La Familia	2	Latino Adults/Older Adults	8
11/14/11	Asian Mental Health	3	Asian Adults/Older Adults	20
11/15/11	West Oakland Health Center	3	African American Adults/Older Adults	4
11/15/11	Native American Health Center	4	Native American Adults/Older Adults	20
<b>Total</b>				<b>121</b>

Focus groups explored what contributes to isolation, what assists in decreasing isolation, who isolated persons were most likely to connect with and what places they would go, and what ideas they had for decreasing the isolation of the target population. Information from the focus groups was used to inform



the demographic profile, provide rationale for the learning questions, and inform the recommended outreach and engagement strategies.

**Notes on Demographics.** Priority was placed on engaging underserved and inappropriately-served populations including South Asian, Latino, African American, Asian, and Native American community members. As a result, the consumer groups were intentionally weighted toward inclusion of those racial and ethnic groups, and do not reflect BHCS client statistics nor Alameda County’s 2010 Census. For example, while gender was representative of countywide BHCS statistics (45% male and 55% female), Native American participation (22%) was much higher than in the countywide demographics (0.4%). Asian participation was at 36%, while it is only 12.3% countywide.

### Family Focus Group: Attendee Geographic Characteristics

Geographic Characteristics	Oakland FERC*	Tri-Valley NAMI**	Ala. Co./ East Bay NAMI	Total	
	10/27/2011	11/5/2011	11/21/2011	Number	Percent
<b>County Region/City</b>					
<b>North County</b>					<b>33%</b>
Oakland	3		4	7	21%
Alameda	1		1	2	6%
Berkeley	1			1	3%
Albany			1	1	3%
<b>Central County</b>					<b>9%</b>
San Leandro			2	2	6%
Hayward			1	1	3%
<b>South County</b>					<b>21%</b>
Fremont			6	6	18%
Union City	1			1	3%
<b>East County</b>					<b>30%</b>
Livermore		7		7	21%
Pleasanton		1	1	2	6%
Dublin			1	1	3%
<b>Outside Alameda</b>					<b>6%</b>
Contra Costa Co.	1	1		2	6%
<b>COUNTY TOTAL</b>	<b>7</b>	<b>9</b>	<b>17</b>	<b>33</b>	<b>6%</b>
<b>Supervisorial District</b>					
District 1		9		9	27%
District 4	7		17	24	73%
Total	7	9	17	33	100%

## Family Focus Group: Attendee Demographic Characteristics

Demographic Characteristics	Oakland FERC	Tri-Valley NAMI	Ala. Co./ East Bay NAMI	Total	
	10/27/2011	11/5/2011	11/21/2011	Number	Percent
<b>Gender</b>					
Female	7	8	12	27	82%
Male	0	1	5	6	18%
Total	7	9	17	33	100%
<b>Race/Ethnicity</b>					
Caucasian	0	7	13	20	61%
Latino	3	2	1	6	18%
African American	2	0	0	2	6%
Other Asian	1	0	1	2	6%
Mixed Race	0	0	2	2	6%
Native American	1	0	0	1	3%
Total	7	9	17	33	100%
<b>Age</b>					
18-35	2	0	1	3	9%
36-50	2	2	0	4	12%
51-59	3	5	1	9	27%
59+	0	2	15	17	52%
Total	7	9	17	33	100%
<b>Language</b>					
English	4	9	17	30	91%
Spanish	3	0	0	3	9%
Total	7	9	17	33	100%

### Consumer Focus Group: Attendee Geographic Characteristics

Geographic Characteristics	Afghan Coalition	Asian Mental Health	Berkeley Drop-In Center	Hedco House	La Familia	Native American Health Center	West Oakland Mental Health	Total	
	11/10/2011	11/14/2011	11/14/2011	11/8/2011	11/14/2011	11/15/2011	11/15/2011	Number	Percent
<b>County Region/City</b>									
<b>North County</b>									<b>62%</b>
Oakland	1	12	8			15	4	40	45%
Berkeley			8			3		11	13%
Alameda		1	1					2	2%
Emeryville			1					1	1%
Albany		1						1	1%
<b>Central County</b>									<b>23%</b>
Hayward				7	8	2		17	19%
San Leandro		1		1				2	2%
San Lorenzo		1						1	1%
<b>South County</b>									<b>14%</b>
Fremont	8	2						10	11%
Union City		1		1				2	2%
<b>East County</b>									<b>1%</b>
Livermore		1						1	1%
<b>COUNTY TOTAL</b>	<b>9</b>	<b>20</b>	<b>18</b>	<b>9</b>	<b>8</b>	<b>20</b>	<b>4</b>	<b>88</b>	<b>100%</b>
<b>Supervisorial District</b>									
District 1	9							9	10%
District 2				9	8			17	19%
District 3		20					4	24	27%
District 4						20		20	23%
District 5			18					18	20%
<b>Total</b>	<b>9</b>	<b>20</b>	<b>18</b>	<b>9</b>	<b>8</b>	<b>20</b>	<b>4</b>	<b>88</b>	<b>100%</b>

### Consumer Focus Group: Attendee Demographic Characteristics

Demographic Characteristics	Afghan Coalition	Asian MH	Berkeley Drop-In Center	Hedco House	La Familia	Native American Health Center	West Oakland	Total	
	11/10/2011	11/14/2011	11/14/2011	11/8/2011	11/14/2011	11/15/2011	11/15/2011	Number	Percent
<b>Gender</b>									
Female	4	11	7	3	4	18	1	48	55%
Male	5	9	11	6	4	2	3	40	45%
<b>Total</b>	<b>9</b>	<b>20</b>	<b>18</b>	<b>9</b>	<b>8</b>	<b>20</b>	<b>4</b>	<b>88</b>	<b>100%</b>
<b>Race/Ethnicity</b>									
African American			14	1			4	19	22%
Native American			1			18		19	22%
Chinese		12	1					13	15%
Afghani	9							9	10%
Latino				1	6	1		8	9%
Caucasian			1	5	1			7	8%
Filipino		2		1	1			4	5%
Vietnamese		4						4	5%
Other Asian		2						2	2%
Mixed Race				1		1		2	2%
Arab			1					1	1%
<b>Total</b>	<b>9</b>	<b>20</b>	<b>18</b>	<b>9</b>	<b>8</b>	<b>20</b>	<b>4</b>	<b>88</b>	<b>100%</b>
<b>Age</b>									
18-35		2	2		1	6		11	13%
36-50	1	5	5	1	3	7	1	23	26%
51-59	7	6	5	1	1	3	1	24	27%
59+	1	7	6	7	3	4	2	30	34%
<b>Total</b>	<b>9</b>	<b>20</b>	<b>18</b>	<b>9</b>	<b>8</b>	<b>20</b>	<b>4</b>	<b>88</b>	<b>100%</b>
<b>Language</b>									
English		2	17	9	3	19	4	54	61%
Dari	9							9	10%
Cantonese		6						6	7%
Mandarin		6						6	7%
Spanish					5	1		6	7%
Vietnamese		4						4	5%
Arabic			1					1	1%
Korean		1						1	1%
Tagalog		1						1	1%
<b>Total</b>	<b>9</b>	<b>20</b>	<b>18</b>	<b>9</b>	<b>8</b>	<b>20</b>	<b>4</b>	<b>88</b>	<b>100%</b>

**INTERVIEWS:** Nine structured interviews were held with advocates and practitioners in the field. *(Several interviews included the participation of more than one person from an agency or organization.)* Forty-five to 90 minute, in-person and telephone-based interviews were conducted with representatives from organizations with significant target population experience as well as organizations serving populations at risk for mental illness and isolation. An interview tool was used to ensure consistent coverage of key study questions. Additional information was also provided in these interviews that has informed this report.

Interviewees were asked about who they thought would be included in the isolated population, what conditions contribute to isolation, what assists in decreasing isolation, who isolated persons were most likely to connect with and what places they would go, and what ideas they had for decreasing the isolation of the target population. The interviews were also helpful to understanding the current system of care and their programs/facilities. In addition to formal interviews, several conversations with staff at BHCS were helpful in learning about the current system of care and ideas regarding the target population and strategies.

### Interviews: Organizations, Target Population, Primary Contact, Location

Organization	Primary Target Population	Primary Contact	Location
African-American Family Support	African American family members	Margot Dashiell	Oakland
Aging and Family Services	Older Adults	Dr. Ray Grimm	Fremont
BACS Senior Home Services	Older Adults with mental illness	Mitchell Foudray	Oakland
Center for Independent Living	People with Disabilities	Demetrius Johnson	Berkeley
Crisis Support Services	Adults in crisis	Nancy Salamy	Oakland
Mental Health Association	Mental health consumers and their families	Steve Bischoff	Oakland
NAMI East Bay	Family members	Liz Rebensdorf	Albany
St. Mary's Center	Homeless and marginally housed Older Adults	Sr. Mary Nolan	Oakland
Telecare STAGES	Older Adults with mental illness	Leslie Kaplan	Oakland

## SUMMARY OF FINDINGS

### CONNECTION

Focus group participants and interviewees were asked about the interactions they (or their family members or program participants) have with other people, what makes them feel connected, and how they tend to spend their time.

#### WHO INTERACTS MOST WITH PEOPLE WHO ARE ISOLATED WITH SERIOUS MENTAL ILLNESS?

Participants in focus groups and in interviews often laughed when this question was asked because their (target population's) interactions with other people are so limited. While family members were the most likely to interact with isolated adults and older adults, many people responded that they interact with no one.

After family, the most common responses cited caregivers such as case managers, In Home Support Services, Meals on Wheels, and primary care providers.

### Common responses

- ▶ Family members
- ▶ No one
- ▶ Case managers or care givers
- ▶ Primary care providers
- ▶ Peers/friends/group participants
- ▶ Other types of service providers
- ▶ Significant others
- ▶ Roommates, Board and Care, or housing related
- ▶ Church members

### Notable responses

- ▶ For older adults, family is a less frequent response

Interviewees at St. Mary’s Center and BACS indicated that family members are less involved with their older adult consumers. They pointed to “burn-out” and the gradual loss of family as people age as causative factors.

---

## WHAT HELPS YOU (OR THEM) TO FEEL CONNECTED TO OTHERS?

Many of the responses people gave centered on feeling safe and supported. The most common factor for respondents was that the other person listens to them. Also common was a desire to feel like they were being treated as an equal or a peer. Individuals cited “feeling accepted for who they are” and a “sense that the other person was being authentic” as essential for feeling connection. Family members who are caregivers of consumers indicated that a person coming to their homes to reach out helps to facilitate connection, however if the person is perceived to be coming at the behest of the family member the consumer may resent them.

### Common responses

- ▶ Listening
- ▶ Understanding
- ▶ Proximity
- ▶ Predictability – Same person over time
- ▶ Acceptance – Unconditional support
- ▶ Validation
- ▶ Honesty
- ▶ Common interests, fun activities
- ▶ One on one interaction
- ▶ Providing useful resources
- ▶ Clear, direct communication
- ▶ When they feel useful in the relationship
- ▶ Respectful communication
- ▶ Honesty

### Notable responses

- ▶ For people participating in programs at the Afghan Coalition in Fremont, their cultural community was a significant source of support, to the exclusion of other sources, in many cases. People there described feeling like only those from Afghanistan could understand the depth of their isolation.

---

## WHAT ARE OTHER CONNECTIONS PEOPLE HAVE OR OTHER PLACES THEY GO?

This question was aimed at trying to identify other possible avenues for reaching people prone to isolation who may not be accessing services. While many responded they or their family members “don’t go anywhere,” people were able to identify a few people they see regularly and places and institutions they visit. Participants indicated that they do not always do as well when they try to access more mainstream services, as they become anxious when confronted with unfamiliar circumstances.

### Common responses

- ▶ “Nowhere” was the most common response
- ▶ Landlord
- ▶ Library (Hayward and SF were cited for great programs for consumers)
- ▶ Coffee shops
- ▶ Corner stores
- ▶ Church (approximately half) or Mosque
- ▶ Alcoholics Anonymous
- ▶ Day programs at Saint Mary’s Center, Berkeley Drop-In Center, and Reaching Across in Fremont
- ▶ Parks
- ▶ Police —several said they go to report people attacking or spying
- ▶ Shopping mall or Wal-Mart—“like the anonymity”
- ▶ Classes or volunteer opportunities

### Notable responses

- ▶ A few older adults said Senior Centers, but many said they are too intimidating. Some interviewees also noted that senior centers did not have a high tolerance for the behaviors exhibited by some consumers.
- ▶ Afghan Coalition participants said they go to their community center
- ▶ NAHC group said they seek out other Native Americans

## ISOLATION

---

### WHAT CONTRIBUTES TO YOUR FAMILY MEMBER FEELING LONELY OR BECOMING ISOLATED?

All groups cited transportation as a major factor leading to isolation. Consumers and family members also pointed to psychological barriers to leaving the house. Some family members and interviewees indicated that isolation is often a manifestation of the negative symptoms of their illness. They can experience tremendous anxiety at new or unfamiliar situations and this leads to withdrawal. Others indicated that stigma impacts isolation as consumers may fear an unpredictable response to them by others. Another psychological factor is consumers who feel as though others around them do not understand their experience which leads to further withdrawal. Finally, interviewees mentioned physical disabilities and a lack of regularly available companions as factors leading to isolation and loneliness.

### Common responses

- ▶ Transportation problems
- ▶ Shame, lack of confidence
- ▶ Stigma
- ▶ Physical challenges
- ▶ Anxiety, panic attacks
- ▶ Negative experiences
- ▶ Not understanding social cues/rules
- ▶ Feel like an outsider
- ▶ Lack of safe or fun places to go
- ▶ Paperwork, difficult entry to programs

- ▶ Medication, lack of medication
- ▶ Change or loss of provider
- ▶ Drug dealing or scary environment, fear of being preyed upon

### Notable responses

- ▶ Asian and Afghan participants said language barriers worsen during mental health crisis
- ▶ Native Americans cited feeling displaced as a culture
- ▶ African American participants in two different groups brought up cultural barriers due to race. They cited cultural stigma and a lack of competence on the part of providers.
- ▶ Older adults more frequently identified stigma as an isolating factor
- ▶ Older adults become more isolated due to physical degeneration

## LIVING SITUATION

### WHAT KINDS OF LIVING SITUATIONS ARE GOOD FOR PEOPLE LIVING WITH MENTAL ILLNESS WHO TEND TO BECOME ISOLATED OR WITHDRAWN?

