

JANUARY 2005

# Mind, Mood and Message:

Pathways in Community Behavioral Health

> "Five million people visit the Grand Canyon each year, and only 1.2% go below the rim. It's like that with behavioral health – less than 2% of us gain insight into who we are."

Faith-based organization

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**St. Luke's Health Initiatives** A Catalyst for Community Health

## Mind, Mood and Message: Pathways in Community Behavioral Health

Learning begins with listening:

"Parenting factors are enormous. Children are parenting children over generations. We've lost mature parents."

Clinical coordinator, children and family service organization

"People come here and see people just like them.

People don't think they're crazy – it's such a relief."

*"If we are doing our jobs, people never know they saw a behavioral health person."* 

Counselor, community health center

"I'm suspicious of gurus like Oprah and Dr. Phil. However, I do hear from my wife and mother that they tune in and find connections with what's going on."

CEO, health management business

"When my mother died, my primary care doctor gave me six weeks worth of antidepressant free samples. He never even talked to me about my needs. He said the #1 prescription he writes is antidepressants. I threw them away."

Counselor, faith-based organization

Yoga instructor

*"We seek understanding, not help."* 

"I see a lot of business executives who have a problem with alcohol. Many think they'll lose their sense of humor if they go to AA, but they find their sense of humor and creativity increases from going to AA."

Barber

"Personally, I've gained the most benefit from support groups and workshops that have been geared toward transformation – the experiential group events."

Physician's assistant

"Dealing with mental health is not cool. This is a strong message."

Psychiatrist, Latino population

"My son got involved with drugs. I took him to the hospital, and they told me that if my son did not want to be admitted and cure himself, that I could not force him to be admitted. This is a silly law."

Recent immigrant

"If we go into a church, a school, a neighborhood and set up a parent resource center, people will show up. But if you advertise that a behavioral health agency is here to do assessments and offer services, no one will show up, especially in Hispanic neighborhoods. It's all in how you package it." Administrator

These quotes are excerpts from recent transcripts of personal interviews and focus groups in the greater Phoenix metro area. Together with new survey and medical encounter data, as well as a review of a growing body of literature on the stunning diversity of attitudes and approaches toward what many people would prefer to call *anything* but 'mental' and 'behavioral' health, they inform this *Arizona Health Futures* issue brief on pathways people use to address these issues in their communities – and how we can connect those pathways to improve the health of us all.

"Forty percent of our client base with diabetes are also seen for anxiety and depression. It's a big, big issue."

Counselor, central city clinic

## Informing **Principles**

This report builds on two earlier AHF issue briefs – one on the integration of physical and mental health, and the other on the power of the resilience model.<sup>1</sup> Here, we articulate the formal and informal pathways people in a fast growing and fragmented urban area use to address issues of mind, mood and health; explore related issues of definition and culture; review what works – and what doesn't – and draw some preliminary conclusions for education, community development and public policy.

While – horrors! – we would never be so bold as to draw conclusions based on common sense as distinct from looking at the "data" first, this research is informed by several principles gleaned from our work over the past five years in health policy and community development:

- LANGUAGE MATTERS. How we describe something determines to a large extent how we regard and react to it. The language of mind and mood as it is embedded in our institutions and techniques is often out of sync with how people actually experience the world.
- THE SELF IS SOCIAL. Left to our own devices, we find myriad ways to connect with each other. Creating and sustaining positive and life affirming social connections is vitally important. One of the ironies of the "medicalization" of the mind – and technological progress generally – is that it can foster isolation as well as recovery.
- HEALTH IS GROUNDED IN BASIC SOCIOECONOMIC CONDITIONS. The idea that a behavioral health service professional can "treat" individuals and families without attending to basic issues of housing, food, education and employment is not only naïve, but pernicious.
- MIND, BODY AND SPIRIT ARE OF ONE PIECE. Our institutions and programs, unfortunately, are not.
- INDIVIDUALS AND COMMUNITIES ARE REMARKABLY RESILIENT. Our dominant culture of deficits and needs often masks the strengths and assets we already have at hand to shape a positive future together.

We will have more to say about these informing principles as we proceed. As always, we invite response to further our common understanding and purpose.

## Background

In 1999 SLHI issued *Into the Light*,<sup>2</sup> a report on Arizona's public behavioral health system for persons with a serious mental illness (SMI). Since then, we have published several other reports on the SMI population, supported the work of mental health education and advocacy organizations, worked with a number of public and private agencies on issues of funding and access to community services, and focused on specific projects such as developing a *Sourcebook for Families Coping With Mental Illness*<sup>3</sup> and establishing *The Family Involvement Center* to address the needs of children with significant mental disorders.<sup>4</sup>

In the process we confirmed that behavioral health issues in Arizona extend far beyond persons with serious mental illnesses and are in fact endemic at every level and strata of society, with huge consequences for the future if left ignored. While trying to avoid the often unproductive and politicized distinctions between what is *serious* and what isn't; or what is an *illness* and what is some type of character, psychological or environmental *defect*, we decided to see if we could map these issues in some useful way.

#### **Basic Questions**

But exactly *what* should we map? Using a broad brush, we sketched out a series of issues in areas such as depression, anxiety, mood disorders and suicide, alcohol and drug abuse, loss and grief, chronic and significant stress, rage and violence, and emotional disturbances in children. While each of these is an important topic in its own right, we thought a good place to begin might be to map them *generally* across the Phoenix metro region by asking a series of questions:

- 1. Are these in fact the major behavioral health issues in the Phoenix metro area? Are there others?
- 2. What is the range of frequency and severity of these issues across the targeted population?
- 3. What attitudes and beliefs exist regarding these issues?
- **4.** What are the formal pathways people use to address these issues in their communities? What are the *informal* pathways?
- 5. How effective are these pathways these approaches and responses?
- **6.** To what degree do these issues manifest differently across demographic descriptors such as age, income and ethnicity? How do attitudes and responses differ?
- **7.** What gaps exist in addressing these issues in our communities? What strengths? How are they related to public policy and community development?

Instead of pursuing these questions solely on the basis of a *risk and deficit model* – need assessment, diagnosis and treatment that inevitably lead to recommendations for more professional services and programs – we opted to emphasize a resilience-based framework in a more preliminary investigation – a type of *environmental scan* – to see what we might uncover by way of opportunities to build on the existing strengths of people and communities to address these issues through further analysis, public education and community development in collaboration with a growing list of community partners.

SLHI ADDRESSED ISSUES IN AREAS SUCH AS

- Depression
- Anxiety
- Mood disorders and suicide
- Alcohol and drug abuse
- Loss and grief
- Chronic and significant stress
- Rage and violence
- Emotional disturbances in children



## Research Design

Research was conducted over a six-month period between April-October 2004. Limited to Maricopa County alone, it combined both quantitative and qualitative methods to address the questions on the previous page, as well as a critical analysis of secondary literature sources.

- The process began with a meeting of nine community leaders with expertise across a broad dimension of community health issues to help frame the questions and methodologies based on their experience and insights, and to recommend a broader list of individuals and groups to participate in the study.
- A Individual interviews were conducted with 27 additional community experts and leaders. Areas included psychiatric medicine, psychology and counseling, faith-based human services and church ministries, employer-based initiatives and EAP programs, public school resources, drugs and alcohol, alternative health care providers, health clinics with an integrated behavioral health component, mental health research, personal life coaching, leadership development, meditation, yoga, personal services (barber, sports guide, etc.), art therapy, Native American and Latino programs and issues, parenting and children's issues, and the gay/lesbian/ bisexual/transgender community.
- Five consumer focus groups were held: Three English-speaking groups segmented by income categories; a bilingual English-Spanish group of individuals who had lived in Maricopa County for an extended period of time; and a monolingual Spanish group of recent immigrants who had lived in the county for less than two years.
- Two provider focus groups were conducted: A more "formal" group comprised of behavioral health care professionals, and a "less formal" group that included providers of alternative therapies and personal services.
- A quantitative Community Behavioral Health Survey was conducted by telephone with randomly selected residents of Maricopa County. The survey included both original questions designed to address the research questions and further topics raised in the qualitative focus group research, and questions designed and validated by previous research: The Connor-Davidson Resilience Scale (CD-RISC)\* and the SF36 Health Status Questionnaire, which measures functional status and well-being in terms of physical and emotional health.
- The Arizona HealthQuery Database, an integrated database of medical encounter records, was used to preliminarily determine the prevalence of behavioral health issues in Maricopa County in clinical settings over a one-year period (2002-2003).
- The current body of secondary literature was reviewed and analyzed across 15 topics: healthy communities and resilience; mental health statistics; culture, race and ethnicity as they relate to mental health; depression, mood disorders and suicide; anxiety disorders; stress and mental health; emotional disturbances in children and adolescents; complementary and alternative medicine (CAM); loss and grief; substance abuse; integration of behavioral health and primary care; behavioral consequences of chronic health conditions; rage and violence; employee assistance programs (EAPs); work/life solutions and workplace productivity; and grandparents raising grandchildren.

\* Connor-Davidson Resilience Scale ©2001, 2003 Kathryn M. Connor, MD, Jonathan R.T. Davidson, MD. All Rights Reserved.

The research team is listed on page 38.

## Mind, Mood and Message

The history of public attitudes toward mental illness over the past half century underscores the importance of the words we use to describe complex physical and psychological phenomena, the images attached to them in the mass media, and the indelible impression messages containing those words and images make on the general public.

To no great surprise, the meaning of the message isn't always the one intended.

Surveys indicate that while Americans have more scientific knowledge and greater understanding of issues concerning mental illness compared to fifty years ago, this knowledge has done little to decrease social stigma.<sup>5</sup> Ample evidence to the contrary notwithstanding, many people associate mental illness with increased violence and loss of control. This in turn engenders fear, and fear feeds stigma.

#### Going 'Mental'

The word 'mental' becomes polluted in the process. Despite the commonplace assertion that "mental health is a state of successful performance of mental function..." and that mental health and mental illness are points along a continuum,<sup>6</sup> large numbers of people pick up on the negative connotations of 'mental' – going crazy, losing your mind, being out of control (as in "Don't go mental on me") – and use the word more as an expression of social exclusion and opprobrium than as a descriptor of some vital characteristic of their own state of health.

As a result, it's legitimate to wonder whether the term 'mental' is too embedded in the darkness of illness, fear and loss of control to ever take on the light of positive emotional well-being and health, and ought to be avoided in clinical practice.