Focus group participants, especially consumers, frequently cited a need for a level of independence beyond what would be expected in a Board and Care. Just as often, they said they should not be too far from family or other supports. In addition to comments about the type of housing that is most appropriate, people in every group mentioned the high price of housing and/or the lack of subsidized housing in safe neighborhoods as presenting a barrier to wellness for the target population.

### Common responses

- ▶ Subsidized independent living with support
- ▶ Senior housing
- ▶ Family home
- ▶ Apartment with freedom
- ▶ A place where you can have privacy and also social opportunity
- ▶ Close to medical services
- ▶ Intergenerational housing
- ▶ Close to cultural community

### Notable responses

- ▶ Family groups were more likely to cite a need for supervision
- ▶ BACS said many older homebound consumers are at risk of losing housing due to organizational challenges, financial problem, hygiene

### WHAT KINDS OF LIVING SITUATIONS ARE BAD FOR PEOPLE LIVING WITH MENTAL ILLNESS WHO TEND TO BECOME ISOLATED OR WITHDRAWN?

### Common responses

- ▶ Dormitory style
- ▶ Jail
- ▶ Far from friends and family
- ▶ Being locked up in psych facility
- ▶ Homelessness
- ▶ With too many people
- ▶ Places that make you leave during the day
- ▶ High crime areas
- ▶ Vulnerable to elder abuse
- ▶ Places where there is little or no activity; where others tend to isolate
- ▶ Rural settings



### **Notable responses**

- ▶ Afghan Coalition response: “We were placed into a Section 8 program away from Fremont and now our lives have become isolated and violent.”
- ▶ African American family emphasized the significance of the housing environment and safety concerns leading to greater isolation.

---

## **SUGGESTIONS TO IMPROVE BOARD AND CARE**

Many consumers and family members had experience with Board and Care housing. Family members felt very strongly about the need for improvement of the living situation of those in board and cares. They cited going in to board and care homes where their family resides and often seeing residents who seem extremely isolated and withdrawn. According to family members, in most cases board and care operators do not appear to make an effort to engage residents, in particular those without family who visit them regularly. Family members also indicated that they were concerned about raising complaints with operators of board and cares as they were considered the housing of last resort for many and they did not want to jeopardize the availability of this housing. They presented the following suggestions for improving the living situation in these programs.

### **Common responses**

- ▶ Activities available to residents either on or off in the sites
- ▶ Programming that encourages physical activity
- ▶ Support and training for the Board and Care owners
- ▶ Animals, therapy dogs, like for cancer patient
- ▶ Some board and care operators do a great job, provide good food, keep the place clean
- ▶ Need day programs
- ▶ Advocate for programs of quality
- ▶ Programs should be tailored to the specific interests of residents – not just generic

One family advocate noted that there is no central clearinghouse with information about available board and cares which makes finding an appropriate board and care home extremely time consuming and onerous.

## **MENTAL HEALTH SERVICES & SUPPORTS**

---

### **WHAT SERVICES OR SUPPORT DO YOU KNOW OF FOR ADULTS LIVING WITH MENTAL ILLNESS?**

In response to this question, consumers were most likely to list the agency where the group was hosted. People showed some awareness of other peer groups, psychiatric, and medical services. Family members indicated that those who they provided care for rarely qualified for county services and therefore they felt as though there were no resources available for their family member. The perception of many family members was that consumers had to be hospitalized multiple times in order to qualify for services. Family members in East County in particular cited a lack of resources.

---

## WHAT MADE THE SUPPORT THEY RECEIVED HELPFUL?

Common themes in response to this question were similar to the “Connections” discussion. Again, “finding someone who will listen” was the most common answer among consumers. Close after came the ability to help with concrete difficulties.

### Common responses

- ▶ Patience and listening skills
- ▶ Follow-up
- ▶ Resources, practical assistance
- ▶ Therapy – hard to get
- ▶ Friendly, open services
- ▶ Cultural, linguistic competence
- ▶ Variety of groups
- ▶ Close to home
- ▶ Skills building opportunities

---

## WHAT WAS NOT HELPFUL ABOUT THESE SERVICES?

Responses to this question tended to fall into two categories: Scarcity of resources, and problems with services. One problem with services cited by many is the “do-it-yourself” nature of the services that are available. For those who are isolated it may be challenging for them to take the initiative to seek out services on their own and be responsible for follow up. In addition, consumers raised concerns about excessive bureaucracy and the barriers created by the need to complete excessive paperwork. Both consumers and family members raised concerns about disrespectful staff persons. Some family members also indicated that current service delivery models are inaccessible because their family member refuses all currently available services.

### Common responses

#### **Scarcity Problems:**

- ▶ Closing programs
- ▶ Waiting Lists
- ▶ Lack of housing resources
- ▶ Location too far away
- ▶ Not enough services tailored to population
- ▶ Private insurance even harder to navigate
- ▶ Limits on number of calls or visits
- ▶ Rushed appointments means focus is just on meds

#### **Problems with Services**

- ▶ Too much persistence and self-advocacy required given population
- ▶ Many programs are geared toward higher-functioning consumers
- ▶ Too much bureaucracy
- ▶ Staff can be rude, act like you are imposing
- ▶ Staff members at Villa Fairmont and John George were hostile and dismissive
- ▶ Incompetence
- ▶ Lack of confidentiality
- ▶ Language barriers

Similarly, when asked what makes it hard to get services, people responded with a mix of logistical and personal barriers.

- ▶ Location/Transportation
- ▶ Systemic barriers
- ▶ Financial barriers
- ▶ Illnesses
- ▶ Stress, anxiety
- ▶ Can't fill out papers

## Notable responses

- ▶ Some family members indicated that services were even scarcer for those with private insurance than for those with Medi-Cal as the private insurance disqualified their family member for access to county services.
- ▶ Family members also expressed frustration with mental health practitioners' unwillingness or lack of time to include the family in assessment and treatment planning, even when confidentiality issues were not relevant.

---

## SPECIFIC CULTURAL CONCERNS

### Questions about cultural barriers or impacts were asked in the following focus groups:

- ▶ Asian Mental Health Clinic (Asian populations included Chinese, Vietnamese, Korean, Filipino. Group conducted in English, Mandarin, Cantonese, Vietnamese)
- ▶ Berkeley Drop-in Center (African American)
- ▶ La Familia (Latino population. Group conducted in English and Spanish.)
- ▶ West Oakland Health Center (African American)
- ▶ Afghan Coalition (South Asian population. Group conducted in English and Dari/Pashto.)
- ▶ Native American Health Center (Native American)

While some participants (particularly in the African American and Latino groups) said they did not feel they had encountered cultural barriers, others cited significant problems with language and cultural stigma.

- ▶ Latino and Asian participants cited cultural taboo against discussing mental illness
- ▶ If someone comes from another country and family member gets taken to hospital may think getting taken away forever. Can be very scary and don't trust system
- ▶ People from other cultures might not recognize symptoms the same way
- ▶ It would be helpful to have more groups in different languages
- ▶ There's a real need for public education so people from cultures with stigma can start talking about MI

---

## HOW DO YOU OR YOUR FAMILY MEMBER LEARN ABOUT AVAILABLE SERVICES AND SUPPORT?

Consumers were most likely to say they learned about services from their case managers or other service providers.

### Common Responses

- |  |                                      |
|--|--------------------------------------|
| ▶ Service providers, Community clinics | ▶ Court system                       |
| ▶ Case managers                        | ▶ CalWORKS                           |
| ▶ NAMI                                 | ▶ Internet                           |
| ▶ Online                               | ▶ Family Resource Center             |
| ▶ Primary care providers               | ▶ Schools and colleges               |
| ▶ 211                                  | ▶ Community Centers / Senior Centers |
| ▶ ACCESS                               | ▶ Libraries                          |
| ▶ Word of Mouth                        | ▶ Regional Center                    |

- ▶ Shelter
- ▶ CPS
- ▶ Consumer champions

### Notable responses

- ▶ When asked if they use the internet, the vast majority of consumers (75%+) said they “do not use it at all.” Most family members also indicated that their family member was unlikely to use the Internet.

## SUPPORT NEEDS OF FAMILY MEMBERS

### WHAT ARE THE BEST SUPPORTS THAT YOU HAVE RECEIVED AS A FAMILY MEMBER OF SOMEONE LIVING WITH MENTAL ILLNESS?

Family members spoke very highly of both the Family Education Resource Centers and NAMI. Individuals learned about these services in a variety of ways including word of mouth, Kaiser, and emergency rooms.

### Common responses

- ▶ NAMI
- ▶ Mental Health Association
- ▶ Family Advocate Services (Family Education Resource Centers)
- ▶ Pacific Sun
- ▶ Consumer Liaison
- ▶ Unemployment

### Notable responses

- ▶ Support services for *caregivers* really lacking
- ▶ Many family members cited their fear that their child or relative will be left without any support when they (the parents) die or become unable to care for others or themselves.

## RECOMMENDATIONS

### WHAT SUGGESTIONS DO YOU HAVE FOR MAKING SURE THAT PROGRAMS AND SERVICES ARE MOST HELPFUL TO ISOLATED ADULTS AND OLDER ADULTS LIVING WITH MENTAL ILLNESS WHO NEED THEM IN ALAMEDA?

Responses to this question were mostly focused on improving existing services or improving access to them. Suggestions for improving access included enhancing transportation and creating more home-based programs that brought services directly to the consumer. In particular for those living with family and who refused to leave the house this was seen as essential. Additional follow-up such as reaching out to consumers who missed appointments or who suddenly no longer sought services was also suggested.

### Common responses

- ▶ Transportation
- ▶ Mobile service model
- ▶ Primary health care integration with BH
- ▶ Training for other providers like B&C, Meals on Wheels, IHSS
- ▶ Health fairs
- ▶ More services, places to go

- ▶ Public education and resource information
- ▶ Education for family, connection within services
- ▶ Easy entry services
- ▶ Supported vocational services
- ▶ Consumer responsive agencies
- ▶ More hours for IHSS

### **Notable responses**

- ▶ Many participants in family and consumer groups spoke of the Creative Living Centers as a wonderful model that is no longer available.
- ▶ Transportation was cited as particularly problematic for East County residents.

---

## **WHAT NEW PROGRAMS OR SERVICES WOULD YOU WANT TO HAVE IN ALAMEDA COUNTY THAT WOULD HELP ISOLATED ADULTS AND OLDER ADULTS LIVING WITH MENTAL ILLNESS?**

In response to the question about potential new programs, people reiterated time and again that there is a lack of meaningful activities accessible to people with serious mental illnesses. Specific ideas included volunteering, skills-building, crafts, and retail or budget training. Models that utilize peers to build connections with consumers also came up repeatedly in focus groups and interviews as needed in Alameda County. As described in a previous question, services specifically related to board and cares was also raised by many.

### **Common responses**

- ▶ Volunteer support programs and centralized information
- ▶ Education for church and clergy groups, senior centers, community centers, libraries
- ▶ Peer based visitation for homebound and isolated
- ▶ Skills-based activities where you learn something useful
- ▶ Learn to care for plants and animals
- ▶ Craft market tied to craft activities for disabled, include retail, etc.
- ▶ Mobile crisis rather than police for 5150 countywide
- ▶ Need different levels of activities —room for growth
- ▶ Anger room at hospital
- ▶ Assistance learning to organize meds
- ▶ Drop-in wellness hub with activities and volunteer opportunities in native languages
- ▶ Tie services to dental care. Dental care is a huge problem

### **Notable responses**

- ▶ All population specific groups cited a need for culturally responsive groups and activities. At the Asian Mental Health Center, staff noted that people with language barriers are even more limited in what they can access.

## APPENDIX C: LITERATURE REVIEW

A brief review of existing academic and professional literature revealed that a variety of research has been done related to social isolation and/or engagement challenges among persons with serious mental illness. Although the target population defined by BHCS as “adults and older adults with serious mental illness (SMI), who are isolated and withdrawn, living with families or in board and care homes or hotels, and their families” is not recognized as a distinct sub-population in the literature, many studies of persons with SMI and programs targeted to them directly or indirectly pertain to this population. To effectively summarize the research, it is presented under six research sub-topics as follows:

- ▶ Use of typologies to identify sub-categories of mental health consumers
- ▶ Outreach and engagement with “difficult to engage” populations
- ▶ Social isolation and the impact of non-traditional social support models
- ▶ Racial, ethnic and language factors contributing to inappropriate treatment or isolation
- ▶ Needs and strategies based on housing setting
- ▶ Strategies to support and involve family members

Research was conducted using internet search tools based on search terms that included “isolated adults with mental illness,” “mental illness and social isolation,” “mental illness and race,” “mental illness and language access,” “isolated and withdrawn adults with serious mental illness,” “board and care isolation,” “family psychoeducation,” “withdrawn adults with mental illness,” “elders and mental health” and “mental health peer support.” In addition, when appropriate sources were identified, the bibliographies of these sources were reviewed for additional relevant research. In general, a review of more recent literature was prioritized, however in some cases where there was a particular dearth of current research, older studies and reports have been cited.

### USE OF TYPOLOGIES TO DEFINE SUB-CATEGORIES OF MENTAL HEALTH CONSUMERS

When examining possible interventions for the target population it is clear that a “one size fits all” approach is inadequate. Although one of the most common distinctions made to define mental health consumers is diagnosis, this may not be the most useful conceptualization for developing outreach strategies and programming for isolated and withdrawn adults and older adults with SMI. The review of current research on this topic found one particularly relevant research project that laid out a new classification system for those with mental illness that could serve to better understand how to effectively engage with mental health consumers in a community support setting. The researchers developed an assessment instrument called the Community Living Skills Indicators which utilized functional assessment scales and a few demographic and diagnostic items. From this they identified five “core clusters,” three of which are subsets of the target population.<sup>1</sup>

The first cluster consists of those with serious mental illness who suffer from hallucinations, delusions, obsessions, or compulsions and often express anger inappropriately. They often refuse treatment and many have been in the mental health system for a long time. The second subcategory includes older adults with co-occurring serious, chronic physical health conditions and psychiatric symptoms. They

---

<sup>1</sup> W. Rubin and P. Panzano, “Identifying Meaningful Subgroups of Adults with Severe Mental Illness,” *Psychiatric Services*, 53 (April 2002): 452-457.

primarily live in nursing homes or are cared for by family members. They are often socially isolated and withdrawn and have lost interest in the world around them.

The third relevant cluster consists of individuals who struggle with anxiety and depression and often avoid growth opportunities. Many appear to be functioning well at home and in the community; however, they experience considerable interference in their lives as a result of anxiety, depression, or passivity.<sup>2</sup> This group may not yet be considered part of the identified target population but may be at risk for a worsening of symptoms leading to increased isolation and withdrawal.

The authors conclude that “the use of clusters can help clinicians understand the interaction effects that become masked when we focus on measuring all consumers on the same outcomes. Paying attention to clusters can contribute to treatment planning and can enhance the efforts of management to facilitate quality improvement, focus staff training, and support the evaluation of services at all organizational levels.”<sup>3</sup> Although the authors do not offer specific recommendations for operationalizing this idea, it may, nonetheless, serve as a useful framework for the development of targeted programming.

## ENGAGEMENT STRATEGIES

### *Engagement of Adults with Mental Illness who are “Difficult to Engage”*

The first core cluster of adults with serious mental illness described above coincides with a group defined in some literature as “difficult to engage.” A study in the *British Journal of Psychiatry* examined the factors that lead mental health patients to disengage with services and also what causes them to re-engage with outreach teams conducting assertive outreach. The study utilized in-depth interviews with forty purposefully selected patients who had disengaged with services at some point and subsequently re-engaged. The results found three common themes leading to disengagement. The first theme was that patients’ desire to be independent led them to have difficulty accepting their mental illness and role as a patient. The second theme was patients reporting not feeling “listened-to” or engaged in their treatment process as a reason for disengagement. Finally, a loss of control due to medication effects was a key reason identified for disengagement with services.<sup>4</sup>

Conversely, staff members who offered practical support and engaged in social activities without a focus on medication were more likely to successfully engage patients. The perception of being treated seriously and afforded an active role in making decisions about their treatment were also some of the factors leading to engagement. The authors concluded that in dealing with ‘difficult to engage’ patients, their findings point to the importance of a comprehensive care model which includes both social and practical support, committed staff with sufficient time to adequately engage patients, and a focus on relationship issues that allow for a partnership model of service provision.<sup>5</sup>

A study undertaken in Italy sought to examine the impact of an intensive 12–18 month psychosocial rehabilitation program for patients with severe mental illness defined as difficult to-treat. All patients

---

<sup>2</sup> Rubin and Panzano, 452-457.

<sup>3</sup> Rubin and Panzano, 452-457.

<sup>4</sup> S. Priebe, J. Watts, M. Chase and A. Matanov, “Processes of Disengagement and Engagement in Assertive Outreach Patients: Qualitative Study,” *The British Journal of Psychiatry*, 187 (November 2005): 438-443.

<sup>5</sup> Priebe et al., 438-443.

had low levels of social functioning and were with defined as “treatment failures” because of repeated engagement problems, failure to attend rehabilitation programs, or lack of improvement despite compliance with treatment. Most were single adult males living with their parents, with low education, a diagnosis of schizophrenic disorder, and a long history of mental illness, and almost all were unemployed. The treatment included three phases: engagement, rehabilitation program implementation, and closure.<sup>6</sup>

Emphasis was on compliance with patient wishes rather than pursuing a rigid professional agenda. The main rehabilitation tool was the establishment of a strong relationship based on trust and alliance, where assertive strategies were replaced by strategies based on patience and continuity. For example, they did not meet in a professional office setting and were able to meet during both the day and night. They focused on meeting the needs and wishes of the patient rather than achievement of outcomes. The community participation mainly involved access to recreational and leisure activities, which according to recent suggestions, possess a number of characteristics that make them useful for facilitating the social inclusion of persons with disabilities. Patients’ improvement in overall social functioning was not impressive. However, there was improvement in measures of interpersonal skills, link with the social network, and participation in the community. General psychological well-being improved in many patients, despite the persistence of psychotic symptoms.<sup>7</sup>

Another outreach and engagement method that has been explored is placing outreach staff in non-mental health settings that individuals with mental illness tend to frequent. For example, in 2009, San Francisco Department of Public Health set up a program in the San Francisco Main Library that provides a psychiatric social worker to interact with homeless and marginally housed individuals with mental health, substance abuse and other psycho-social conditions. Within 10 months, the library saw a marked decrease in behavioral incidents and patrons were directed into services such as counseling, medical care, and housing. The social worker has also acted as a resource for Library staff, helping them understand how to respond most effectively to inappropriate behaviors.<sup>8</sup>

### ***Engagement of Older Adults Not Connected to Existing Service Systems***

The second core cluster, which consists of older adults with SMI, has been more extensively researched. Several studies exist that specifically evaluate access of mental health services by elders. In 1997, an article published in the book *Innovative Approaches for Difficult-to-Treat Populations* reviewed a number of programs specifically designed to treat elderly populations with mental illness. Sixteen demonstration projects for elderly mental health patients across the country were reviewed, in addition to available research, and the authors concluded that in order to be effective, programs should recognize and treat the multiple emotional, cognitive, physical and socioeconomic needs of elderly consumers. In addition, “projects that are home-based, provide auxiliary services (transportation,

---

<sup>6</sup> A. Barbato, G. Agnetti, B. D’Avanzo, M. Frova; A. Guerrini and M. Tettamanti, “Outcome of Community-Based Rehabilitation Program for People with Mental Illness Who are Considered Difficult to Treat (2007), *Journal of Rehabilitation Research & Development*, 44.6 (2007): 775–783.

<sup>7</sup> Barbato et al., 775–783.

<sup>8</sup> Knight, H. “Library adds social worker to assist homeless,” *San Francisco Chronicle*, January 11, 2010



respite care), and use a multidisciplinary team approach seem to best address the multiple needs of elderly neuropsychiatrically-ill individuals.”<sup>9</sup>

In 2004, Aricca Van Citters and Stephen Bartels published a comprehensive literature review analyzing the effectiveness of community-based mental health outreach services for older adults. Their review notes that “older adults are unlikely to use traditional clinic-based mental health services for a variety of reasons, including physical frailty, transportation difficulties, isolation, and stigma.” The overview notes that geriatric mental health outreach services are being promoted as an effective mechanism for increasing access to mental health care for older adults, and the research review seeks to answer the question of whether that is accurate. The article reviews two categories of intervention: the gatekeeper model and in-home care management. Both types of intervention appear promising, although the authors note that many of the studies reviewed had methodological limitations and therefore conclusions may not be generalizable.<sup>10</sup>

**GATEKEEPER MODEL:** The gatekeeper model recruits community service personnel who have frequent contact with older persons, such as meter readers and utility workers, to identify and refer individuals for assessment. Two studies were evaluated to determine the effectiveness of this approach. The conclusion of the researchers is that the gatekeeper approach reaches individuals who are less likely to gain access to services through conventional referral approaches and in particular this approach reaches individuals who live alone and those who are more likely to be socially and economically isolated.<sup>11</sup>

**IN-HOME CARE MANAGEMENT:** Twelve studies were evaluated which utilized a care management approach to provide services at the older adults’ place of residence. All of the interventions analyzed were associated with significant improvement in depressive symptoms. The review included several studies of programs that provided in home assessment, followed by interventions that included referral and linkage to either outpatient treatment or to in-home psychiatric care. These multidisciplinary geriatric mental health outreach interventions were associated with improved global functioning, reduced psychiatric symptoms, and fewer behavioral disturbances relative to baseline measurements of symptoms and functioning. In addition, these interventions were associated with maintained independence and were perceived as helpful to caregivers and referring agents.<sup>12</sup>

No other academic research was identified on the topic of geriatric mental health outreach; however the Mental Health and Aging Project (a project of the Mental Health Association of Southeast Pennsylvania) published an on-line article in 2003 regarding the barriers to access for elders experiencing symptoms of mental illness. Although this piece is based more on the anecdotal experience of practitioners than rigorous academic research, it provides an interesting overview of some of the factors that may impact mental health service access for older adults. Reasons cited include:

---

<sup>9</sup> M. Rowland, B. Burns, G. Schafft, F. Randolph, and C. McAninch, “Innovative Services for Elderly Populations,” in S. Henggeler & A. Santos, eds., *Innovative Approaches for Difficult-to-Treat Populations*, (Washington, D.C.: American Psychiatric Press, 1997), 289-310.

<sup>10</sup> A. Van Citters and S. Bartels, “A Systematic Review of the Effectiveness of Community-Based Mental Health Outreach Services for Older Adults,” *Psychiatric Services*, 55 (November 2004): 1237-1249.

<sup>11</sup> Van Citters and Bartels, 1237-1249.

<sup>12</sup> Van Citters and Bartels, 1237-1249.

- ▶ A resistance to seeking treatment due to the stigma associated with mental illness
- ▶ Ageism resulting in a deprioritization of mental health services for elders
- ▶ A lack of mental health training for primary care doctors to whom older adults may turn rather than specialized mental health professionals
- ▶ A lack of coordination between mental health, older adult and primary health systems
- ▶ A lack of organized support for this specific population

The author suggests that effective programs include those that conduct outreach efforts to locate and identify older persons who are depressed, have mobile service delivery that allow for treatment at their homes, and cross-training between aging and mental health systems.<sup>13</sup>

The same organization presented findings in 2002 of a project known as “Elder Reach” that provided some insight into effective programming. The program utilizes non-traditional referral sources such as hairdressers, neighbors, church members and mail carriers who identify older adults lacking other supports. During the 9-month period studied, 130 referrals were received, 70% of which were for women. Twenty-three of the referrals were determined to have serious mental illness. Lessons learned from the program included the value of cross training between older adult and mental health systems; that older adults were not likely to ask for help; that engaging older adults in services required a great deal of effort, including starting with practical assistance such as grocery shopping, transportation, etc.; that loneliness and isolation was very prevalent among the older adult population; and that cases were complex, often with multiple residents in the home requiring intervention and the need for ongoing case management services due to the complex needs of older adults.<sup>14</sup>

## SOCIAL ISOLATION AND EVALUATION OF SOCIAL SUPPORT MODELS

Beyond engagement, what types of supports are likely to be effective at improving quality of life for the target population is a key question. The research reviewed does not identify adults with SMI who are “isolated and withdrawn” as a distinct population about which research has been conducted; however, studies exist that examine the relationship between social isolation and mental health. In the literature the term social isolation refers to the objective absence of a social network. One’s own perception of the condition is defined as degree of loneliness<sup>15</sup> or one’s perception of being alone.<sup>16</sup> The studies reviewed generally looked not solely at the objective size of one’s social network as an indicator of social isolation but also measured the subjective experience of loneliness.

Some researchers approached the subject by examining how a lack of social support can lead to a decline in mental health. In particular a lack of social support has been found to be a major precipitant of depression and may increase one’s risk of substance abuse.<sup>17</sup> Another line of research has examined

<sup>13</sup> T. Persky, “Overlooked and Underserved: Elders in Need of Mental Health Care,” *Journal of the California Alliance for the Mentally Ill*, 9 (1998): 7-9.

<sup>14</sup> Kathy Latimer, *Erie County: Project Elder Reach*, Mental Health and Aging, <http://www.mhaging.org/info/latimer.html> (November 4, 2011).

<sup>15</sup> N. Drew, “Combating the Social Isolation of Chronic Mental Illness,” *Journal of Psychosocial Nursing and Mental Health Services*, 29.6 (1991): 14-17.

<sup>16</sup> Stephen Ilardi, *Social Isolation: A Modern Plague*, Psychology Today, <http://www.psychologytoday.com/blog/the-depression-cure/200907/social-isolation-modern-plague> (November 4, 2011).

<sup>17</sup> <http://www.psychologytoday.com/blog/the-depression-cure/200907/social-isolation-modern-plague>

the social networks typical of those with mental illness as compared to the general population finding that those with mental illness often have smaller social networks than people without SMI. In addition their networks often consist largely of mental health or social service professionals, family members, and peers with psychiatric conditions, the last of which may even increase the feelings of social isolation and loneliness.<sup>18</sup> Little research was found that examined effective outreach and engagement strategies to reach those who are isolated and withdrawn and living with SMI however research conducted on the use of various social support models with people with SMI has been fairly extensive.

A report published in Britain in 2004 looked extensively at the relationship between social isolation and mental health and included a series of recommendations to combat social exclusion and the accompanying worsening of mental health symptoms. These included:

- ▶ Creating inclusive communities by reducing stigma and discrimination.
- ▶ Creating systems of care that allowed consumers to exercise personal choice.
- ▶ Enhancing programs designed to assist mental health consumers to obtain employment.
- ▶ Promoting broader social participation through education, training or volunteering, particularly in mainstream settings, including sports and arts activities (volunteering in particular was cited by nine of ten consumers interviewed as giving them a sense of purpose and achievement).
- ▶ Engaging family members and friends in reintegration into communities.
- ▶ Making services more welcoming, in particular to ethnic minorities.<sup>19</sup>

## SOCIAL SUPPORT MODELS

Social support has been demonstrated by the research to be a possible antidote to worsening mental health conditions.<sup>20</sup> Several studies have examined the role that social support can play in improving the lives of adults with SMI. The SMART Fund, a Canadian program that funds community-based health promotion initiatives conducted a review of studies which linked social support to positive health outcomes among certain vulnerable populations including mental health consumers. Social support is defined as the combination of the degree of integration through social networks along with the supportive resources gained through such networks including emotional support, informational support and tangible support. The review concluded that:

- ▶ Higher levels of perceived social support is associated with fewer hospitalizations for individuals with severe mental illness (SMI), a lower incidence of SMI episodes, better overall functioning in individuals with SMI, and recovery from mental illness.
- ▶ Increased social network size is associated with increased self-esteem, increased satisfaction with social relationships and social activities, increased social skills and cognitive function, and greater satisfaction with health.