#### Is 'Behavioral' Any Better?

behavior

But what to replace it with? Some practitioners prefer the term 'behavioral,' which connotes a focus on selected manifestations of mental states – behaviors – and cuts a wider swathe than a focus on illness alone. In probing both practitioner and consumer focus groups on

some of these issues as part of this report, we asked people what they thought of terms like 'behavioral' and 'mental,' and whether there were other

terms they preferred to use to refer to issues of mind, mood and emotions. To summarize:

> Both the formal and alternative provider groups voiced strong objections to using the terms 'mental health' and 'behavioral health' to describe their services. These were thought to be "too clinical," and too much associated with a medical and disease model of health, from which many of them wished to distance themselves.

In their work with individuals and groups, practitioners prefer to see themselves as facilitators, managers, counselors and healers, and to use language that is strength-based, client-based and focused on hope and recovery.

O Consumers, too, did not like to use the terms 'mental' and 'behavioral' to describe the range of psychological and emotional issues they encounter in their lives, but were nevertheless quick to describe their feelings and emotions (angry, anxious, depressed) and seek ways both to understand and improve their particular situation.

○ Some defined a "mental problem" as something you *can't* control yourself without medical intervention (therapy, drugs), and a "behavioral problem" as something you *can* control yourself, although it often helps to have the support of others.

Many people associate mental illness with increased violence and loss of control. This in turn engenders fear, and fear feeds stigma. ○ Most consumers readily identified *others* as having a "mental problem," but this wasn't a term they were comfortable in using to describe *their* problem.

#### A Language of Connection

These responses suggest one key to the language quandary: The models we use to describe the world do not necessarily reflect the way we experience it.

Terms like 'mental' and 'behavioral' are grounded in clinical models of research, diagnosis and treatment. As science breaks down the biological and psychological components of behavior and reassembles them in ever more sophisticated and powerful technological interventions, the language of *fragmentation* is mapped onto the *unity* of mind, body and spirit in the human experience, with the predictable result of alienation and dislocation – the *Humpty Dumpty Syndrome* described in an earlier *Arizona Health Futures* report.

Both practitioners and consumers in the focus groups were unanimous in their discomfort with the reductionist language of the medical model and searched for a common language of **CONNECTION**, a way to describe the unity of mind and body that science – ironically – confirms through dissection.

We will return to explore the language of connection further, and how it can it be empowered through the pathways people use in their communities to address common issues of mind, mood and healing.

## Modern Life: Doing the Numbers

Issues related to mental/behavioral health are endemic in modern societies like the United States, where rapid economic, social and cultural change engenders equally frantic biological and psychological dislocation and adjustment.

The World Health Organization estimates that the "burden of disease" of neuropsychiatric disorders, self-inflicted injuries and violence accounted for 15.8% of all disability and death throughout the world in 2002 – but 30.2% in countries like the United States, where these disorders are more prevalent.<sup>7</sup>

There are myriad ways to count this. Studies in the late 1990s estimated the U.S. direct costs for mental health and substance abuse treatment to be between 7-8% of total direct health care spending, and 15-16% of all indirect costs (loss of productivity at work or school, disability, etc.). Together, these numbers would add up to approximately \$270 billion in 2004, assuming the percentages remain roughly the same.<sup>8</sup>

But these numbers, as large as they are, don't necessarily tell the full story. They may miss behavioral health issues treated under other physical diagnoses (e.g., depression in people with diabetes) by primary care practitioners, treatment not recorded in some "formal" system of care (cash payments to independent counselors, etc.) and a wide variety of care and support provided informally (faith-based groups, support groups, etc.).

According to a recent national survey,<sup>9</sup> 27% of American adults – 59 million people – received some form of mental health treatment in the past two years. Another 24 million people – just over one in ten of the total adult population – experienced sufficient distress to warrant treatment, but didn't receive it.

Even this doesn't begin to capture the breadth and depth of behavioral and emotional issues in our "postmodern" world. More importantly, it neither defines nor acknowledges the remarkable diversity of connections people make in their communities to work through what they much prefer to define as issues of *emotional well-being*.

## Valley Mind and Mood:

### A Community Behavioral Health Survey

SLHI commissioned a public survey of Maricopa County residents in September 2004 to inform the following questions:

- **1.** What are the self-reported prevalence and range of mental and behavioral health care issues and needs in the Valley?
- **2.** How do people respond when these issues arise in their lives? How do they perceive the effectiveness of treatment and support?
- **3.** What attitudes exist regarding issues of confidentiality, cost and stigma associated with seeking care?
- 4. How resilient are Valley residents when it comes to addressing a wide range of "life issues?"

## Health Status

A sizable proportion of Maricopa County residents reported some level of limitation in their normal routines during the past month as a result of physical health or emotional problems.

#### **Physical Health**

- ♦ 40% ACCOMPLISHED LESS than they would have liked with work/activities, and were significantly more likely to report:
  - Lower income
  - Separated or widowed
  - Age 30 or younger, or 46 or older
- **33% WERE LIMITED IN WORK/ACTIVITIES** and were significantly more likely to report:
  - Lower income
  - Single, divorced, separated or widowed
  - Age 30 or younger, or 46 or older
- **33% HAD DIFFICULTY PERFORMING WORK/ACTIVITIES,** and were significantly more likely to report:
  - Lower income
  - Age 30 or younger, or 46 or older
- **23% CUT DOWN ON THE AMOUNT OF TIME** spent on work/activities, and were significantly more likely to report:
  - Lower income
  - Divorced, widowed or separated
  - Age 30 or younger, or 46 or older

45% of respondents said that physical health or emotional problems interfered with normal social activities with family, friends, neighbors or groups within the past month.

#### Emotional Problems (depression, anxiety, etc.)

- **32% ACCOMPLISHED LESS** than they would have liked with work/activities.
- **21% DID NOT DO WORK/ACTIVITIES AS CAREFULLY** as usual.
- **20% CUT DOWN** on the amount of time spent on work/ activities, and were significantly more likely to report:
  - Age 18-30 or 46-59

#### Together

Almost half (45%) of respondents said that physical health or emotional problems interfered with normal social activities with family, friends, neighbors or groups within the past month. Women were significantly more likely to report some level of interference than men.

## Survey Methodology<sup>10</sup>

The research instrument included both original questions and questions designed and validated by others:

- The Connor-Davidson Resilience
  Scale (CD-RISC) was used to develop
  a "resilience score" for each participant.
  Comprised of 25 items, the CD-RISC
  instrument has been used and validated
  extensively in other settings.<sup>11</sup>
- A subset of questions from the SF36 Health Status Questionnaire<sup>12</sup> was used to assess limitations in activities related to physical and emotional health problems.
- Original questions were designed to address research objectives and to gather more information on issues introduced by the qualitative research (focus group) participants conducted prior to the field survey.

Results are based on 385 completed interviews, with a 5% margin of error or less.

## Resilience

The resilience of people in Maricopa County – their ability to cope with stress and thrive in the face of adversity – is relatively strong.

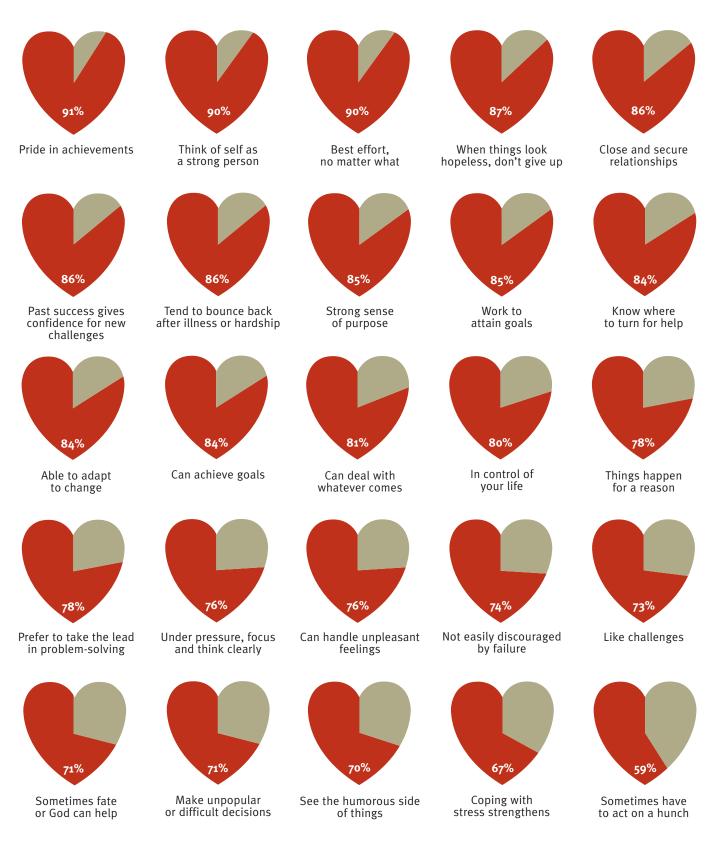
The mean resilience score for Valley residents was 81.4 (standard deviation 12.7) on a 100-point scale. This is comparable to the mean of 80.4 (standard deviation 12.8) for another general population sample measured by the developers of the CD-RISC instrument.<sup>13</sup>

- In the Valley population, there is a statistically significant association between a lower resilience score and:<sup>14</sup>
  - Younger age
  - Lower income
  - Latino/Hispanic origin
  - Asian/Pacific Islander racial identification
- There is no statistically significant association between resilience score and level of education or marital status.
- There is a statistically significant association between a *lower resilience score* and respondents who reported experiencing the following limitations during the past month, as measured by the SF36 Health Status Questionnaire:
  - Accomplished less than would have liked as a result of physical health.
  - Were limited in the kind of work or other regular daily activities as a result of physical health.
  - Had difficulty performing work or other regular daily activities as a result of physical health.
  - Cut down on the amount of time spent on work or other regular daily activities as a result of emotional problems, such as feeling depressed or anxious.
  - Accomplished less than would have liked as a result of emotional problems.
  - Did not do work or other regular daily activities as carefully as usual as a result of emotional problems.
  - Physical health or emotional problems interfered with normal social activities with family, friends, neighbors or groups.
- There is a statistically significant association between resilience score and other aspects of behavioral health measured by the survey. Individuals with a *lower resilience score* were significantly:
  - More likely to have participated in a 12-step program, like AA. This was the only one of the response behaviors measured that showed an association with resilience.
  - More likely to report depression, anxiety, relationship problems, a problem with drugs, a problem controlling anger, experiencing grief that lasted longer than it should have and/or attention deficit disorder at some point in their lives.
  - More likely to report the use of prescription medications in the past three years to help with a personal, emotional or mental health problem.
  - Less likely to feel certain that conversations and records would be kept confidential if they or a family member sought professional services for an emotional or mental health issue.
  - More likely to report that concerns about out-of-pocket costs would be likely to keep themselves or a family member from seeking professional treatment.