---

<sup>18</sup> B. McCorkle, E. Rogers, E. Dunn, A. Lyass and Y. Wan, "Increasing Social Support for Individuals with Serious Mental Illness: Evaluating the Compeer Model of Intentional Friendship," *Community Mental Health Journal*, 44.5 (2008): 359-366.

<sup>19</sup> Office of the Deputy Prime Minister, "Mental Health and Social Exclusion Social Exclusion Unit Report," June 2004, London.

<sup>20</sup> R. Kessler, J. McLeod, S. Cohen (Ed) and L. Syme (Ed), "Social Support and Mental Health in Community Samples," *Social Support and Health*, xvii (1985): pp. 219-240.

- ▶ Recurrence of illness is predicted by lower levels of perceived social support, but protected against through the development of strong informal (non-professional) relationships.<sup>21</sup>

A 2008 review of existing literature also supports the theory that “for people with SMI, perceptions of adequate social support are associated with several psychological benefits, including increased self-esteem, feeling of empowerment, functioning, quality of life, and recovery, while the absence of social support appears related to greater psychiatric symptoms, poorer perceptions of overall health, and reduced potential for full community integration.”<sup>22</sup>

A study published in 2008 examined one specific model of social support known as the Compeer Model of Intentional Friendship. The particular intervention studied provides interaction with community members through regularly scheduled meetings between consumers with SMI and community volunteers for social and recreational activities. Consumers and volunteers met for at least four hours per month for one year and subsequently several domains were assessed to examine whether increases in social support were related to quantifiable improvements in subjective well-being and psychiatric symptoms. The study found that the Compeer intervention was successful at increasing social support for people with SMI as measured by a social support index. Overall, treatment participants did not show improvement in subjective well-being and psychiatric symptoms, but those who showed an increased level of social support demonstrated significant improvement in subjective well-being and psychiatric symptoms as compared to the control group. The authors note that their sample contained an overrepresentation of Caucasian females and therefore may not be generalizable to men and other ethnicities.<sup>23</sup>

An article published in 2004 in the *Psychiatric Rehabilitation Journal* provides an overview specifically of peer support programs for adults with SMI. Peer support is divided into six categories: self-help groups, Internet support groups, peer-delivered services, peer-run or operated services, peer partnerships (defined as organizations in which administration and governance responsibilities are shared between peers and non-peers) and peer employees within mainstream mental health organizations. The analysis found that peer support programs can be of particular benefit as a mechanism for serving individuals in need of mental health services who have been alienated from the traditional mental health system.

Service components that were key to success include the use of a process in which the peer providers related to other consumers from their own personal experience, a mutual benefit model (helping others helps oneself), and the use of natural social support – the voluntary nature of services and primary control of service delivery by consumers. Those who provided the services were most effective when peer providers had experience with the mental health delivery system, were stable and in recovery and were not currently a substance abuser. System components that supported success were diversity and accessibility of the types of peer-provided services, services that reflected the cultural diversity of the

---

<sup>21</sup> Jolene Lansdowne, *The Links between Social Support and Improved Health Outcomes, The SMART Fund, Vancouver Coastal Health, 2011*  
[http://www.smartfund.ca/docs/social\\_support\\_improved\\_health\\_outcomes\\_report\\_jan2011.pdf](http://www.smartfund.ca/docs/social_support_improved_health_outcomes_report_jan2011.pdf) (November 4, 2011).

<sup>22</sup> McCorkle et al., 359-366.

<sup>23</sup> McCorkle et al., 359-366.

community and systems in which peer services served as an adjunct to traditional mental health services.<sup>24</sup>

A 2006 research review of peer support programs used three similar, although less-detailed, categories: mutual support, participation in consumer or peer-run programs, and the use of consumers as providers of services and supports. The review focused on the third of these categories. The authors of this review examined four studies looking at programs that provided conventional case management services and compared the effectiveness of those delivered by mental health consumers versus non-mental health consumers. Overall, the studies indicated that peers providing conventional services appear, for the most part, to produce the same outcomes as non-peers who provided these same services. Two additional studies were reviewed that employed consumers as “peer specialists” and trained them to use their own life experience with mental illness to provide services and supports. In these cases, consumers who received both traditional case management services and peer support fared better in the short term than those who received only case management, but the differences decreased over time. The authors conclude that more research is needed to determine what factors are most essential for effective peer support programs.<sup>25</sup>

There has been some research conducted on the role social support places in the well being of elderly populations. The Cornell Institute for Translational Research on Aging published a paper on reducing social isolation in older people, although the research does not focus specifically on those with SMI. A review of existing research found that group-based interventions, in particular those that were neighborhood-based, were effective in either reducing loneliness and or increasing social integration. Interventions that allowed for the expression of emotions had the greatest and longest lasting impact. One-on-one interventions that involved visits with the elderly person by a professional care person were not shown to be as effective.<sup>26</sup>

There has been limited research done on the question of whether providing opportunities for mental health consumers to interact with animals can increase social functioning and reduce isolation. Much of the literature describes anecdotal evidence of the benefits of animal interaction but there has been some more rigorous research conducted on this question. The studies identified regarding the use of animals both with mental health consumers and other populations all focused on the use of animals in institutional settings rather than community based settings.

One study which brought puppies weekly to chronically mentally ill residents of a community adult home found statistically significant improvements in measures of social interaction, psychosocial function, life satisfaction, mental function, depression, social competence, and psychological well-being. A second study involved bringing a dog into a psychiatric hospital ward. The study found an increase in interaction with other humans by patients following the dog’s visit. A third study examined the impact of using animals in group therapy sessions with psychiatric inpatients. The investigators report that patients in the animal group engaged in greater social interaction with other group members than did

---

<sup>24</sup> Phylis Solomon, “Peer Support/Peer Provided Services Underlying Processes, Benefits and Critical Ingredients, *Psychiatric Rehabilitation Journal*, 27. 4 (2004): 392-401.

<sup>25</sup> L. Davidson, M. Chinman, D. Sells and M. Rowe, “Peer Support Among Adults With Serious Mental Illness: A Report From the Field,” *Schizophrenia Bulletin*, 32.3 (July 2006): 443–450.

<sup>26</sup> Cornell Institute for Translational Research on Aging: Consensus Workshop Paper, Social Isolation: Strategies for Connecting and Engaging Older People, March 2007  
<http://www.citra.org/Assets/documents/Social%20Isolation.pdf> (November 4, 2011).

patients in the control group.<sup>27</sup> Finally, a program operated in New Zealand at a State Psychiatric Hospital has been using animals as therapy since the mid 1990s with positive outcomes.<sup>28</sup>

Various types of programs exist which provide supported volunteer opportunities for those with mental illness however a review of the research compiled by the Institute for Volunteer Researching in England notes that research identifying the mental health benefits of volunteering for those with mental illness is relatively rare. There has been more extensive research regarding the overall health benefits of volunteering among the general population including one study in which 81 per cent of people felt that volunteering had a positive effect on their mental health.<sup>29</sup> One study published in the *Journal of Developmental Disabilities* reported very positive results including increased self-confidence and more positive feelings about oneself from a supported volunteer program for persons with “complex disability needs.”<sup>30</sup>

## RACIAL, ETHNIC AND LANGUAGE FACTORS

A review of the literature suggests that an analysis of the factors that contribute to isolation as well as how to successfully outreach to those who are isolated and withdrawn must include recognition of racial and ethnic factors. A significant amount of research has been conducted on the disparities in mental health access by ethnic minorities and non-English speakers, including recommendations on more effectively outreaching to these populations. The most frequently cited research on this topic is the 2001 Surgeon General’s Report on *Mental Health: Culture, Race & Ethnicity* which clearly documented disparities in treatment based on race and ethnicity. The report states that racial and ethnic minorities have less access to and availability of care, receive generally poorer quality mental health services, and experience a greater disability burden from unmet mental health needs.<sup>31</sup>

The report includes a discussion of the cultural and social factors that contribute to mental illness including, the social and economic environment of inequality including racism, discrimination, violence, and poverty that leave minorities with greater exposure to mental illness; the racism and discrimination that have an adverse effect on mental health; the mistrust of mental health services that deters minorities from seeking help; and the clinical environments that are often inadequate to accommodate the needs of racial and ethnic minorities. Recommendations provided by the report were summarized by the American Psychiatric Association as follows:

- ▶ **EXPAND THE SCIENCE BASE.** This includes more research to assess the influence of variables such as acculturation, stigma, spirituality, socioeconomic status, education, and perceived discrimination on mental health outcomes. Further study is also needed on the efficacy of evidence-based treatments for racial and ethnic minorities, the differential response to medications by race and ethnicity, clinician bias and diagnostic accuracy, and the differences in

---

<sup>27</sup> L. Urichuk and D. Anderson, *Improving Mental Health Through Animal-Assisted Therapy*, The Chimo Project (2003)

<sup>28</sup> NHS Scotland, “Animals as Therapy in Mental Health: Guidance for establishing Animal Therapy in a Healthcare setting” (2007)

<sup>29</sup> “Volunteering and Mental Health: A Review of the Literature”, Institute for Volunteer Researching

<sup>30</sup> Becky L. Choma and Joanna Ochocka, “Supported Volunteering: A Community Approach for People With Complex Needs,” *Journal on Developmental Disabilities*, Vol. 12, No. 1 (2005)

<sup>31</sup> U.S. Department of Health and Human Services, *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General* (Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (2001).



stress, coping and resilience that will provide the groundwork for new prevention and treatment strategies.

- ▶ **IMPROVE ACCESS TO TREATMENT.** This includes improving geographic availability of mental health services, integrating mental health care and primary health care, improving language access, and coordinating care to vulnerable, high-need groups such as people who are incarcerated or homeless.
- ▶ **REDUCE BARRIERS TO MENTAL HEALTH CARE.** This requires addressing the cost of services, the fragmented organization of these same services, and the stigma toward mental illness.
- ▶ **IMPROVE QUALITY OF MENTAL HEALTH SERVICES.** The report encourages providers to deliver treatment based on evidence-based professional guidelines, with treatments being tailored to the individual according to the person’s age, gender, race, ethnicity, and culture. Further study of “ethnic- specific” and “culturally-competent” practice models may reveal how these models can contribute to important aspects of quality care for racial and ethnic minorities.
- ▶ **SUPPORT CAPACITY DEVELOPMENT.** All mental health professionals should develop their skills in tailoring treatments to age, gender, race, ethnicity and culture. However, racial and ethnic minorities are encouraged to enter the field because they are underrepresented among providers, researchers, administrators, policy makers, and consumer and family organizations. Further, leadership from within the community is required to better facilitate the design, planning and implementation of mental health service systems.
- ▶ **PROMOTE MENTAL HEALTH.** The reduction of negative social conditions such as poverty, community violence, racism, and discrimination is likely vital to improving the mental health of racial and ethnic minorities. Efforts to prevent mental illness and promoting health should build on community strengths such as spirituality, educational attainment, local leadership, and focus on families.<sup>32</sup>

Beyond this pivotal report, others have also examined issues related to race, ethnicity, and language and mental health access. In 2005, the California Department of Mental Health commissioned a study to assess existing language access policies. The focus of the study was to assess the effectiveness of California’s “threshold language” policy that requires Medi-Cal services to be provided in a patient’s native language if the number of beneficiaries in a County who speak that language is over 5% of the Medi-Cal population. The study additionally looked at three techniques to overcome language barriers: bilingual providers, cultural competency training, and ethnic- and language-specific treatment programs. The results suggest that, for Medi-Cal eligible consumers who speak Spanish or an Asian language, the threshold language requirements had a significantly positive effect on penetration rates. This policy appears to be effective in improving access, primarily in the counties that had the lowest access rates and fewest language-access activities prior to the initiation of the policy. The study also suggests that bilingual providers and language-specific clinics/programs have a positive effect on language access and, in some cases, have given a boost to the implementation of the threshold language policy.<sup>33</sup>

---

<sup>32</sup> National Alliance on Mental Illness, *Eliminating Disparities in Mental Health: An Overview*, 2006, [http://www.nami.org/Content/NavigationMenu/Find\\_Support/Multicultural\\_Support/Annual\\_Minority\\_Mental\\_Healthcare\\_Symposia/DisparitiesOverview.pdf](http://www.nami.org/Content/NavigationMenu/Find_Support/Multicultural_Support/Annual_Minority_Mental_Healthcare_Symposia/DisparitiesOverview.pdf) (November 4, 2011).

<sup>33</sup> J. Bloom, M. Masland, C. Keeler, N. Wallace and L. Snowden, “Overcoming Language Barriers to Public Mental Health Services in California,” *California Program on Access to Care, California Policy Research Center, University of California*, (April 2005): 1-2, <http://www.ucop.edu/cpac/documents/cpacfindings4.pdf> (November 4, 2011).