Resilience is the ability of individuals to cope with stress and thrive in the face of adversity.

## The **Heart** of Resilience

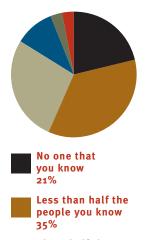
Valley residents view themselves as optimistic, capable and resilient. Respondents at the following percentage levels reported that these items were true often or true nearly all of the time during the past month:



#### **BOTTLED UP**

**Respondents in the** qualitative phase of the project reported that many people bottle up their feelings or withdraw from others when facing emotional challenges. Survey participants were asked about their perception of how many people take this approach. The responses suggest that almost two-fifths of the population is likely to withdraw when facing problems.

#### PERCEPTIONS ABOUT BOTTLING FEELINGS/ WITHDRAWING



About half the people you know 27%

More than half the people you know 10%

Almost everyone you know 3%

Not sure 3%

## A Portrait of Prevalence

## Valley residents reported experiencing the following problems at some time in their lives:

Problem	Percentage
Problems with relationships, such as spouse or significant other	46%
Depression	35%
Problem with controlling anger	26%
Anxiety or being unreasonably afraid of things	25%
Grief that lasted longer than you think it should have	23%
Trouble in raising children, beyond what you'd consider normal challenges	14%
Eating disorder	13%
Problem with alcohol	10%
Attention deficit disorder (respondent's condition, not including family)	9%
Problem with drugs, either prescription or street drugs	8%

- Women were more likely to have experienced depression and/or an eating disorder.
- Men were more likely to have had a problem with alcohol and/or with controlling their anger.

## **Response** and Relief

When asked to consider the range of issues and stress in daily life, having a difficult time emotionally, or being worried about psychological well-being:

- ♦ 60% would try to handle it on their own, then talk or seek help if they didn't feel they were improving.
- ∳ 26% would talk with or seek help right away from another person.
- № 14% would handle it on their own, without ever talking to anyone else.
- Women were significantly more likely to talk or seek help from another person right away, while men were more likely to try to handle it on their own, without ever talking to anyone else.
- Individuals with higher levels of education were more likely to say that they would try to handle a problem on their own for a while, then talk or seek help if they didn't feel they were improving.



#### When is it Time to Seek Help?

When asked an open-ended question about *how they would know if it was time to seek professional help* for themselves, a family member or a close friend, the following indicators were mentioned in order of frequence:

- **1.** Abnormal behavior patterns (eating, sleeping, mood swings, crying)
- 2. Unable to function as usual, affecting job, family, daily activities
- 3. Can't solve the problem by themselves
- 4. Depression, sadness, unhappiness
- 5. Don't know how to tell
- 6. Feeling out of control, overwhelmed, lost

# What Works

Respondents were asked if they had ever responded in any of the following ways to stress or emotional problems, and if so, the degree to which they found it helpful:

RESPONSE	PERCENTAGE	FOUND IT VERY HELPFUL
Spent time alone to think things through	89%	55%
Talked about the problem with a family member, friend or co-worker	81%	53%
Prayed about the situation	79%	60%
Talked about the problem with a spouse or significant other	75%	58%
Engaged in physical exercise	67%	57%
Sought help from a minister, priest, rabbi or other spiritual advisor	41%	65%
Sought help from a mental health professional such as a psychologist, counselor, therapist, psychiatrist or social worker	36%	55%
Sought help from a primary care physician	30%	53%
Participated in a circle of people who come together for a specific purpose, and share leadership and responsibility	26%	69%
Engaged in yoga or meditation	24%	54%
Gone to an organized support group other than a 12-step program	15%	71%
Attended a class or workshop focused on the issue	15%	48%
Sought help from an alternative provider (hypnotherapy, energy work, body work or acupuncture)	11%	52%
Sought help from an Employee Assistance Program (EAP)	11%	35%
Participated in a 12-step program, such as AA	10%	54%

The responses that received the highest percentage of "very helpful" assessments were:

- Going to a support group other than 12-step program (71%)
- Participating in a circle (69%)
- Seeking help from spiritual advisor (65%)

Conversely, the low percentage of individuals who sought help from an EAP program (11%) – and found it "very helpful" (35%) – is notable.

#### BEHAVIORAL HEALTH LITERACY?

The fifth most common response was not knowing how to tell when it was time to seek professional help. This is of interest in light of the resilience scale (CD-RISC), where 84% of respondents indicated they would know where to turn for help. It suggests that while people have knowledge about sources of help, they may lack behavioral health literacy about when it is appropriate to access professional services.

### Demographic Factors

Some of the more significant associations between ways of seeking help and demographic factors are the following:

- ✓ Women were more likely than men to have talked about the problem with a family member, friend or co-worker; to have sought help from a primary care physician; to have attended a class or workshop on the problem; to have participated in a circle and/or to have prayed about the problem.
- ✓ People ages 45 and younger were more likely to have participated in a 12-step program like AA.
- ✓ Those who identified themselves as Latino/Hispanic or Asian/Pacific Islander and respondents ages 60 and older were less likely to say they sought help from a mental health professional.

✓ Those who identified themselves as Latino/Hispanic or Asian/Pacific Islander were less likely to have talked about the problem with a family member, friend or co-worker.

✓ Those of Latino/Hispanic origin were less likely to say they sought help from a primary care physician or alternative provider and/or engaged in some type of physical exercise when having a difficult time emotionally.

 $\checkmark$  Those who identified themselves as White were more likely to have attended a class or workshop on the problem.

### **Prescription** Medications

✓ 14% of respondents reported taking prescription medications in the past three years to help with a personal, emotional or behavioral health problem. Of these, 66% had been taking the medication 12 months or longer. Overall, 69% of those taking a medication found it "very helpful."

✓ Women were significantly more likely – and Latino/Hispanic respondents less likely – to say they had taken a medication.

### Herbal Therapies

10% of respondents reported taking herbs such as St. John's Wort, Kava, Gingko or Valerian in the past three years to help with a personal, emotional or behavioral health problem. Of these, 32% found it "very helpful," while 43% said it was "not at all helpful."

### Stigma

Based on data collected during the qualitative research phase of this project, respondents were told, "We've heard that pride, embarrassment or a fear of being labeled with a mental health diagnosis keeps some people from seeking professional help." Participants were then asked about their perceptions of stigma as a stumbling block among the people they know. Valley residents *did not think stigma issues are a problem* for a majority of people. Responses are shown to the right.

The perception among survey participants that stigma is not a major factor in seeking help is contrasted with the views of many practitioners in the research focus groups, who said stigma was a major reason why more people didn't seek help. In addition to differences among practitioners and consumers in how terms like 'mental' and 'behavioral' are defined and used, it's possible that survey respondents were uncomfortable in acknowledging the stigma – fear – that many of them felt.

### **Confidentiality** Issues

- ✓ 50% of respondents would be extremely or very certain that if they or a family member sought professional services for an emotional or mental health issue, their conversations and records would be kept strictly confidential. 46% were only somewhat or not at all certain, and 4% weren't sure.
  - Latino/Hispanic and Asian/Pacific Islander respondents were significantly less likely to be certain about confidentiality.
- ✓ 41% said concerns about confidentiality would be very or somewhat likely to be a barrier to seeking professional treatment, while 55% said this was not at all likely to be a barrier, and 4% weren't sure.
  - Respondents of Latino/Hispanic origin and other minority racial/ethnic groups were more likely to say confidentiality concerns might keep them from seeking treatment.
- ✓ 62% said concerns about their insurance company knowing that they sought professional behavioral health services would not be at all likely to keep them or a family member from using insurance coverage for treatment. 31% said this was somewhat or very likely to be a barrier, while 5% weren't sure.

PERCEPTIONS OF STIGMA AS A STUMBLING BLOCK



The perception among survey participants that stigma is not a major factor in seeking help is contrasted with the views of many practitioners in the research focus groups.

# Snapshot! Mental Disorders in Maricopa County

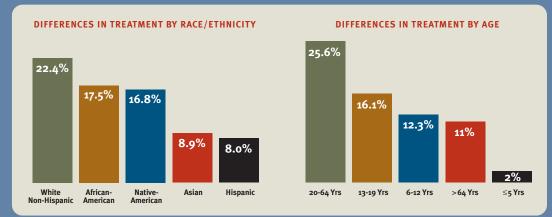


Arizona HealthQuery Database is an integrated database of inpatient and outpatient records that is supported by SLHI and is in the process of being developed by researchers at the School of Health Management and Policy, W.P. Carey School of Business, Arizona State University. To flesh out the prevalence of behavioral health issues in Maricopa County from another perspective, SLHI reviewed medical encounter records in the *Arizona HealthQuery Database*, an integrated database of inpatient and outpatient records that is supported by SLHI and is in the process of being developed by researchers at the School of Health Management and Policy, W.P. Carey School of Business, Arizona State University.

Although the database is still under construction, and medical information is being added and updated all the time, we thought it would be instructive to review information already entered into the system to determine in a preliminary way the incidence of mental disorders in Maricopa County, defined here as receiving medical care for ICD9 diagnosis of Mental Disorders and/or receipt of a prescription drug used to treat these illnesses within the time period of 7/1/02-6/30/03.<sup>15</sup>

Records from 558,465 individuals in Maricopa County were analyzed. A few highlights:

- 15.3% of the population were treated for a mental illness in the 2002-2003 study period.
- There were marked differences in treatment by race/ethnicity:



• There were marked differences in treatment by age:

National studies in the 1980s and 1990s suggest that approximately 20% of the U.S. population in the 20-54 age range are affected by mental disorders during a given year. The prevalence of mental disorders in children is not as well documented as that for adults, but approximately 20% of children are thought to have mental disorders with at least mild functional impairment. A 2002 National Survey of America's Families with children 6-17 years old found that approximately 7.7% of parents reported using mental health services for their child in a one-year period.<sup>16</sup>

The Arizona HealthQuery research confirms the low use of mental health services by Hispanics and Asians – slightly more than one-third the rate of Whites. Culturally, there are major differences in how these issues are defined and treated – or not – in communities.

It was also interesting to observe that males (16.8%) were more likely to receive treatment than females (14.1%). This is contrary to the conventional wisdom and what we found in the survey and focus groups, where men were perceived to be much less likely to seek treatment for a behavioral problem. Anecdotally, we hear from primary care practitioners that men are increasingly likely to show up in their clinic and casually say, "Oh, by the way, my wife told me to ask if there was something I could take for my mood swings."

# Listen

## Emotional Well-Being and Community Health

A significant part of this project involved listening to people talk about behavioral health issues in their lives, and how they deal with them in their communities.

In addition to in-depth interviews with experts and community informants, researchers conducted five consumer focus groups – three segmented by income (<\$40,000, >\$40,000, >\$75,000) and two by ethnicity (resident bilingual Latinos, newly arrived monolingual Latino immigrants).

They also convened two focus groups of practitioners: credentialed persons practicing in more "formal" settings such as clinical outpatient programs (psychologists, counselors, nurses), and those practicing in alternative settings (massage, hypnotherapy, meditation), including persons who found themselves dealing with emotional issues of clients as part of offering an unrelated service (beauticians, outdoor adventure guide, etc.).

A general summary of what we heard follows.

## Practitioners and Informants

#### Prevalence

- The top behavioral health issue among adults is *depression*, or what one informant described as the "co-morbidity of our time." (see sidebar on page 18)
- Other top issues among adults: anxiety, addictions (alcohol, drugs, food, gambling, sexual), violence/anger (domestic, physical/verbal abuse), grief and loss, psychological effects of chronic and prolonged illness, suicide (elders specifically), relationship issues, stress (workplace, family).
- Top issues among children and teens: attention deficit hyperactivity disorder (ADHD), attention deficit disorder (ADD), depression, suicide, anger issues, oppositional defiant disorder, alcohol/drug abuse, eating disorders. There was particular emphasis on social adjustment and coping issues for children in the foster care system.
- Practitioners all noted an increase in fear, anxiety and stress across the board since 9/11.
- Many practitioners, especially those in informal/alternative settings, spoke eloquently about seeing more issues of isolation and loneliness, a search for purpose and meaning, a deepening sense of sadness and disappointment in self and others, more emphasis on safety and security and a desire for deeper connections and relationships with "real people" instead of disappearing into a technological cocoon of computers, cell phones and "screens."



## Depression

Depression can be an emotion, a symptom or a disease.

As an *emotion*, depression is experienced by all people at one time or another, and is a normal expression of a full life. As a *symptom*, depression can arise from a mental disorder or any number of other medical diseases, such as diabetes and post viral syndromes. As a *disease*, depressive disorder "...is responsible for as many as one of every five visits to primary care doctors; it occurs everywhere and affects members of all ethnic groups."<sup>17</sup>

Cultural norms and values affect how depression is viewed and treated. What is part of one culture's normal emotional response – say, grief lasting for years – is part of another culture's classification as a depressive disorder, and thus a candidate for professional treatment. Some believe that the trend in advanced technological societies like the U.S. is for "normal" emotional responses to be classified as treatable disorders, driven in large part by the political economy of the pharmaceutical industry: Someone feels blue and a little down, describes their symptoms to the physician, asks about a drug advertised on television and walks out with a prescription.

Members of the Hispanic and Asian communities are inclined to do much less of this than Anglos, as both the Maricopa County medical data and focus group research confirmed. We encountered strong opinions on all sides of the debate on whether we are too quick in the United States to prescribe pharmaceuticals for every conceivable mood aberration; what constitutes a legitimate medical disorder and what doesn't; and whether we run the risk of turning into a nation of "legal junkies."

### Finding **Resources**

In an age awash with information, *word-of-mouth* is still the way many people find resources to address their emotional issues.

#### **Formal Settings**

- In addition to word-of-mouth, practitioners in more formal settings noted that clients found them through hospitals, the courts, information and referral lines, contracts with other agencies, web sites and occasionally through the phone book.
- This group of practitioners said that prior to coming to them, their clients might have accessed services through emergency rooms and urgent care clinics, AA, churches, non-denominational faith-based programs, health fairs, beauticians/barbers/bartenders, physicians/nurses, friends and informal support groups.
- Some practitioners in this group noted the growing importance of crisis intervention training for Phoenix police officers, which helps to get people into treatment rather than incarcerating them.
- All practitioners in more formal settings noted the importance of referral resources. A representative list might include ValueOptions (the Maricopa County Regional Behavioral Health contractor), St. Vincent de Paul and other church-related organizations, community health clinics, Salvation Army, social service agencies, Area Agency on Aging and many others.

#### **Alternative Settings**

- Practitioners in alternative settings see clients primarily as the result of word-of-mouth, personal referrals ("networking"), the Internet, advertising and information provided by "alternative" venues such as metaphysical bookstores.
- Practitioners in alternative settings noted that many of their clients are already familiar with their work through "New Thought" churches, books and newspaper articles, volunteering and taking classes.
- Referral resources in the alternative group included other alternative practitioners, groups such as medical doctors and psychologists, and beauticians and others who encounter emotional issues in clients as the result of providing an unrelated service. This group of practitioners consistently stressed the importance of establishing a referral system of "personal connection" with others, where good "chemistry" between practitioner and client is a prerequisite to success.
- Persons seeking resources in these less formal settings may also access directories such as the worldwide Cranio-Sacral Directory and the Whole Life Directory.



Time and again, both practitioners and consumers mentioned the television and media "ministries" of Dr. Phil and Oprah as important sources of information on issues of psychological dysfunction and emotional well-being, and especially for helping to "normalize" these issues in the general public and make it more acceptable to acknowledge them and seek help.

Stigma remains strong, especially in Latino, Asian and Middle Eastern communities, but the popularity of Dr. Phil and Oprah, and other media "gurus" is beginning to break down some of the barriers. We encountered clinicians who questioned the

accuracy and usefulness of what one termed "psychobabble" on television, movies, the Internet and the popular press, but there was general acknowledgement of the view that the more comfortable we are in discussing these issues openly, the better our chances of improving understanding and treatment.

### **Client** Profiles

#### **Formal Settings**

- Practitioners report seeing an increase in both severity ("lack of connection") and complexity of issues (multiple issues in the same client/family) compared to five-ten years ago.
- Many reported the increased prevalence of drug abuse, especially "hard core street drugs," and the general availability of drugs in the community.
- Practitioners mentioned the large number of individuals and families moving to the Valley who don't bring their "support system" with them.
- A great deal of discussion centered on seeing more emotional disorders in children: more violence; more disorders due to fetal alcohol syndrome ("just seeing the tip of the iceberg"); intergenerational issues of abuse; an increase in attachment issues, especially for children who frequently move among foster homes; more diagnoses of serious mental disorders ("do we see more because we know more about it, or is it over-diagnosis?"); issues of isolation, depression, suicide.

#### **Alternative Settings**

- Practitioners report that many of their clients are educated, informed and motivated to try alternative pathways to emotional well-being outside the traditional medical model.
- Alternative practitioners report seeing a much wider range of clients than before, from youth investigating hypnosis and meditation to seniors looking into "adventure excursions."
- A change in client issues and mood since 9/11: Feelings of fear, help-lessness, being out of control, powerlessness.
- More clients seeking to balance work and family issues.
- A greater awareness and understanding of the basic unity of mind, body and spirit; seeking ways to expand spirituality in every dimension of life (training for physicians in ways to incorporate a concern for spirituality in practice settings).
- Clients have a broader awareness than before of different types of therapy and their uses. Focus is not only on seeking therapy because of a specific diagnosis (e.g., depression), but also on therapy that can be used to foster healing and well-being across a broad spectrum of life issues.

### Perspectives and Trends

(all informants and practitioners)

#### Attitudes

- Denial is prevalent. Many people let problems escalate. It usually takes a crisis to occur before people seek formal services.
- People often "self-medicate" with alcohol or drugs to mask core issues even when they know the consequences.
- Stigma is slowly decreasing, but is still a major issue in the Latino, Asian and Middle Eastern communities.
- Front-line therapists find that many of their clients still feel shame and guilt when seeking help.
- Non-judgmental listening helps to break down stigma and barriers to care.
- Most people are looking for a "quick fix;" a minority seek deep work.
- Anonymity is important; some people won't seek assistance without it. The desire for anonymity has precipitated the increased use of telephone group therapy, email therapy, group lists and chat rooms on the Internet.
- More employers are beginning to understand the bottom-line impact of both recognizing and treating behavioral health issues among employees, but some employees remain reluctant to disclose problems to their employer.
- A broad range of motivation exists among clients. It is generally high among those who seek treatment through alternative therapies, and lower among those referred by the courts, although some persons in the latter category are highly motivated to succeed and keep their family intact.

#### **Personal Connections**

- There is a growing interest in people who seek connections through structured *circles* of support gathering, coming together, giving, receiving, listening, speaking. In a safe environment, people hunger to tell their story.
- Empathy and a non-judgmental atmosphere are important for success, as is treating people with respect and allowing them a measure of dignity.
  - Many mention the importance of "wise friends" and family fulfilling archetypal roles – comforter, healer, elder, mentor, counselor.

#### Mind/Body/Spirit

There is a growing awareness of the interrelatedness of the mind, body and spirit among both practitioners and consumers. Some expressed frustration that there are those in the medical community who still don't "get it."

For some, taking care of the body (exercise, yoga, massage) is a more direct route to emotional well-being than taking care of the mind (therapy, counseling, support groups).

Faith-based services, whether through churches or various community organizations and programs, are growing in importance. In addition to the recognition of the role spirituality plays in emotional and physical healing, faith-based groups generally do a good job of not stigmatizing the need for services.

There is a growing awareness of the interrelatedness of the mind, body and spirit among both practitioners and consumers.

#### Hispanics/Latinos

- Some believe the "severe lack" of linguistically and culturally appropriate behavioral health services in the Maricopa County Hispanic/Latino community approaches a "crisis."
- The Hispanic community itself is diverse, and "ethnicity is not equivalent to culture." Services should follow accordingly.
- Stigma is widespread. Some Catholic priests in the Hispanic community are perceived to lack knowledge about behavioral health issues and tell congregants that depression is a "crisis of faith." There is a need for grassroots initiatives in public education and advocacy.
- There is a prevalent belief among Hispanics that behavioral/emotional problems should be addressed within the family setting. *Plática* (informal, traditional means of self-support) is used effectively in the aftermath of tragic events and grieving, but is not widely used for depression or anxiety.
- The experiences and needs of undocumented Hispanics in the behavioral health arena are "parallel to being in a war."

#### **Native Americans**

- As in other ethnic communities, there is a lack of culturally competent care. Lack of funding restricts access to services for Native Americans.
- There is a broad spectrum of beliefs about behavioral/emotional health among Native Americans in Maricopa County, where a multitude of tribes live in a sprawling urban setting. Many blend modern medical science with traditional belief systems. Some return to reservations for traditional healing ceremonies, while others live too far away and feel like "strangers in a strange land."
- Behavioral health needs remain under-identified and reported, especially co-morbidities (depression) with diabetes.

#### Seniors

Depression and mood disorders among seniors are not adequately diagnosed and addressed.