Results regarding the effectiveness of cultural competency training have been inconclusive.<sup>34</sup> A 2007 review of cultural competence models found that there is a wide range of effectiveness and that existing studies focused primarily on the satisfaction level of the professional receiving the training as an outcome measure rather than examining the experience of consumers more rigorously. More research is needed regarding the use of cultural competency training and the types of programs that are most effective.<sup>35</sup>

A 2007 report documented the results of a study of mental health access based on English language skills using data from the 2001 California Health Interview Survey (CHIS). The results were dramatic. In the whole sample, 51% of those who expressed a need for services and spoke only English received them, compared to 8% of those who did not speak English. This disparity held true when race/ethnicity and other associated factors, such as poverty, insurance status, U.S. nativity, and length of time in the United States were controlled. Since limited English proficiency (LEP) is concentrated among Asian/Pis and Latinos, the authors conclude that LEP contributes to racial/ethnic disparities in mental health care. The study also noted that members of minority racial/ethnic groups are particularly likely to seek help for mental health problems from primary care providers, yet the mental health concerns of minority patients are more likely to go unnoticed in primary care.<sup>36</sup>

Other studies have noted that barriers identified as negatively affecting the use of mental health–related services are likely more complex than just looking at English proficiency and that they include cultural barriers (e.g., stigma, loss of face, causal beliefs), culturally unresponsive services (lack of language match, lack of ethnic match, poor cross-cultural understanding), limited access to care (cost, lack of insurance coverage), and lack of awareness or understanding of services.<sup>37</sup> A 2007 study regarding Asian American access to mental health services found that individuals who were categorized as third or later generation had higher rates of use of any services (19.3%) than did individuals who were first (7.4%) or second (8.1%) generation, as well as higher rates of both specialty mental health and general medical care use. In contrast to some other studies, years in the United States and English language proficiency were not associated with service use at all.<sup>38</sup>

There has also been research conducted regarding the provision of mental health services to those who do not face potential language barriers including African-Americans and Native-Americans. As part of an earlier phase of the Innovations effort in Alameda County, the County commissioned a study on African American utilization of mental health services. The study found that African-American adults are often misdiagnosed and their conditions are often exacerbated by poverty. They often receive treatment in restrictive environments and most of them experience co-occurring conditions and may use substances as a way to self-medicate. Services are rarely delivered by clinicians who have a similar race and life experience to those who they are treating. The report cites a need for more culturally competent

---

<sup>34</sup> Bloom et al., 1-2.

<sup>35</sup> K. Bhui, N. Warfa, P. Edonya, K. McKenzie and D. Bhugra, “Cultural Competence in Mental Health Care: a Review of Model Evaluations,” *BMC Health Services Research*, 7:15 (2007), <http://www.biomedcentral.com/1472-6963/7/15> (November 4, 2011).

<sup>36</sup> T. Sentell, M. Shumway and L. Snowden, “Access to Mental Health Treatment by English Language Proficiency and Race/Ethnicity,” *Journal of General Internal Medicine*, 22.Suppl 2 (2007): 289–293.

<sup>37</sup> J. Abe-Kim, D.T. Takeuchi, S. Hong, N. Zane, S. Sue, M.S. Spencer, H. Appel, E. Nicdao, M. Alegría, “Use of Mental Health-Related Services Among Immigrant and US-born Asian Americans: Results from the National Latino and Asian American Study,” *American Journal of Public Health*, 97.1 (2007): 91-98.

<sup>38</sup> Abe-Kim et al., 91-98.



services, expanded peer counseling opportunities, improved coordination between County-operated agencies and improved mental health screening in the primary care setting.<sup>39</sup>

Mental health issues are of significant concern to Native American communities which have some of the highest rates of suicide in the nation. A review of factors that impact Native American mental health in 2005 found that, within Native American populations, stigma associated with mental illness can be a significant barrier to seeking treatment, although the degree to which stigma is a factor varies considerably by tribe and degree of assimilation of the individual into the dominant culture. The legacy of historical mistreatment at the hands of Caucasian Americans is also a significant factor that may impede a Native Americans' motivation to seek mainstream treatment. A third key issue is the need for mental health professionals who work with Native Americans to be culturally competent about the traditional belief systems that are embraced by the particular Native American group. For example, the conception of mental illness can range from a form of supernatural possession to the expression of a special gift to a hopeless, terminal stage of an illness. Many Native Americans embrace a view of health that is based on maintaining inner and outer balance. An understanding of the complexities surrounding this concept is essential to cultural competence.

## NEEDS BASED ON HOUSING SETTING

The target population as identified by ACBHCS specifically references those with SMI living with family members, in board and cares or in residential hotels. A review was conducted to determine if research exists which is specific to any of these three subcategories of living situations. Individuals with SMI living with family are not generally identified as a distinct population in the literature and as such, it is difficult to glean information that is specific to this subgroup. Individuals with SMI residing in hotels are also not identified as such in the literature other than in the context of utilizing hotels to implement housing-first models for homeless people.

Those living in board and cares have been researched to some degree as a distinct population. A study published in 2002 examined the relationship between the residential environment of seriously mentally ill patients living in board and care homes and quality of life. Participants included 162 seriously mentally ill veteran patients living in 26 board and care homes in Los Angeles. The study used structured interviews to assess participants' satisfaction with their living situation and general sense of well being, along with their level of social functioning and ability to engage in activities of daily living. Results from this study showed that social climate was significantly and positively associated with both satisfaction with current living situation and with general well-being. Interpersonal conflict was negatively associated with general well-being.<sup>40</sup> This implies that efforts to improve the quality of social interaction and mediate conflict within board and care homes could be of benefit to consumers residing in board and cares.

A second study published in 2000 evaluated the hypothesis that monthly case management visits would reduce the likelihood of psychiatric hospitalization because of case managers' ability to identify acute stressors during home visits and to intervene before patients relapsed and required hospitalization. The authors tracked veterans living in board and care homes in Los Angeles to determine if monthly home

---

<sup>39</sup> Alameda County Behavioral Health Care Services, *African American Utilization Report*, Winter 2011, [http://www.acinnovations.org/pdfs/AlamedaAARReport\\_FINAL.pdf](http://www.acinnovations.org/pdfs/AlamedaAARReport_FINAL.pdf) (November 4, 2011).

<sup>40</sup> A. Mares, A. Young, J. McGuire, R. Rosenheck, "Residential Environment and Quality of Life Among Seriously Mentally Ill Residents of Board and Care Homes," *Community Mental Health Journal*, 38.6 (Dec 2002) 447-458.

visits from case managers reduced the incidence of hospitalization. Among subjects in the program group who received the visits, the median number of psychiatric bed-days used decreased significantly from 59 days to 50 days over two years. No significant change in the median number was observed for comparison subjects suggesting that such home visits had a positive impact on the incidence of hospitalization.<sup>41</sup>

In addition to these two academic studies, the Robert Wood Johnson Foundation conducted an analysis in 1993 on how to improve the quality of life for elderly board and care residents. This report included the following findings:

- ▶ **Regulatory stringency did not appear to influence the number of services provided within the home.** This suggests that increased regulatory efforts may not lead to better care for elderly board and care home residents. Instead, efforts to facilitate connections of board and care homes with outside agencies may be a more fruitful approach to enhancing the quality of care.
- ▶ **Board and care staff that assist with drug administration typically have no medical training in drug management.** The report recommended regulatory intervention to ensure proper care for older residents of board and care homes including the involvement of pharmacists as part of the care process and mandated staff training programs in drug characteristics and management.

It is unclear from the research whether these problems continue to exist as little was found with more recent information.<sup>42</sup>

## STRATEGIES TO SUPPORT FAMILY MEMBERS

In addition to a review of relevant literature regarding the identified consumer target population, a review of strategies to support family members of those with mental illness was also undertaken. Strategies to improve outcomes for mental health consumers through intervention with family members have focused largely on what is known as a psychoeducational approach. In 1997 William McFarlane described two different models of psychoeducation. The single-family model includes individual sessions with family members conducted by clinicians and attendance at educational classes. The multiple-family model combines the elements of the single-family model with the creation of social support networks between families designed to reduce isolation and stigma. McFarlane presents evidence of the effectiveness of the multi-family model of engagement.<sup>43</sup>

A 2001 literature review looked at twenty-five studies that examined the effect of including relatives in schizophrenia treatment. This analysis clearly found that including the relatives in treatment programs is an effective way of reducing relapse and rehospitalization rates in schizophrenia patients. The success of family interventions was particularly evident when these interventions lasted longer than 3 months. The study found that both psychoeducational interventions (such as educational lectures and educational relatives' groups) and intensive therapeutic interventions (including family and group therapy) were both effective at reducing relapse and hospitalization. Studies which tracked results over

---

<sup>41</sup> Alvin Mares and James McGuire, "Reducing Psychiatric Hospitalization Among Mentally Ill Veterans Living in Board-and-Care Homes," *Psychiatric Services*, 51 (July 2000): 914-921.

<sup>42</sup> Robert Wood Johnson Foundation, *Board and Care Homes Vary in Services Offered, Need Stricter Regulation*, December 1997, <http://www.rwjf.org/reports/grr/016772s.htm> (November 4, 2011).

<sup>43</sup> William McFarlane, "Family Psychoeducation: Basic Concepts and Innovative Applications," in S. Henggeler & A. Santos, eds., *Innovative Approaches for Difficult-to-Treat Populations*, (Washington, D.C.: American Psychiatric Press, 1997), 211-238.

the long term after the cessation of the intervention seem to indicate that such intervention's effects last for months or years beyond the treatment. Another finding noted was that family interventions did not only improve the competence of relatives in dealing with the patients, implying that fewer rehospitalizations became necessary due to acute crises, but actually decreased the occurrence of acute crises considerably.<sup>44</sup>

In 2006, the VA sponsored a forum to identify challenges to implementing family psychoeducation and involving families in mental health care, as well as determining how to best move forward to expand effective family programs. Four themes were identified from this conference:

1. Psychoeducational programs (defined as programs which have an emphasis on illness education, an empathic stance, formal or informal problem-solving training, and support for treatment adherence) which last at least nine months are effective at reducing symptomatic relapse and hospitalization rates and in improving medication compliance in schizophrenia. Adequate research, however, has not been conducted to determine which variables, such as proportion of time the consumer is present in the family sessions, the location of the intervention (home, clinic, or both), the degree of emphasis on formal skills training, the format (individual, group, or combination), the intensity of contact (weekly, biweekly, or monthly), and the length beyond nine months impact program effectiveness.
2. A top down mandate from agency leadership to implement family psychoeducation will not lead to sustainable programs unless mechanisms for additional and continued supports are built in to such programs. Key stakeholders, clinic-level opinion leaders, and potential referral sources should be involved in the planning process from the outset.
3. Psychoeducation should not be the only family-based intervention studied. This may include community-based services such as the National Alliance on Mental Illness' Family-to-Family education program which utilized a peer education model and briefer interventions for those with less need.
4. It is important to identify the expected outcomes of family involvement in care within each of the two broad program categories (less intensive family education and consultation and family psychoeducation).<sup>45</sup>

More recent studies have taken the model further by examining how to incorporate the recovery model more concretely into family support programs. The authors of a 2006 study note that with the shift from a medical model to a recovery model, the center of care becomes an active "consumer" of services, not a passive "patient" to be treated. They are supportive of this shift and express the perspective that while basic level family interventions are in accord with a recovery orientation insofar as they are primarily community-focused there are ways to fine tune these models to be more in line with the recovery model.<sup>46</sup>

---

<sup>44</sup> G. Pitschel-Walz, S. Leucht, J. Bäuml, W. Kissling and R. Engel, "The Effect of Family Interventions on Relapse and Rehospitalization in Schizophrenia — A Meta-Analysis," *Schizophrenia Bulletin*, 27.1 (2001): 73–92.

<sup>45</sup> A. Cohen, D. Perlick, S. Glynn, A. Rotondi, A. Murray-Swank, S. Sayers, C. Barrio, M. Sherman, E. Fischer, L. Dixon and S. McCutcheon, "The Family Forum: Directions for the Implementation of Family Psychoeducation for Severe Mental Illness," *Psychiatric Services*, 59 (January 2008): 40-48..

<sup>46</sup> S. Glynn, A. Cohen, L. Dixon and N. Niv, "The Potential Impact of the Recovery Movement on Family Interventions for Schizophrenia: Opportunities and Obstacles," *Schizophrenia Bulletin*, 32.3 (2006) 451–463.

The authors' perspective is that many existing models embrace more of a "successful management of a chronic illness" theme rather than a recovery orientation and that the value of consumer peer support is not incorporated sufficiently into existing models. Another issue raised by the authors is the perspective from their own review of existing literature that most family support models assume that the family member is the biological parent of the consumer. The authors found in their own research review that little attention is paid to spouses, children and siblings of consumers although these family members are increasingly being found in the caregiver role. Also noted was that little attention is paid to phase-of-life issues, and that interventions offered within the broad spectrum of services for adults differ little regardless of the age of the consumer. Similarly, they indicate that not enough attention has been paid to cultural differences and how that impacts the effectiveness of different family intervention models.

Another concern raised in their research is that families often have very little access to the treatment team. "Most empirically validated family interventions were designed as contained 'treatments' to be provided by mental health professionals for a specific number of sessions to accomplish well-articulated goals (e.g., improve knowledge about the illness, increase problem-solving skills). Although participants might be coached informally about how to interact optimally with members of the mental health treatment team, this effort was almost never a core component of any of the existing manuals, and little systemic effort was spent on the provider's side to expand the concept of the treatment team formally to include family members."<sup>47</sup>

Finally, the authors cite evidence indicating that participation in family support programs is generally low and the authors note that the barriers and impediments to participation should be further researched. Although there is not much research about these barriers, the authors speculate that barriers may include that "consumers may not wish their families to be involved in treatment, or may be too unstable to participate in regular appointments themselves. Family members may not understand their relative is ill, may not want any involvement with mental health professionals, may not wish to have contact with their relative, may encounter logistical impediments in coming to sessions (no transportation, only available at night when the staff is not available), may be ill themselves, may have other caretaking responsibilities, or may feel stigmatized by their relative's illness. Mental health providers may already be overburdened with large caseloads and not believe they have the time to meet with families. They may have a clinical orientation that emphasizes individual autonomy over family interdependence, may feel unskilled in interacting with families and providing family interventions, may be provided with no support from management to meet the special needs of families (e.g., longer sessions, meeting in the evenings, larger meeting rooms), and/or they may be concerned about lack of reimbursement for family services. Furthermore, the consumer, family member, or provider may be too demoralized to want to engage in a new round of intervention."<sup>48</sup>

## CONCLUSION

Existing research provides insight into potentially promising practices and effective outreach strategies to successfully engage isolated and withdrawn adults and older adults with SMI living with family, in board and cares or in hotels as well as their families. The literature also highlights areas where additional research and evaluation is needed to determine the efficacy of specific approaches.