#### Integration of Care<sup>18</sup>

- Emotional issues often manifest themselves through physical complaints. With a majority of behavioral health disorders being diagnosed in primary care clinics, there is a need to offer behavioral health services in primary care settings.
- Some expressed a concern that primary care physicians (PCPs) do not always have the training and expertise to effectively diagnose and manage behavioral health needs. They get most of their drug information from pharmaceutical representatives. "PCPs are under-medicating and under-referring."
- Many stressed the importance of recognizing and treating the co-morbidity of chronic illnesses with depression/anxiety/phobias/mood disorders.

#### Access/Availability Issues

- There is inadequate access to formal services for the "working poor," undocumented immigrants, Hispanics/Latinos and Native Americans.
- There is a serious lack of culturally and linguistically appropriate services for minority populations.



Depression and mood disorders among seniors are not adequately diagnosed and addressed.

- There are not enough psychiatrists in Maricopa County, especially those who specialize in the behavioral disorders of children. As a result, it is hard to manage medications, and there are long waits for appointments.
- There is widespread confusion among consumers about how to determine whether formal services are needed (is it depression, or just a series of "bad days?"). "People are unsure of which route to take first."
- There is not an affordable continuum of services (inpatient to outpatient to community support) for substance abuse in Maricopa County.
- The number of visits and length of time authorized by managed care for behavioral health treatment are often inadequate to address and resolve problems.
- Those who have behavioral health benefits as part of their health insurance plan often do not know their extent nor how to access services.

### Consumers

Note: The responses among English-speaking residents, bilingual Latino residents and newly arrived Latino immigrants were sufficiently diverse to be summarized separately. With a few exceptions where noted, there were no significant differences in response among those participants segregated by income. The discussion with newly arrived Latino immigrants took place prior to the passage of Proposition 200.

### **Responses** to Emotional Problems

#### **English-speaking residents**

- Participants spoke openly about their experience with "everyday" emotional problems, but said that pride, embarrassment and fear of judgment and labeling prevent many people from seeking professional help.
- Participants spoke of two typical initial approaches (not mutually exclusive) that were helpful in responding to emotional challenges: (1) Making connections with others (family, friends, co-workers) to vent and get support, and (2) spending time alone to think things through (often including physical exercise or a wide variety of "self-help" activities).
- Negative responses include "bottling up" feelings (which often leads to hostility, anger, aggression, physical and/or emotional abuse to self and others), with-drawal from others (including excessive sleeping), excessive drinking and use of illicit drugs.
- Participants reported seeing widespread denial. Most thought that expressing emotions is healthy, and "getting it out is half the battle."

#### **Bilingual Latinos**<sup>19</sup>

- Participants were slow to engage in a discussion of "everyday" emotional problems. "Machismo" and socialization of children, self-reliance, trust, respect and faith were among the topics raised.
- Participants said they were aware of community resources to help individuals and families with emotional problems, but that Latinos prefer to deal with these issues on their own.
- Latino first-line support systems include parents, family and friends. Older family members were mentioned repeatedly elders offer life experience, wisdom and insight into dealing with "life's problems."
- "Machismo" was mentioned repeatedly. In the words of one male participant, "Men don't cry. We deal with it and hope that it will go away, even if it takes 20 years."



Participants spoke openly about their experience with "everyday" emotional problems. Several women mentioned that they couldn't see the men in their lives crying, as "they are the head of the family." Some expressed sadness at this, attributing "machismo" and the way Latino children are socialized as key to the problems that result in personal and family dysfunction.

- The use of alcohol as a means to cope with stress and emotional problems was mentioned often. Several identified their own fathers as alcoholics and stated that "Mexicans would never admit to being alcoholics."
- Faith plays a major role for both Latino men and women, who address emotional issues through prayer and going to church. Churches were also identified as places where educational brochures were readily available. On the other hand, some wondered whether Catholicism and the process of confession behind a barrier was one reason why some Latinos were uncomfortable in seeking professional help.
- Participants mentioned accessing the Internet, television shows (Dr. Phil, Court TV) and libraries as ways to learn more about addressing emotional problems "without anyone else knowing what's going on."

#### New Immigrants (monolingual Spanish)

- Participants were primarily concerned with basic issues of safety, food, shelter and companionship. They spoke of their traumatic experiences at the hands of the "Coyote," their fear of being abused, and fear of being apprehended by INS.
- Their chief emotional problems stem from loneliness and lack of support services, coupled with anti-immigrant sentiment. Their first line of support to combat a sense of helplessness is to seek out other immigrants who share similar experiences.
- Participants expressed cultural shock and dismay at what they perceive to be the excessive liberties, lack of sense of responsibility and diminished values and morals in the U.S ("like getting a new toy without instructions").
- Being able to work is the first order of business, particularly to pay off the "Coyote." Not being able to work, and fear of being apprehended while looking for work or working, increases anxiety and alters their "good mood." Lack of a support system, unemployment, loneliness and distrust can lead newly arrived immigrants to selfmedicate with alcohol or drugs, which are perceived to be more readily available in the U.S. than in their country of origin.
- Participants mentioned the importance of their faith and the Church as a first line of support. They expressed concern that "many who arrive here from Mexico are very religious, but once here, they lose it all."

### Anatomy of Support

#### **English-speaking residents**

- People know it's time to seek help when they reach a "breaking point:" when work or sleep is affected, when a crisis occurs such as divorce or suicidal thoughts, when the problem is affecting their children or spouse, when they realize things are not improving, or when someone else points out the significance of the problem.
- All participants indicated that they or someone close to them (family, friends) had sought professional counseling or crisis support at some point. They agreed that the person must want to improve in order for counseling to be helpful. Some expressed reluctance to use mental health insurance benefits and employment-assistance programs (EAP) because they didn't want their use of services documented.

Faith plays a major role for both Latino men and women, who address emotional issues through prayer and going to church. **Participants** expressed divergent attitudes about pharmaceutical therapy. While some reported good experiences with drugs for depression, anxiety and ADHD, others thought that drugs were a "quick fix" and sometimes were used to avoid dealing with the underlying issues.

- Men were perceived to internalize emotions and be less likely to seek support, while women were more prone to talk about problems and seek the help of others. Participants acknowledged that this may be changing as men learn more about depression, anger and the benefits of counseling.
- Participants expressed divergent attitudes about pharmaceutical therapy. While some reported good experiences with drugs for depression, anxiety and ADHD, others thought that drugs were a "quick fix" and sometimes were used to avoid dealing with the underlying issues. There was heated debate in the English-speaking focus groups on the use of drugs with children specifically.
- Counselors, psychiatrists, psychologists, neurologists, social workers, hospice services and volunteers were mentioned as helpful. Others included grief and marriage counseling, 12-step programs, "Survivors of Suicide," anger management classes, the Teen Challenge drug and alcohol abuse program, a child abuse hotline and various support groups.
- Many participants mentioned the importance of prayer and support provided by church groups and clergy. The >\$75k group mentioned this most frequently.
- Hospice programs were mentioned repeatedly as a model of outstanding training, "customer service," compassion and follow-up.
- "Not being labeled" is a major concern when seeking support. People want to be treated with compassion, empathy and respect, and seek a "feeling of belonging." They want quick access, a comfortable and confidential environment, respect for their time, competent providers who listen to them and fast results.
- While services were generally viewed as helpful, participants considered access to be a major problem. People don't always know about available resources, there are sometimes long waiting lists, and cost is a barrier. In the words of one participant, "Why is it easier to file bankruptcy than to get help if you're emotionally bankrupt?" Some in the <\$40k group expressed difficulty in getting behavioral health referrals through their PCPs, while those in the >\$40k groups did not find this to be a problem.
- All participants thought that education is needed about signs and symptoms of emotional problems that might require help, and where to find it. All groups look to the Internet for information, with the highest use among the >\$75k group; the lower income groups mentioned the need for a comprehensive, widely distributed catalog of available resources in the County, supported by a 24/7 hotline. All participants mentioned the importance of television and shows like Dr. Phil to "get the word out."
- Without prompting, those in the lower income groups emphasized the importance of building stronger communities through personal volunteer efforts, corporate support and legislative action. When asked to design "something for Maricopa County to help people get the help they need when they need it," they suggested neighborhood-based "Community Well-Being Centers" that offered a range of easily accessible professional services, support groups, classes and exercise options without labeling people who went there. When asked the same question, the >\$75k group focused on the need for a broad-based advertising campaign that advised people to "seek help, no matter where they got it from," and employed non-stigmatizing, "sexy" messages stressing that the emotional problem "doesn't have to last forever."

#### **Bilingual Latinos**

- Consistently, participants stressed that "Latinos do not seek help."
- Participants were skeptical about the character, morals and values of behavioral health professionals. They expressed distrust: They might be qualified to provide services, but they may be "questionable" on a personal level. While this prevents many Latinos from seeking services, participants wondered how they might go about answering questions about "professionals as people." Participants were more likely to see a professional who has similar life experiences to themselves (loss of a parent, divorced, child with drug problem, etc.).
- People know it's time to seek help from others when they feel helpless or fear for the safety of their loved ones. Examples mentioned: bereavement following the death of a parent or child, divorce, and a young adult experiencing the loss of a first love relationship.
- Participants expressed a great deal of interest in alternative approaches to dealing with emotional issues, such as meditation, reflection, listening to music and "learning from Eastern medicine." They were interested in holistic services that "used positive energy in the healing process."
- Cultural messages associated with "be a man," "take care of your own" and "deal with it yourself" were presented as key barriers to seeking services. Recommended outreach strategies included changing words like 'help' to 'understand.' While Latinos are reluctant to seek help, they are interested in understanding why they or a loved one may be feeling or acting a certain way.
- Participants demonstrated a good working knowledge of community services and how to access them. Some worried that if they took advantage of them, they would be viewed as "loco."
- Some expressed a distrust of physicians generally, especially of their competency to make a mental health diagnosis "when they can't always make an accurate medical diagnosis." Physicians were described as "quick to place blame" on mental health concerns compared to taking the time to conduct a comprehensive medical assessment to rule out physical factors.
- On the subject of how to improve education and access to behavioral health services, some mentioned placing ATM-like machines in places that Latinos frequent. These machines would be private and provide a wide menu of conditions, information and resources.

#### **New Immigrants**

- Participants indicated that the problems they face as recent (undocumented) immigrants are reason enough to seek help. Language, transportation, legal status and fear of deportation were identified as the principal barriers to seeking support.
- Social solidarity is a key to support. "When we can't do anything else on our own, we seek help through our neighbors, the church, the Mexican consulate and rehabilitation centers." Participants stressed community living multiple individuals sharing the cost of an apartment as a way to band together and help each other out.
- As part of their social solidarity, new immigrants mentioned the importance of talking, sharing, going dancing and reminiscing about the life and family they left behind. They reported drinking herbal tea to relax and taking Sucrol tablets for "nerves." Women reportedly "give the men pills in their water, they hide it in their food. These pills are so the men won't drink."

People know it's time to seek help from others when they feel helpless or fear for the safety of their loved ones. "We need a plan that helps us, one where we are able to make payments, but maybe at a reduced rate based on our income. We don't want free things, but we want it to be within our reach."

Latino participant

- New immigrants mentioned the importance of local hospitals. While many may not receive help, hospitals are viewed as locations to find information and to become familiar with other potential resources of support.
- Churches and church groups provide various types of support, including clothing, food, emergency assistance and companionship. Participants complained that Latinos in the U.S. mistreat them and make them feel inferior. Most indicated they preferred to work for or deal with an Anglo person instead of a Latino. Anglos were described as more kind and generous.
- New immigrants are not looking for "free" services. According to one participant, "We arrive from Mexico, we don't have money, we need a plan that helps us, one where we are able to make payments, but maybe at a reduced rate based on our income. We don't want free things, but we want it to be within our reach."
- Affordable Spanish-language services are important to new immigrants. Confidentiality, particularly information associated with legal status, is paramount.
- New immigrants rely heavily on Spanish-language radio for information and support. "We ride to work and listen to the radio. That's how we find out what's going on."
- Interestingly, the September 11, 2001, phenomenon was perceived as an event that had tremendous impact on Mexico's economy, resulting in dislocation and increased migration to the U.S. According to one immigrant, "While in Mexico, I worked for the Ford Company for 15 years. September 11th was a bad cold in America, but in Mexico it turned into pneumonia. Many companies were closed down, production decreased, the workforce decreased."

## Maricopa County Directory of Human Services

According to the 2004 Maricopa County Directory of Human Services, there are 527 governmental, public, private and nonprofit agencies/programs spread out over 39 separate categories that provide formal behavioral health services:<sup>21</sup>

CATEGORY OF NEED*	# RESOURCES LISTED	CATEGORY OF NEED*	# RESOURCES LISTED
CHEMICAL DEPENDENCY COUNSELING	Ĵ	COUNSELING	
Adult	31	Abuse	25
Older Adult	20	Death and Dying	26
Youth	20	Eating Disorders	5
Crisis Counseling	7	Family/Individual	70
CHEMICAL DEPENDENCY RESIDENTIA	LTREATMENT	Marriage	30
Men	8	Private	5
Older Adult	9	Psychiatric	13
Women	10	Rape/Incest	11
Youth	5	Suicide	8
CHEMICAL DEPENDENCY SMI	7	Youth	41

## Pathways in Community Behavioral Health

Problems associated with behavioral and emotional disorders present a particular challenge for the risk model, because their underlying causes are complex and even opaque, the efficacy of interventions and their reception in targeted populations and communities exhibit wide variability, and definitional issues of problem statement and solution are normative at the core, and therefore often contentious.

### The Problem is the Problem

The problem, it turns out, is defining what the problem is in the first place.

For example, interviews with key informants and a review of the relevant data indicate that Phoenix is significantly below the average of similar U.S. metro areas in the number of employed psychiatrists. The problem in this case is the lack of skilled professionals, and the recommended intervention is to recruit and employ more psychiatrists, especially in high need areas like child and adolescent psychiatry.

Alternatively, based on feedback from the Latino community summarized earlier, Latinos don't necessarily seek help, but *understanding*. They recognize and fully appreciate the emotional and behavioral problems they encounter in daily living, but instead of framing the problem in terms of lack of access to skilled psychiatrists and other professionals, they frame it in terms of lacking the understanding of how to effectively address these issues *themselves* in their own communities of family, social and spiritual support.

These quite different perspectives inform and cross-pollinate each other to create a rich tapestry of pathways in behavioral community health. That's the point: the danger lies not in combining them, but in using one set of pathways to the exclusion of others, which fosters fragmentation and isolation.

We briefly summarize some of these pathways,<sup>20</sup> then conclude with some lessons for health policy and practice.

Under a risk-based model, the standard approach is to identify a problem, establish its underlying causes, intervene to eliminate or reduce those causes and see if the problem is solved or ameliorated.

CATEGORY OF NEED*	# RESOURCES LISTED	CATEGORY OF NEED* # RESOURC	ES LISTED
CRISIS COUNSELING		PSYCHIATRIC SERVICES	
Abuse	14	Advocacy 7	,
Alcohol	8	Case Management 5	
Domestic Violence	7	Co-Dependency 4	<u>.</u>
Drug	8	Crisis Counseling Center 24 7	,
Family/Individual	11	Day Treatment 15	5
Psychiatric	5	Employment 4	÷
Rape/Incest	4	Hospitals 10	C
Suicide	4	Residential Living 16	5
Youth	8		
HOUSING DRUG ABUSE ADULT COED	4	TOTAL NUMBER OF BEHAVIORAL HEALTH CATEGORIES	39
HOUSING SMI	7	TOTAL NUMBER OF BEHAVIORAL HEALTH SERVICES	527
LEGAL DOMESTIC VIOLENCE	28	* Related to behavioral health.	

#### ALCOHOLICS ANONYMOUS

There are close to 1,600 Alcoholics Anonymous meetings in the Valley every week, starting at 5:30 a.m. and going until 12 midnight. Meetings are both in English and Spanish, and can range anywhere from just a handful of people to several hundred.

And that doesn't include the countless spin-off groups and meetings, the dinners and social outings, the lasting relationships formed. In the words of one member, "AA is my church. It's where I go to learn how to live."

#### HOSPICE

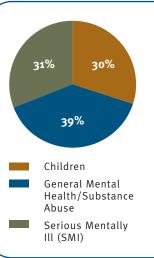
In the consumer focus groups, we heard glowing testimonials for hospice services, both in terms of grief and loss specifically and as a preferred model for helping with a wide dimension of emotional needs. More than once, we heard the comment, "hospice is what all of health care should be like."

As a holistic health care model, hospice offers support, safety, respect, understanding and empathy within an integrated setting. It fosters connectivity – and therefore social capital – during one of the most challenging and difficult periods of life. When it works, it is more than just another service. It's a way of life.

## ADHS/BHS

The total FY 2004-2005 behavioral budget for the Arizona Department of Health Services/Behavioral Health Services (ADHS/BHS) is \$897 million for approximately 100,000 enrollees.<sup>22</sup>

With a budget of approximately \$450 million in Maricopa County, 65,534 people were receiving services at the end of June 2004. In the previous 2002-2003 fiscal year, ValueOptions (the Maricopa County Regional Behavioral Healthcare Provider) spent \$333 million on program services serving 51,246 clients in all capacities (see chart), including individuals seeking access to services and crisis line calls.



## ValueOptions Expenditure Categories 2002-2003

In the 1997-2001 period, Arizona moved up from #18 to #15 among all states for total amount of dollars spent through state behavioral health agencies. However, Arizona's population increased even faster, and the state's per capita ranking for behavioral health expenditures decreased slightly from #17 to #18.<sup>23</sup> In 2001, Arizona spent \$89 per resident for public behavioral health services compared to a national average of \$83.52.

### Faith-Based Services

To develop an appreciation of the breadth of services offered through faith-based congregations and organizations to address behavioral and emotional health issues, researchers reviewed a representative sampling across the Valley rather than conduct an exhaustive survey of all churches and faith-based organizations. The sample included 13 groups representing various religious and denominational perspectives, and ranged from smaller community-focused congregations to Valley-wide social services.<sup>27</sup>

All congregations offered pastoral and/or professional counseling on a case-by-case basis for a variety of issues. Each offered regular group and individual services on a weekly, monthly or appointment basis. The mean and median were 14 and 5 groups or services respectively. Examples of support groups and services offered:

- 12-step support groups (anger, chemical dependency, co-dependency, sexual addiction)
- Alcoholics Anonymous
- Alternative lifestyle support
- Al-Anon
- Anxiety and stress
- Blended family support
- Caregivers support

- Childhood abuse support
- Chronic illness support
- Chronic pain
- Compulsive habits support
- Confident Kids support
- Couples Connection
- Divorce crisis
- Emotional health

- Empowered women
- Infant or young child loss
- Mixed-step support
- Overcoming depression
- Overeaters Anonymous
- Parents of murdered children
- Pornography/sexual compulsion
- Post-abortion care and encouragement

- Power of being and presence
- Power of positive thinking
- Pre-divorce support
- Raising our consciousness
- Self-esteem
- Singles support
- Women's support group

## Are Outcomes Related to Resources?



What determines the level of resources sufficient for the services required?

One common approach to this question is to map the availability of resources per population served on a comparative basis, note differences in health outcomes and derive some acceptable minimum standards to gauge the adequacy of community resources.

The issue, especially when it comes to the complexity of behavioral health, is that outcomes are influenced by a multitude of factors that extend well beyond health system resources.

The Phoenix metro area generally lags national averages in terms of common measures of health care resources, such as physicians and hospital beds per population. In behavioral health, the Phoenix metro region ranks below the mean and median of comparable metro regions in the number of employed psychologists, and noticeably lower in employed psychiatrists.

Alternatively, Phoenix is above the median and mean in the number of employed social workers and about average in the number of "other" counselors (substance abuse, marriage and family, etc.).<sup>24</sup>

With regard to general health outcomes, Arizona is close to national averages – 23rd among 50 states according to a recent 2004 report released by the United HealthCare Foundation.<sup>25</sup> The state does even better on some measures of general behavioral health, such as the Behavioral Risk Factor Surveillance System, which tracks the "mean number of mentally unhealthy days" with a national survey. For the period 1993-2001, Arizonans reported a mean monthly number of 2.25 days, compared to a national average of 3 days.<sup>26</sup>

**The upshot:** The solution to improving outcomes in behavioral health is not necessarily to put more resources into the system. We clearly need to address resource deficiencies such as excessive case loads in the public system and not enough psychiatrists specializing in disorders affecting children and adolescents. But we also need to look at how resources are deployed, how they are integrated (or not) in a seamless web of care, and how to increase access to pathways of support that extend well beyond the formal behavioral health system into the deep social structures of community life.

### Media

**GOOGLE THIS** There are over 600,000 online listings for mental health services and support, including chat rooms, list serves, support groups, counseling and other services, educational resources and associations.

**OR BUY A BOOK** Millions do – a typical online search yielded over 700,000 titles in mental/behavioral health categories, with the top listings under the categories of self-help, well-being, stress, anger, anxiety and depression. Of note, the categories of 'mental' and 'behavioral' health themselves had the fewest listings.