---

<sup>47</sup> Glynn et al., 451–463.

<sup>48</sup> Glynn et al., 451–463.

## APPENDIX D: METHODS

This project was commissioned by the Alameda County Department of Behavioral Health Care Services (BHCS) to develop a demographic analysis and provide a summary of the significant behavioral health care needs of the target population defined as “*adults and older adults with serious mental illness (SMI), who are isolated and withdrawn, living with families or in board and care homes or hotels, and their families.*” The purpose of the project was to provide BHCS with an analysis of the needs of the target population to inform the development of learning questions; to recommend outreach and engagement strategies; and to provide other pertinent information regarding the target population.

Specific deliverables required for the project include

- ▶ a demographic profile of the target population;
- ▶ a brief literature review on the population and community and evidence-based practices to address the population’s behavioral health needs;
- ▶ ten focus groups, including groups with adults, older adults and family members, and including one in every supervisorial district and five targeting underserved ethnic and language populations and inappropriately-served populations; and
- ▶ individual interviews for more in-depth information addressing the specific needs of the target population.

All deliverables were required to be completed and submitted within 67 calendar days (48 working days) of the contract start. The rest of this section describes the methods used to complete each of the project deliverables and to develop the suggested learning questions and final report.

**Literature Review:** A review of the academic and professional literature was conducted using internet search tools and incorporating literature referenced by interviewees. The search used terms that included “isolated adults with mental illness,” “mental illness and social isolation,” “mental illness and race,” “mental illness and language access,” “isolated and withdrawn adults with serious mental illness,” “board and care isolation,” “family psychoeducation,” “withdrawn adults with mental illness,” “elders and mental health,” “schizophrenia and social functioning,” “schizophrenia and social isolation,” “bipolar and social functioning,” “bipolar and social isolation,” “major depression and social functioning,” “major depression and social isolation,” and “mental health peer support.” In addition, when appropriate sources were identified, the bibliographies of these sources were reviewed for additional relevant research. In general, a review of more recent literature was prioritized, however in some cases where there was a particular dearth of current research, older studies and reports have been cited. The literature review is provided in full in Appendix C: Literature Review and was also used to inform the Demographic Profile and the rationale for the suggested learning questions.

**Demographic Profile:** The project required the submission of a profile to “identify and describe the target population” including size, age range, ethnic, cultural and linguistic composition, and geographic distribution. To create this profile, the consultants used prevalence information from the literature review, estimates from key informant interviews, and three data sets.

- ▶ **DATA SET 1—GENERAL POPULATION:** The consultants used data from the 2010 Census and the 2005-2009 *American Community Survey* to describe the overall population in Alameda County in terms of age, gender, race, ethnicity and geography; apply estimates of the prevalence of serious mental illness from the California Mental Health Services Act; and to develop estimates of the range of rates of mental illness and isolation.

- ▶ **DATA SET 2—ADMINISTRATIVE DATA:** BHCS provided a de-identified dataset from its INSYST system on just over 11,000 unduplicated consumers who received any service between January 1, 2010 and October 27, 2011, including information on age, gender, race, ethnicity, and geography, as well as primary and secondary diagnosis, and most recent services. This data was used to describe the over and underrepresented populations in the current service system, analyze service utilization issues, and to develop estimates of the potential size of the target population.
- ▶ **DATA SET 3—MENTAL HEALTH STATISTICS IMPROVEMENT PROGRAM SURVEY DATA:** BHCS provided a de-identified dataset from a countywide consumer satisfaction survey, the *Mental Health Statistics Improvement Program (MHSIP) Consumer Perception Survey*, conducted during May 2009. This survey consists primarily of questions regarding how the respondents feel about their experiences with services they have received, and questions addressing consumers' perspective on their own quality of life, especially as it relates to social relations and their living situation. Information on the age, gender, race, and ethnicity of the respondent is coded as well as the geographic location at which the survey was administered (though not that of the respondent's home address). This information was used to help estimate the potential size of the target population and to identify racial, gender, and geographic differences within the potential target.

**Focus Groups:** Ten focus groups with consumers and family members were held throughout the county between October 27 and November 15, 2011. Each focus group followed a similar protocol and had both a facilitator and a recorder present. Eighty-eight consumers and 33 family members participated. The following chart summarizes the focus groups held, their location, supervisorial district, primary target population, and attendance.

Date	Location	Super- visorial District	Primary Target Population	Attendance
10/27/11	Oakland Family Education & Resource Center (FERC)	4	Family members	7
11/5/11	Tri-Valley National Alliance on Mental Illness (NAMI)	1	Family members	9
11/8/11	Hedco House	2	Older Adults	9
11/10/11	Afghan Coalition	1	Afghani Adults/Older Adults	9
11/12/11	Alameda Co. & East Bay NAMI	4	Family members	17
11/14/11	Berkeley Drop-in Center	5	African American Adults/Older Adults	18
11/14/11	La Familia	2	Latino Adults/Older Adults	8
11/14/11	Asian Mental Health	3	Asian Adults/Older Adults	20
11/15/11	West Oakland Mental Health	3	African American Adults/Older Adults	4
11/15/11	Native American Health Center	4	Native American Adults/Older Adults	20
<b>Total</b>				<b>121</b>

Focus groups explored what contributes to isolation, what assists in decreasing isolation, who isolated persons were most likely to connect with and what places they would go, and what ideas they had for decreasing the isolation of the target population. Information from the focus groups was used to inform the demographic profile, provide rationale for the learning questions, and inform the recommended

outreach and engagement strategies. A detailed summary of the focus group participation, results and a copy of the protocol can be found in Appendix B: Focus Group and Interview Summary.

**Interviews:** Nine structured interviews were held with advocates and practitioners in the field. (*Several interviews included the participation of more than one person from an agency or organization.*) Forty-five to 90 minute, in-person and telephone-based interviews were conducted with representatives from organizations with significant target population experience as well as organizations serving populations at risk for mental illness and isolation. An interview tool was used to ensure consistent coverage of key study questions. Additional information was also provided in these interviews that has informed this report.

Organization	Primary Target Population	Primary Contact	Location
African-American Family Support	African American family members	Margot Dashiell	Oakland
Aging and Family Services	Older Adults	Dr. Ray Grimm	Fremont
BACS Senior Home Services	Older Adults with mental illness	Mitchell Foudray	Oakland
Center for Independent Living	People with Disabilities	Demetrius Johnson	Berkeley
Crisis Support Services	Adults in crisis	Nancy Salamy	Oakland
Mental Health Association	Mental health consumers and their families	Steve Bischoff	Oakland
NAMI East Bay	Family members	Liz Rebensdorf	Albany
St. Mary’s Center	Homeless and marginally housed Older Adults	Sr. Mary Nolan	Oakland
Telecare STAGES	Older Adults with mental illness	Leslie Kaplan	Oakland

Interviewees were asked about who they thought would be included in the isolated population, what contributes to isolation, what assists in decreasing isolation, who isolated persons were most likely to connect with and what places they would go, and what ideas they had for decreasing the isolation of the target population. The interviews were also helpful to understanding the current system of care and their programs/facilities. Please see Appendix B: Focus Group and Interview Summary for a list of persons and organizations included in the interviews and a copy of the interview tool. In addition to formal interviews, several conversations with staff at BHCS were helpful in learning about the current system of care and ideas regarding the target population and strategies.

All of the research methods (termed “deliverables” in the work agreement) were used to inform the creation of the population profile and suggested learning questions, and to provide recommendations for outreach and engagement strategies that the Department can use for its existing programs and services.



## APPENDIX E: SUMMARY TABLE OF DATASETS USED FOR NEEDS ASSESSMENT

Data Source	Dataset #1 Census 2010, ACS 05-09	Dataset #2 BHCS Adults and Older Adults Served 2006-2011	Dataset #3 MHSIP Consumer Perception Survey, May 2009
Total N in dataset (# cases)	1,510,271	11,019	1,484
Percent	100.0%	100.0%	100.0%
<b>AGE GROUPS</b>			
Adult 18-59	923,050	9,283	1,308
Percent	61.1%	84.2%	88.9%
Older Adults 60+	246,600	1736	164
Percent	16.3%	15.8%	11.1%
<b>GENDER</b>			
Male	740,573	4,992	839
Percent	49.0%	45.3%	57.3%
Female	769,698	5,976	626
Percent	51.0%	54.2%	42.7%
<b>RACE</b>			
Caucasian	709,450	2,976	514
Percent	47.0%	27.0%	34.9%
African American	194,135	3,709	502
Percent	12.9%	33.7%	34.1%
Amer. Indian, Alaskan Native	8,002	48	6
Percent	0.5%	0.4%	0.4%
Asian/Pacific Islander	383,322	1,358	192
Percent	25.3%	12.3%	13.0%
Other Race	150,290	676	29
Percent	10.0%	6.1%	2.0%
Two or More Races	65,072	N/A	N/A
Percent	4.3%	N/A	N/A
<b>ETHNICITY</b>			
Hispanic	339,889	2,252	207
Percent	22.5%	20.4%	14.1%
Not Hispanic	1,170,382	8,767	1,265
Percent	77.5%	76.6%	85.9%
<b>GEOGRAPHY</b>			
North	616,411	5,352	447
Percent	40.8%	49.8%	50.2%
Central	366,577	2,930	248
Percent	24.3%	27.3%	27.8%
South	325,166	1,220	114
Percent	21.5%	11.4%	12.8%
East	202,117	467	82
Percent	13.4%	4.3%	9.2%
		(does not total 100% due to persons with out of county addresses)	( based on location survey was administered; only 60% have a location identified)



## APPENDIX F: MHSIP RESULTS: SOCIAL RELATIONS AND LIVING ARRANGEMENTS

ACBHCS provided a de-identified dataset from a county-wide consumer satisfaction survey, the *Mental Health Statistics Improvement Program (MHSIP) Consumer Perception Survey*, conducted during May 2009. This information was used both to help estimate the potential size of the target population and to identify ethnic, gender, and geographic differences within the potential target population.

Questions in the survey ask respondents how they feel about various aspects of their lives. Most questions relate to their satisfaction with the services they have received but some questions address the respondent’s perspective on their own quality of life, as it relates to social relations and their living situation. Answer choices include “Terrible,” “Unhappy,” “Mostly Dissatisfied,” “Mixed,” “Mostly Satisfied,” “Pleased” and “Delighted.” Information on the age, gender, race, and ethnicity of the respondent is coded as well as the geographic location at which the survey was administered (though not that of the respondent’s home address).

For the rest of this analysis the percent reported as “dissatisfied” are those responding with an answer choice of Terrible, Unhappy, or Mostly Dissatisfied. It should be noted that this survey was given at 48 services sites across the county so the respondents were persons engaged in support services and probably do not fully represent the most socially isolated persons with SMI in the county.

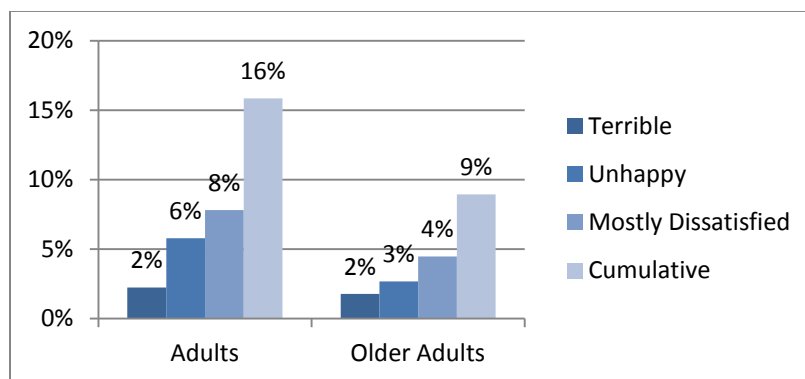
### OVERALL RATES OF DISSATISFACTION WITH SOCIAL RELATIONSHIPS

For each of four questions analyzed from the survey related to quality of life and feelings about social relations, approximately 8-10% of respondents answered that they felt “terrible or unhappy.” Another 7-10% in each question answered that they were “mostly dissatisfied.” We were unable to analyze whether the same persons are providing the same answers on these questions.

### FEELINGS ABOUT SOCIAL RELATIONSHIPS AND FRIENDSHIPS

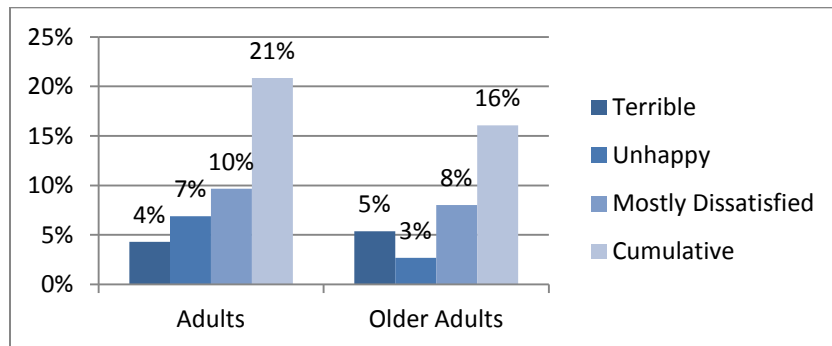
Questions analyzed regarding quality of time and relationships with other people include “how do you feel about the amount of time you spend with other people?” and “how do you feel about the amount of friendship in your life?” Sixteen (16%) of adults were dissatisfied with the amount of time they spend with other people while only 9% of older adults reported being dissatisfied.