**OTHER MEDIA** Focus group research stressed the importance of television and radio as sources of information and support related to behavioral health. Popular magazines were also mentioned, as were newspapers. As important as these media pathways are, none was mentioned as frequently as word-of-mouth among family, friends and social networks.

### Employment Assistance Programs

Employment Assistance Programs (EAPs) are worksite-based programs designed to address productivity issues and to help "employee clients" in identifying and resolving such personal concerns as alcohol and drug abuse, depression and stress, marital and family issues and other issues that may affect job performance.<sup>28</sup>

While EAP enrollees have dramatically increased over the past decade (130% between 1993-2003), EAPs are primarily available through large employers (>1,000 employees), and only 10% of employers with 50 or less employees offer the services.

We did not quantify the use of EAPs in Maricopa County, except to note through survey results that of the 11% of respondents who reported using EAPs in the past, only 35% found it "useful." While focus group participants noted that work and family balance were often "out of whack," they were reluctant to let their employer know about their personal emotional issues and were concerned about confidentiality. Alternatively, several participants found EAPs to be "very helpful."

### Self-Help

All participants, whether they had sought outside assistance for behavioral health issues or not, engaged in self-help activities to "relieve stress, slow down, get a new perspective and reconnect with 'what matters.'" Besides doing a wide range of activities by themselves (reading, gardening, fly fishing, exercise, journaling, painting, music, etc.), all sought deep social connections with others.



There are over 600,000 online listings for mental health services and support, including chat rooms, list serves, support groups, counseling and other services, educational resources and associations.

## Spirituality

Spirituality and the mind-body-spirit continuum of health also resonate widely in the community. Fully 79% of survey respondents indicated they prayed when facing stress or emotional problems, and 41% had sought help from a minister, priest, rabbi or other spiritual advisor.

In addition to the religious dimensions of spirituality, community informants and focus group participants spoke of enriching their spiritual life through deep connections with nature and each other; rafting trips, hiking and "singing around the campfire" were described as spiritual experiences.

Without exception, all participants pointed out the need to infuse medical and behavioral health practices with spirituality, and the importance of treating the "whole person," not just the body or mind separately. Practitioners themselves especially emphasized this holistic perspective.

## Circles

In the words of one participant, a circle is "a space where you can be heard, witnessed, honored and accepted. Everyone in the group can count on that, and that, in itself, is transformational."

The circle concept, which is used widely (business "quality circles," for example), resonated powerfully through all discussions. Some characterized them as "small groups" that get together on some regular basis – book clubs, breakfast clubs, a regular "night out" with a close group of friends, prayer groups, sports groups, hobby groups – where the gathering, even if it is for the purpose of discussing a book or engaging in a particular activity, leads to honest, reflective communication and mutual support.

Others characterized circles more formally, as in the example of an informant who convenes Grandmother Circles to help older women experience the spirituality and empowerment of aging. Her vision is to develop "circle trainers" who will go out into the community and help people create "safe spaces for speaking and listening."

More than one-quarter (26%) of survey respondents indicated they had participated in a circle of people who came together for a specific purpose, sharing leadership and responsibility. The focus group itself is a type of circle. In the safe environment created by the focus group process, people were eager to talk about their own emotional issues and those of people they knew.

## Alternative Therapies

Alternative therapies are growing in importance as pathways in dealing with a wide variety of physical, emotional and behavioral issues. In addition to utilizing techniques such as yoga, meditation, massage, Tai Chi, art therapy and "breath work," people are turning to diet and nutrition, vitamins and herbs; visiting Acupuncturists and Naturopathic and Homeopathic practitioners; and participating in traditional healing ceremonies (e.g., Native American ceremonies and sweat lodges).

National research confirms that a growing number of people are using complementary and alternative medicine therapies (CAM) – 36% of the population in 2004, and 62% when the definition of CAM is expanded to include "prayer specifically for health reasons."<sup>29</sup> However, only 12% of people sought care from a licensed CAM practitioner, confirming that most people pursue these therapies on their own.

In behavioral health, depression and anxiety are cited as top reasons for using CAM therapies. "A man hears what he wants to hear, and disregards the rest."

"The Boxer," by Paul Simon

The language of modern medicine is increasingly the language of industry and commerce. It is not the language of health, and it is certainly not the language of connection.

## Only Connect Changing the Paradigm

There is a certain addiction to doom and gloom in health care these days. We've talked about being in a state of crisis for so long – back to the 1970s and even before – that we don't know exactly how to react when someone tells us they "seek understanding, not help."

We're programmed to fill up the holes, so holes are what we look for. The professional culture of health care isn't programmed to see the wells of strength and hope waiting to be tapped.

We found plenty of holes to be filled in our analysis of behavioral health pathways in Maricopa County. But if that were all we found – and if all we could recommend were more services, more funding, more staff, more programs, more regulatory oversight – we would simply be perpetuating the dominant model of deficit and needs, where communities are conceived solely as service environments, and citizens are reduced to clients and consumers.<sup>30</sup>

We believe there is another paradigm, and we found ample evidence of it in the research. We offer the following set of observations and suggestions for leveraging the remarkable strength and resilience of Arizona communities to sustain and nourish pathways to better health.

We even offer up a few holes to fill.

### The Language of **Connection**

Our research confirms the importance of the language we use to describe behavior, and the labels we attach to persons and conditions as a "shorthand" for describing their "condition."

People intuitively understand they are more than the sum of their behaviors and conditions – alcoholism or "alcoholic" describes neither the essence nor totality of who someone is – but in our shorthand, one-minute culture, the compulsion to "name" the thing is often taken to be the first and final judgment.

"Oh, he's an alcoholic." As if that were all we needed to know about the person.

Conversely, participants in this project, from undocumented immigrants to high-income residents of North Scottsdale, from traditional medical professionals to providers of alternative therapies, repeatedly stressed the importance of strong connections with other people as the bedrock foundation for emotional well-being. They all used a language of connection to describe how this foundation unfolds in their lives. Deceptively simple on the surface, the depth of this language is profound:

Caring, Giving, Receiving, Empathy, Dignity, Respect, Understanding, Listening, Speaking, Circle, Connect, Conversation, Being Heard, Non-judgmental, Counsel, Spiritual, Safe

The language of labeling is the language of commerce and consumers. The language of connection is the language of human beings, the intersection of self and others in the mutuality of caring communities.

The language of modern medicine is increasingly the language of industry and commerce. It is not the language of health, and it is certainly not the language of connection.

#### **Implications for Policy and Practice**

There is only one way to learn a language, and that is to *practice* it. The language of connection is not reducible to policy or some diagnostic and labeling scheme. Like life itself, it is not reducible to any backward descriptive explanation but can only be instantiated in actual experience or practice.

We found ample evidence that people practice the language of connection in the Valley. They actively seek out deep connections with others, most of which occur outside formal systems of care in the everyday social fabric of friends, family, work and myriad circles of support around common interests, needs and issues. This capacity for connection lies at the heart of resilience in both individuals and communities.

It is naïve to assume we can – or even ought to – derail either the language of modern medicine or the economic and technological engines propelling us toward an unknown future. But we *can* learn the language of connection by practicing it within both the formal and informal pathways of care briefly outlined in this report.

- If we are *policy leaders* considering funding and program alternatives in such areas as drug and alcohol abuse, foster care, services for those with serious mental illnesses and others, we can ask for a review of these programs in terms of whether they actually practice and promote a language of connection, and not solely in terms of whether they meet some formal accountability metric, such as how many visits a client had with her case manager.
- If we are *clients* who use these programs and services, we can model and teach the language of connection through our own actions and attitudes, and ask those who provide the services to do likewise.
- ☐ If we are *behavioral health professionals*, researchers, educators, reporters and others who either work in or disseminate information about programs and practices, we should not only "walk in the moccasins" of others, but begin to think of imaginative ways to describe these issues of mind and mood other than in the cold and clinical language of medicine. Bold and idealistic though it may seem, we must invent a new language, a more inviting way of talking about health. A reworking of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) would be a start.

### **Culture** and Connection

Our research confirms the central role of culture in determining attitudes toward issues of emotional and behavioral health, and the importance of employing culturally appropriate language and practice in community pathways.

Maricopa County is at the vanguard of a new America, a multicultural, multiracial and multilingual society where the challenge – and the opportunity – is to fashion deep and lasting social connections out of *difference*. We know the danger – fragmentation, dislocation, separateness and conflict – and what it implies for the future if we don't succeed in establishing the language of connection across cultural differences. We also know how difficult it is, because identities, values and beliefs fashioned in the cauldron of one culture do not always translate well into another, usually dominant culture.

For example, Latinos in Maricopa County access the health system for what medicine classifies as "mental disorders" at approximately one-third the rate of the adult Anglo population. This is a problem to the extent that one believes Latinos are under-diagnosed and under-treated for these disorders, which we heard from a number of psychiatrists, psychologists and other practitioners. On the other hand, while most Latinos acknowledge the presence of behavioral and emotional issues that need attention, many prefer to deal with them "on their own" in ways embedded in their culture (family, faith) instead of "talking to strangers" about their personal lives. The same is true for Asian-Americans.

Our research confirms the central role of culture in determining attitudes toward issues of emotional and behavioral health, and the importance of employing culturally appropriate language and practice in community pathways. Establishing connections between cultures is made all the more complicated by variations within cultures themselves and the degree to which they are assimilated within the broader American culture (the definition of which is another story entirely). We were struck by the differences in attitude between recent Hispanic immigrants and Hispanics who have been in the United States for some time. We also noted differences between Native Americans who were used to living in an urban environment like Maricopa County and Native Americans who still maintained strong ties to families living on tribal reservations. The former may take modern medications and schedule appointments with counselors, while the latter may feel the need to first consult with a tribal medicine man and participate in a traditional healing ceremony.

The danger lies in assuming there is one preferred pathway in community behavioral health, especially in a multicultural urban environment like Maricopa County, where the churn of new people, jobs and communities alone calls for a multi-faceted approach.