**Table 1: Amount of Time Spent with Other People — Age**



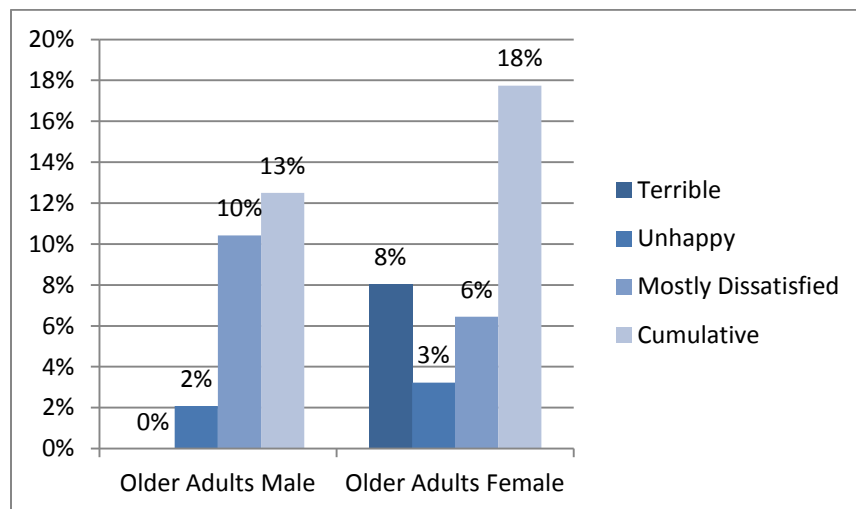
Both groups had higher rates of dissatisfaction with the amount of friendship in their lives, 21% of adults and 16% of older adults expressing dissatisfaction.

**Table 2: Amount of Friendship in Your Life — Age**



Overall, males (20%) and females (22%) express similar rates of dissatisfaction in the amount of friendship in their lives, but among older adults it was notably different: 11% of females responded they felt “terrible” or “unhappy” compared to only 2% of older adult males.

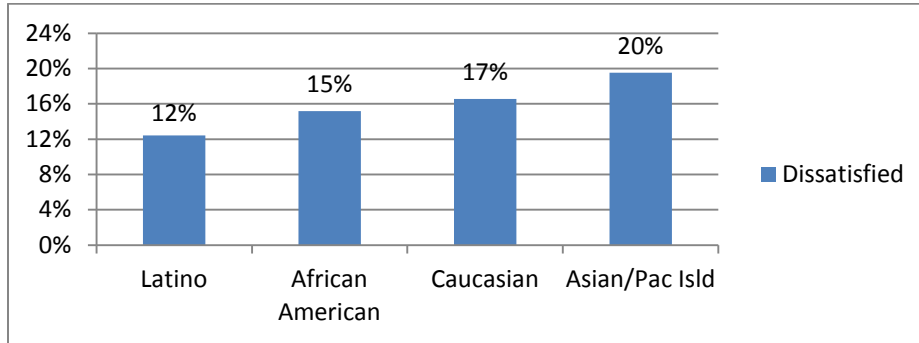
**Table 3: Amount of Friendship in Your Life — Older Adults by Gender**



In terms of ethnic groups, Asian Pacific islanders were the most dissatisfied with the amount of time that they spent with other people (20%) while Latinos were the least dissatisfied (12%).<sup>49</sup>

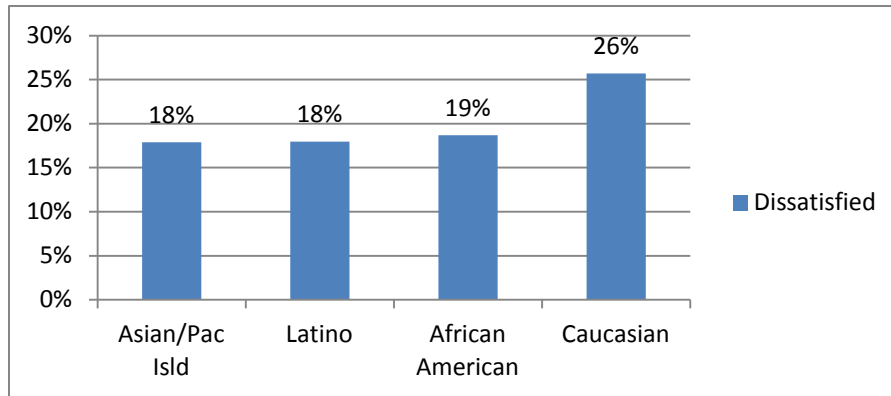
<sup>49</sup> Note: the number of responses from those who identified as Native American or Other was too small for analysis. Also, due to small numbers in each category, analysis of Older Adults by ethnic group was not conducted.

**Table 4: Amount of Time Spent with Other People — Ethnicity**



Caucasians, on the other hand, were the most dissatisfied with the amount of friendship in their life (26%) while African Americans, Asians and Latinos reported between 18 and 19% dissatisfaction with the amount of friendship in their life.

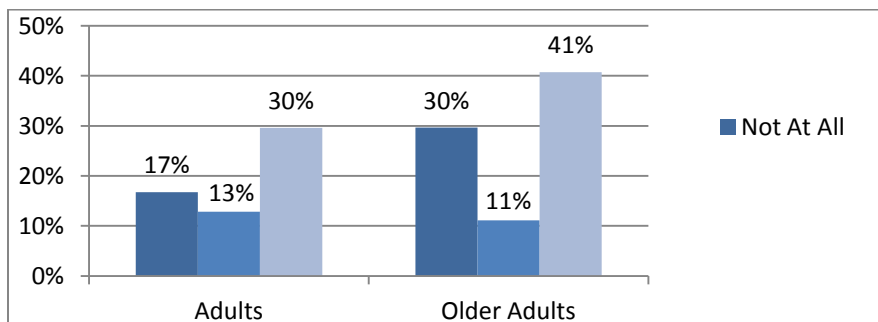
**Table 5: Amount of Friendship in Your Life — Ethnicity**



## FREQUENCY OF VISITING WITH OTHERS

Asked “how often do you visit with someone who doesn’t live with you?” 30% of adults responded they saw someone less than once a month (13%) or not at all (17%). While this question was not included in the survey specifically targeted to older adults, 27 older adults answered the adult survey, and 41% of these answered either less than once a month (11%) or not at all (30%).

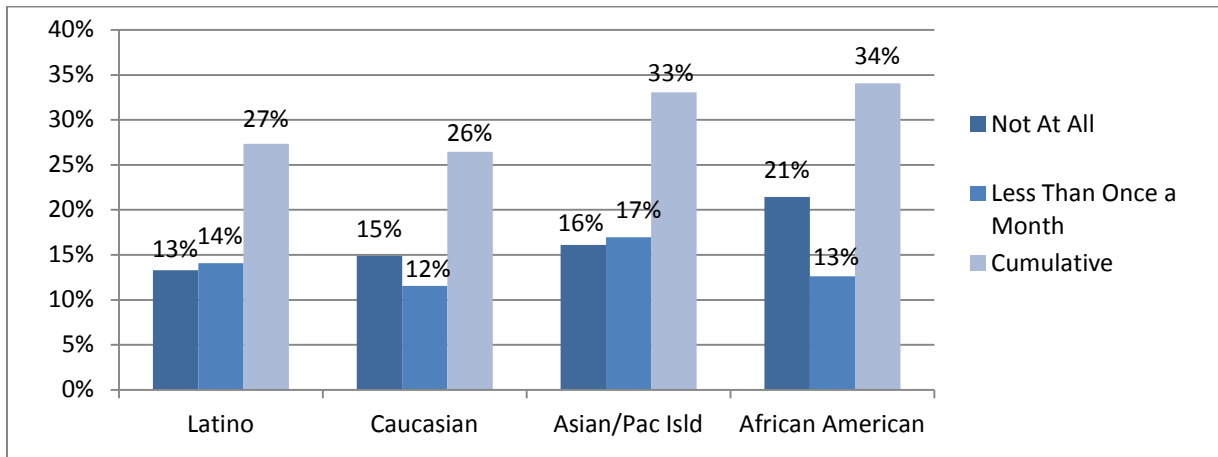
**Table 6: How Often Visit Someone Who Does Not Live With You — Age**



Males in the data set reported higher rates of having no visitors (20%) versus females (13%).

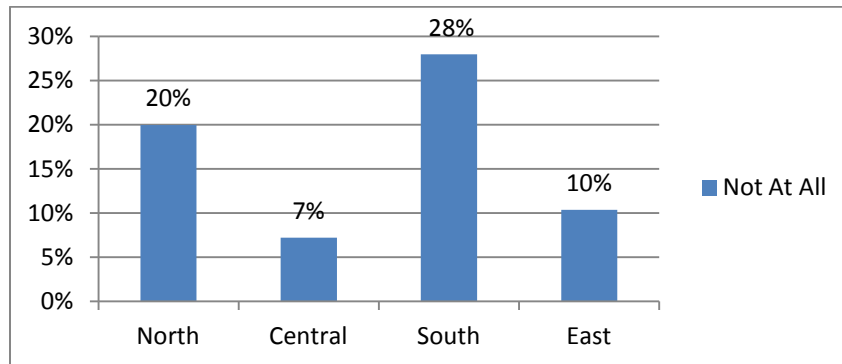
African-American adults reported the highest rate of not seeing another person with whom they do not live at 21%, Asian and Pacific islanders 17%, Caucasians 15% and Latinos 13%.

**Table 7: How Often Visit Someone Who Does Not Live With You — Ethnicity**



Geography was a notable factor in terms of how often people saw someone else. Twenty (20%) of North County residents said they never visited with another person, 7% in Central County, 28% in South County, and 10% in East County. It should be noted that County designation is based on where the person receives their services, not where they are living.

**Table 8: How Often Visit With Someone Who Does Not Live With You — Geography**

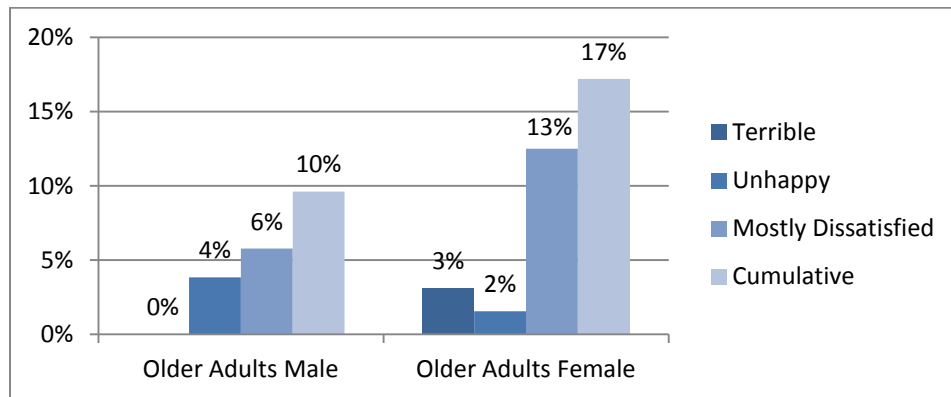


## QUESTIONS ABOUT LIVING SITUATION

Asked “how do you feel about the living arrangements’ where you live” approximately 17% of adult respondents of both sexes expressed their dissatisfaction with their living arrangements, including 10% who responded “Terrible or Unhappy.”

There was no notable difference in dissatisfaction with living arrangements by gender in the total data set. However for older adults, 17% of females were dissatisfied with their living arrangements as compared to only 10% of older adult males.

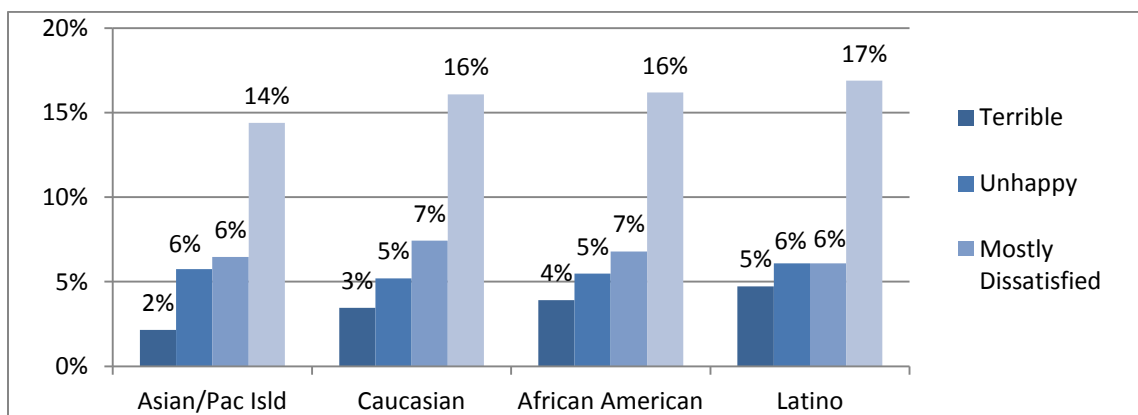
**Table 9: How Feel About Living Arrangements — Older Adults by Gender**



Twenty-three percent (23%) of all adults were dissatisfied with the prospect of living where they were living for a long period of time while only 14% of older adults were similarly dissatisfied with the prospect of continuing to live there for a long period.

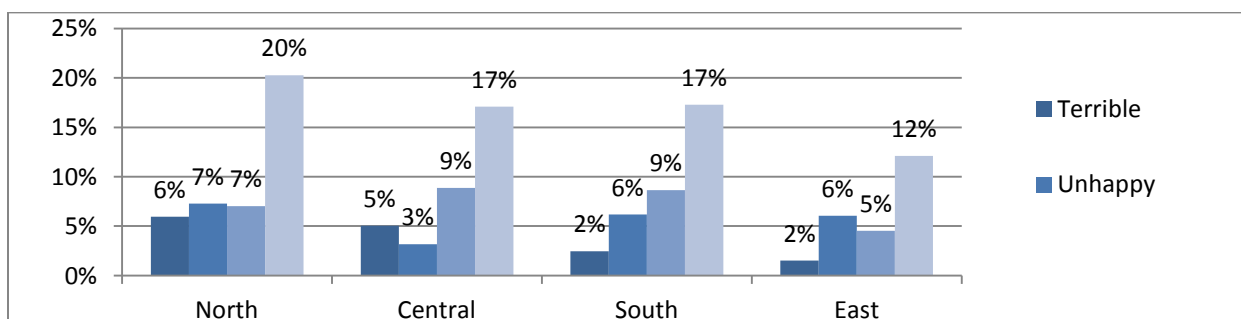
Dissatisfaction by race and ethnicity ranged from 14% of API who were dissatisfied with their living situation up to 17% of Latinos, with Caucasians and African-Americans both reporting approximately 16%.

**Table 10: How Feel About Living Arrangements — Ethnicity**



Geographically, people living in North County were the most dissatisfied with their living situation (20%) while people living in East County were the least dissatisfied (12%), Central and South County both reported 17% dissatisfaction.

**Table 11: How Feel About Living Arrangements — Geography**



## APPENDIX G: BIBLIOGRAPHY

- J. Abe-Kim, D.T. Takeuchi, S. Hong, N. Zane, S. Sue, M.S. Spencer, H. Appel, E. Nicdao, M. Alegría, "Use of Mental Health-Related Services Among Immigrant and US-born Asian Americans: Results from the National Latino and Asian American Study," *American Journal of Public Health*, 97.1 (2007): 91-98.
- Alameda County Behavioral Health Care Services, *African American Utilization Report*, Winter 2011, [http://www.acinnovations.org/pdfs/AlamedaAARReport\\_FINAL.pdf](http://www.acinnovations.org/pdfs/AlamedaAARReport_FINAL.pdf) (November 4, 2011).
- Alameda County Behavioral Health Care Services, *Revised Mental Health Services Act Community Services & Support Plan*, (January 17, 2006).
- Alameda County Mental Health Association, "Results of 2010 Committee on Isolation" (unpublished), 2010
- A. Barbato, G. Agnetti, B. D'Avanzo, M. Frova; A. Guerrini and M. Tettamanti, "Outcome of Community-Based Rehabilitation Program for People with Mental Illness Who are Considered Difficult to Treat (2007)," *Journal of Rehabilitation Research & Development*, 44.6 (2007): 775–783.
- Brian Barry, *Social Exclusion, Social Isolation and the Distribution of Income*, Governance and Social Development Resource Centre (GSDRC) (1998)
- K. Bhui, N. Warfa, P. Edonya, K. McKenzie and D. Bhugra, "Cultural Competence in Mental Health Care: A Review of Model Evaluations," *BMC Health Services Research*, 7:15 (2007), <http://www.biomedcentral.com/1472-6963/7/15> (November 4, 2011).
- J. Bloom, M. Masland, C. Keeler, N. Wallace and L. Snowden, "Overcoming Language Barriers to Public Mental Health Services in California," *California Program on Access to Care, California Policy Research Center, University of California*, (April 2005): 1-2, <http://www.ucop.edu/cpac/documents/cpacfindings4.pdf> (November 4, 2011).
- Becky L. Choma and Joanna Ochocka, "Supported Volunteering: A Community Approach for People with Complex Needs," *Journal on Developmental Disabilities*, Vol. 12, No. 1 (2005)
- A. Christensen, R. Dornink, S. Ehlers, S. Schultz, "Social Environment and Longevity in Schizophrenia," *Psychosomatic Medicine* (1999) 61: 141-145
- A. Cohen, D. Perlick, S. Glynn, A. Rotondi, A. Murray-Swank, S. Sayers, C. Barrio, M. Sherman, E. Fischer, L. Dixon and S. McCutcheon, "The Family Forum: Directions for the Implementation of Family Psychoeducation for Severe Mental Illness," *Psychiatric Services*, 59 (January 2008): 40-48.
- Cornell Institute for Translational Research on Aging: Consensus Workshop Paper, Social Isolation: Strategies for Connecting and Engaging Older People, March 2007 <http://www.citra.org/Assets/documents/Social%20Isolation.pdf> (November 4, 2011).

- L. Davidson, M. Chinman, D. Sells and M. Rowe, "Peer Support among Adults with Serious Mental Illness: A Report from the Field," *Schizophrenia Bulletin*, 32.3 (July 2006): 443–450.
- N. Drew, "Combating the Social Isolation of Chronic Mental Illness," *Journal of Psychosocial Nursing and Mental Health Services*, 29.6 (1991): 14-17.
- Duke Today, "Americans have fewer friends outside the family, Duke study shows," <http://today.duke.edu/2006/06/socialisolation.html> (June 23, 2006)
- S. Glynn, A. Cohen, L. Dixon and N. Niv, "The Potential Impact of the Recovery Movement on Family Interventions for Schizophrenia: Opportunities and Obstacles," *Schizophrenia Bulletin*, 32.3 (2006) 451–463.
- Harder + Company, "A Brief Profile of San Francisco's Socially Isolated, Older Adults," Prepared for San Francisco Department of Public Health, October 2011.
- W. Hirschberg, "Social Isolation among Schizophrenic Out-patients," *Social Psychiatry*, (1985) 20: 171-178
- Stephen Ilardi, *Social Isolation: A Modern Plague*, Psychology Today, <http://www.psychologytoday.com/blog/the-depression-cure/200907/social-isolation-modern-plague> (November 4, 2011).
- R. Kessler, J. McLeod, S. Cohen (Ed) and L. Syme (Ed), "Social Support and Mental Health in Community Samples," *Social Support and Health*, xvii (1985): pp. 219-240.
- Heather Knight, "Library adds social worker to assist homeless," *San Francisco Chronicle*, January 11, 2010
- Jolene Lansdowne, The Links between Social Support and Improved Health Outcomes, *The SMART Fund, Vancouver Coastal Health*, 2011  
[http://www.smartfund.ca/docs/social\\_support\\_improved\\_health\\_outcomes\\_report\\_jan2011.pdf](http://www.smartfund.ca/docs/social_support_improved_health_outcomes_report_jan2011.pdf) (November 4, 2011).
- Kathy Latimer, *Erie County: Project Elder Reach*, Mental Health and Aging, <http://www.mhaging.org/info/latimer.html> (November 4, 2011).
- F. Lipton, C. Cohen, E. Fischer, S. Katz, "Schizophrenia: A Network Crisis," *Schizophrenia Bulletin*, 7:1 (1981) 144-151
- A. Mares, A. Young, J. McGuire, R. Rosenheck, "Residential Environment and Quality of Life Among Seriously Mentally Ill Residents of Board and Care Homes," *Community Mental Health Journal*, 38.6 (Dec 2002) 447-458.
- Alvin Mares and James McGuire, "Reducing Psychiatric Hospitalization Among Mentally Ill Veterans Living in Board-and-Care Homes," *Psychiatric Services*, 51 (July 2000): 914-921.

- B. McCorkle, E. Rogers, E. Dunn, A. Lyass and Y. Wan, "Increasing Social Support for Individuals with Serious Mental Illness: Evaluating the Compeer Model of Intentional Friendship," *Community Mental Health Journal*, 44.5 (2008): 359-366.
- William McFarlane, "Family Psychoeducation: Basic Concepts and Innovative Applications," in S. Henggeler & A. Santos, eds., *Innovative Approaches for Difficult-to-Treat Populations*, (Washington, D.C.: American Psychiatric Press, 1997), 211-238.
- Vijaya Murali and Femi Oyeboode, "Poverty, Social Inequality and Mental Health," *Advances in Psychiatric Treatment* (2004) 10: 216-224
- National Alliance on Mental Illness, *Eliminating Disparities in Mental Health: An Overview*, 2006, [http://www.nami.org/Content/NavigationMenu/Find\\_Support/Multicultural\\_Support/Annual\\_Minority\\_Mental\\_Healthcare\\_Symposia/DisparitiesOverview.pdf](http://www.nami.org/Content/NavigationMenu/Find_Support/Multicultural_Support/Annual_Minority_Mental_Healthcare_Symposia/DisparitiesOverview.pdf) (November 4, 2011).
- NHS Scotland, "Animals as Therapy in Mental Health: Guidance for establishing Animal Therapy in a Healthcare setting" (2007)
- OECD, *Society at a Glance: OECD Social Indicators*, OECD (2005), Paris
- Office of the Deputy Prime Minister, "Mental Health and Social Exclusion Social Exclusion Unit Report," June 2004, London.
- T. Persky, "Overlooked and Underserved: Elders in Need of Mental Health Care," *Journal of the California Alliance for the Mentally Ill*, 9 (1998): 7-9.
- G. Pitschel-Walz, S. Leucht, J. Bäuml, W. Kissling and R. Engel, "The Effect of Family Interventions on Relapse and Rehospitalization in Schizophrenia — A Meta-Analysis," *Schizophrenia Bulletin*, 27.1 (2001): 73–92.
- M. Pope, "Determinants of Social Functioning in Bi-polar Disorder," *Bipolar Disorders* 9 (2007) 38-44
- S. Priebe, J. Watts, M. Chase and A. Matanov, "Processes of Disengagement and Engagement in Assertive Outreach Patients: Qualitative Study," *The British Journal of Psychiatry*, 187 (November 2005): 438-443.
- Robert Wood Johnson Foundation, *Board and Care Homes Vary in Services Offered, Need Stricter Regulation*, December 1997, <http://www.rwjf.org/reports/grr/016772s.htm> (November 4, 2011).
- C. Rodriguez, M. Elkind, L. Clemow, M. Di Tullo, R. Sacco, S. Homma, B. Boden-Albala, "Association Between Social Isolation and Left Ventricular Mass," *American Journal of Medicine*, (February 2011) 124(2): 164-70
- M. Rowland, B. Burns, G. Schafft, F. Randolph, and C. McAninch, "Innovative Services for Elderly Populations," in S. Henggeler & A. Santos, eds., *Innovative Approaches for Difficult-to-Treat Populations*, (Washington, D.C.: American Psychiatric Press, 1997), 289-310.



- W. Rubin and P. Panzano, "Identifying Meaningful Subgroups of Adults with Severe Mental Illness," *Psychiatric Services*, 53 (April 2002): 452-457.
- T. Sentell, M. Shumway and L. Snowden, "Access to Mental Health Treatment by English Language Proficiency and Race/Ethnicity," *Journal of General Internal Medicine*, 22.Suppl 2 (2007): 289–293.
- Phylis Solomon, "Peer Support/Peer Provided Services Underlying Processes, Benefits and Critical Ingredients," *Psychiatric Rehabilitation Journal*, 27. 4 (2004): 392-401.
- U.S. Department of Health and Human Services, *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General* (Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (2001).
- L. Urichuk and D. Anderson, Improving Mental Health Through Animal-Assisted Therapy, The Chimo Project (2003)
- A. Van Citters and S. Bartels, "A Systematic Review of the Effectiveness of Community-Based Mental Health Outreach Services for Older Adults," *Psychiatric Services*, 55 (November 2004): 1237-1249.

## APPENDIX H: ACKNOWLEDGMENTS

Many persons and organizations assisted the consultants in the preparation of this report. In addition to the many consumers, family members, advocates, and providers who met with us in ten focus groups, and interviewees who gave generously of their time (and are listed in Appendix H), the authors would like to thank the following people for their assistance:

- ▶ Staff and volunteers with the family groups assisted in the scheduling of meetings including Steve Bishoff, Karina Foote, Liz Rebensdorf, Marsha McInnis, Margot Dashiell and Austra Jauger.
- ▶ Community agencies assisted with the scheduling, advertisement, and translation for consumer focus groups. Instrumental agencies included Asian Community Mental Health Clinic, Native American Health Clinic, Alameda County Network of Mental Health Clients, West Oakland Health Center, Bay Area Community Services, La Familia, and the Afghan Coalition.
- ▶ Several staff at Alameda County BHCS assisted us by providing information and insight including Linda Leung Flores, Toni Tullys, Gigi Crowder, Dr. Robert Ratner, Dr. Aaron Chapman, Peter Alevizos, Lillian Schaechner, Clint Nix, Rosa Warder, Margaret Walkover, Jay Mahler, Tracy Hazelton, Janet Biblin, and Chris Shaw.
- ▶ Malik Looper and Renu Madan took notes and assisted with focus group set-up and facilitation.
- ▶ Phil Alonso of Focus Strategies put in countless hours gathering, cleaning and analyzing data.
- ▶ Harder and Company generously shared their project summary and focus group protocols from a related study in San Francisco.

## APPENDIX I: ABOUT THE CONSULTANTS



**Focus Strategies:** Focus Strategies works with communities to use locally-available data to identify the unmet needs of underserved populations, assess current system and program outcomes and allocate resources effectively. To do this, Focus employs data analysis and community facilitation with stakeholders to identify areas of strength and strategies to achieve improvement. Focus Strategies is a joint venture of Katharine Gale Consulting and MKS Consulting—firms specializing in improving community efforts to increase affordable housing and end homelessness. For this project, Katharine Gale, Focus co-principal acted as project manager and primary author. Megan Kurteff Schatz oversaw data analysis and assisted in the development of the final report.

### KORWIN CONSULTING

*Advancing Social Justice Solutions*

**Korwin Consulting:** Korwin Consulting works closely with government institutions, nonprofits, and philanthropic organizations conducting needs assessments, evaluations, and other planning efforts. Using a blend of demographic data analysis, key informant interviews, focus groups, literature review, group facilitation, and surveys, Korwin Consulting has conducted evaluations and needs assessments at the local, state, and national levels.

For this project, Korwin Consulting partnered with Debbie Raucher (**Debbie Raucher Consulting**) and Kerry Abbott (**Abbott Consulting**) to conduct the focus groups and key informant interviews. Raucher and Abbott are Bay Area based consultants who have extensive experience with populations that are traditionally viewed as harder to engage. Raucher has been working in the fields of housing, homelessness and mental health for 15 years and has worked as a consultant since 2007, providing services to local governments and non-profit organizations. Abbott has more than 20 years of experience in housing and human services work and has performed focus group and needs assessment work in Alameda, San Francisco, San Mateo, and Contra Costa Counties.