#### **Implications for Policy and Practice**

- As a matter of *public policy*, we need to make a concerted effort to ensure that more minorities and members of ethnic communities are represented in the health care professions. "While Hispanics, African Americans and Native Americans represent more than 25 percent of the U.S. population, they comprise fewer than six percent of doctors and nine percent of nurses. Minority patients are frequently treated by professionals from a different ethnic background in so-called 'race discordant' relationships."<sup>31</sup> This is an issue in all dimensions of care, but especially in behavioral health, where the practitioner and patient may approach the issues from quite different cultural perspectives. There is a serious lack of culturally and linguistically appropriate services for minority populations in Maricopa County, and we need to address it.
- As *practitioners*, we need to be sensitive to the cultural backgrounds and perspectives of clients, and take special care to use a language of connection and healing, and not solely the language of clinical medicine. The reductionist language of biology, while powerful as an explanatory model for the biochemical genesis of many behavioral health disorders, is incapable of capturing the rich intersection of biology, culture and values, and especially for acknowledging the strengths that many clients possess to aid in their own recovery. "We seek understanding, not help" is an extremely powerful insight, and comes from a much different cultural place than "better living through chemistry."
- As *patients, family members, friends and participants* in everyday community life, we need to celebrate the diversity of pathways to improving health and emotional well-being, and not rush to fit everyone into one preferred pathway, even when proven to be effective. Someone may eventually seek assistance from medical professionals, but it should be in addition to, and not exclusive of, other pathways of care that may ground them in a culture important to their sense of identity, such as seeking spiritual guidance, participating in health ceremonies, talking to family members or using alternative therapies. A participant in Alcoholics Anonymous put it this way: "I know AA's success rate with alcoholism isn't any better than some other approaches, but I come to these meetings because I learn how to make a life here. It's my tribe."

As practitioners, we need to be sensitive to the cultural backgrounds and perspectives of clients, and take special care to use a language of connection and healing, and not solely the language of clinical medicine.

### **Circles** of Connection

The self is social. Our sense of identity and purpose is first grounded in personal relationships that extend out into communities through circles of connection. Whether one is volunteering, participating in activity groups, gathering with friends and family for a meal, or attending a structured group therapy session, we nourish our own health and well-being through creating meaningful circles of communication and support with others.

One of the ironies of our consumer-oriented, market-driven society is that it can foster isolation, loneliness and social fragmentation as it brings more of us together in the pursuit of commodities and services. Listening to Valley residents talk about their experiences with depression, anxiety, fear and anger, we were struck by a hunger for social connection that extends considerably beyond superficial economic transactions and centers on authentic speaking, listening and hearing. Many residents found this in informal circles of connection established through long-time social relationships (book clubs, dinner groups, girls night out), while others found it in more formal support groups organized around specific issues, such as drug and alcohol use, anger management and counseling for couples. Regardless of type or level of structure, all of these circles provide a safe, supportive environment in which to speak with others about "things that ultimately matter." Of all of the responses to dealing with stress or emotional problems, Valley residents indicated they found circles (69%) and support groups (71%) to be most helpful.

#### **Implications for Policy and Practice**

In light of the critical importance of circles of connection to our health and emotional well-being, it's worth noting that we pay little attention to them in our formal systems of assessment and accountability. We tend to measure system effectiveness in terms of input and throughput factors (number of case managers, number and condition of clinics, adherence to a formal treatment plan, etc.) and pay less attention to output (do people get better?) and the critical role that circles of social connection plays in the process.

For example, SLHI recently provided support for persons diagnosed with a serious mental illness to develop a sports recreational group. They get together to participate in an activity like baseball or basketball, then gather for a meal. It provides occasion for authentic communication and to demonstrate sociality and competence. It provides occasion to practice the language and techniques of social connection that many of us too often take for granted. It aids in recovery. Where in our "systems" of care do we measure this?

As *policymakers*, we should be clear on what it is we are trying to accomplish by implementing and funding pathways in community behavioral health, and not become blinded by process measures of accountability to the point where we miss the value of circles of social connectedness. Our regulatory apparatus should encourage practitioners and clients to come together in both formal and informal circles of connection; our accountability criteria should include new measures of social capital that such connections create. Instead of first asking what new programs we need, we ought to ask how we can encourage the active participation of existing circles of connection, whether they occur in faith-based organizations, nonprofits, businesses, social clubs or other community groups. This isn't a call to deemphasize the importance of adequate funding and regulation of formal pathways in behavioral health so much as it is to acknowledge and encourage those circles of connection deeply embedded in our lives, and which provide a measure of strength and resilience in our communities.

Of all of the responses to dealing with stress or emotional problems, Valley residents indicated they found circles (69%) and support groups (71%) to be most helpful. "You need to know that you don't have to feel like this. You're not alone. You can get help."

Participant

- As *practitioners*, we should make a concerted effort to use these circles of connection in our work, and especially as extensions of our work in the wider community. They provide a structure for the greater integration of clinical and community care, such as aftercare support groups for people coming out of intensive inpatient and outpatient programs. Of note, physicians and other traditional medical providers are starting to use support groups to address ongoing issues of care with people who suffer from chronic diseases, such as diabetes and arthritis, where talking about health issues and sharing stories and information in an environment of mutual support have proven to be therapeutic.
- As *clients, educators and community members*, we should look for opportunities to participate in circles of connection in our own lives. One of the recommendations from our focus group research was to disseminate information on where and how to find such circles (as well as other services and support) and, more importantly, on *when* to seek them out. Many expressed a measure of fear and misgiving about seeking help through more formal circles of support ("Will they think I'm crazy, that I'm a weak person, a failure?"), but others expressed surprise and relief to find out that they fit right into the group and found help there. As one participant stated, "You need to know that you don't have to feel like this. You're not alone. You can get help."

## Only **Connect:** An Agenda For the Future

We conclude with lessons learned and an agenda for the future:

- 1. WE HELP OURSELVES BY HELPING EACH OTHER. We help each other by establishing strong and resilient social connections in our communities. The first step, then, is to invest in the social, economic and cultural antecedents of those connections.
- 2. CREATE OPPORTUNITIES FOR SELF-HELP. If we can help others, we aren't helpless ourselves. Instead of 250,000 alcoholics in the Valley who need help, reframe it as 250,000 alcoholics who can help each other. This shifts the emphasis to what already lies *inside* the individual and community, rather than relying on external interventions by experts. The result: self-determination, pride, inner strength, regenerative healing and resilience.
- 3. LANGUAGE MATTERS. Use the language of connection. Use the language of attraction, not promotion. Avoid negative labeling always.
- **4. UNDERTAKE A PUBLIC EDUCATION CAMPAIGN** to reduce the fear and stigma associated with illnesses of mind and mood. Focus not on the fact of diagnosis, but on the promise of recovery.
- 5. INVEST IN IMAGINATIVE AND INVITING SETTINGS TO DEVELOP INTEGRATED PHYSICAL AND BEHAVIORAL HEALTH SERVICES IN COMMUNITIES. Instead of thinking in terms of hospitals, clinics, inpatient and outpatient, think in terms of health campuses, healing centers, self-help resource kiosks, churches and clubs. Think on-line as well as off-line, real-time as well as virtual-time.
- 6. RECONFIGURE MEDICAL EDUCATION AND SERVICE DELIVERY TO INTEGRATE PRIMARY CARE AND BEHAVIORAL HEALTH SERVICES. People prefer it, and the science clearly supports integrated treatment of mind and body. We might as well be good at it.
- **7. PROMOTE VOLUNTEERISM**, which builds social connectedness, which builds social capital, which builds resilient and sustainable communities.
- **8. RECRUIT AND TRAIN A CULTURALLY DIVERSE HEALTH CARE WORKFORCE** that reflects and is sensitive to our multicultural population.
- 9. BUILD FROM MICRO-COMMUNITIES OUT IN THE FORM OF CIRCLES OF CONNECTION AND SUPPORT. Invest in educating people about the power of small groups and in the training of people to help start and sustain them.
- **10. INVEST IN BETTER DATA AND MONITORING SYSTEMS,** especially those that are integrated across all medical and behavioral health services, sites and plans. It is especially important that we develop new indices of measuring the social capital of communities (such as the informal pathways of support discussed in this report) in order to inform and promote a resilience-based approach to community health and well-being.
- **11. INVEST IN THE NURTURE AND EDUCATION OF OUR CHILDREN.** "As the twig is bent, so grows the tree."

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## Notes

- See The Humpty Dumpty Syndrome: Integration and Behavioral Health, Fall 2003, and Resilience: Health in a New Key, Winter 2003. St. Luke's Health Initiatives, www.slhi.org.
- 2 Out of print.
- 3 A collaboration under the direction of Michael Berren at the Community Partnership of Southern Arizona. www.cpsa-rbha.org.
- 4 www.familyinvolvementcenter.org.
- 5 Mental Health: A Report of the Surgeon General, 1999, Ch. 1. www.surgeongeneral.gov/library/mentalhealth/chapter1/sec1.html.
- 6 Ibid.
- 7 GDB 2002 Estimates Revised: DALYS, World Health Organization: Burden of Disease Project. www.who.int/.
- 8 This rough projection is based on *National Estimates* of Expenditures for Mental Health and Substance Abuse Treatment, 1997, U.S. Department of Health and Human Services – Substance Abuse and Mental Health Services Administration, June 2000. Indirect cost estimates (1996) are from Mental Health: A report of the Surgeon General, 1999, op. cit.
- 9 Therapy in America, 2004, Pacificare and Psychology Today, http://cms.psychologytoday.com/pto/press\_ release\_050404.html.
- 10 More specific information on survey design and methodology is available from SLHI.
- 11 See Kathyrn Connor, et. al., "Development of a New Resilience Scale: The Connor-Davidson Resilience Scale (CD-RISC)," *Depression and Anxiety* 18 (2003).
- 12 The well known SF36 instrument is described as "a ubiquitous measurement tool used across all health care industry sectors." See Measuring Employee Productivity: A Guide to Self-Assessment Tools, 2001 edition, Wendy Lynch, John Reidel, editors, William M. Mercer and Institute for Health Productivity and Management, p. 20.
- 13 By way of comparison, the CD-RISC instrument has been used with primary care and psychiatric outpatients, and with people suffering from generalized anxiety disorder and post-traumatic stress disorder. These groups had resilience means ranging from 47.8 to 71.8.
- 14 Lower resilience scores for ethnic groups may be affected by cultural and language issues. Many recent immigrants, for example, exhibit high resilience in the face of adapting to a new culture, language and work. It's considerably more complex than a simple "correlation" between ethnicity and a resilience scale would suggest.
- 15 We excluded categories for dementia, drug psychoses, organic psychotic conditions, delays in development and mental retardation. Records included all inpatient/ outpatient/medication data for the AHCCCS population, and inpatient (including emergency room) data from the

John C. Lincoln Health System, St. Joseph Medical Center and Scottsdale Healthcare System. The results are exploratory, and should not be interpreted as definitive.

- 16 www.urban.org/UploadedPDF/311053\_B-60.pdf.
- 17 A. Kleinman, "Culture and Depression," *New England Journal of Medicine*, 351:10, September, 2004, p. 951.
- 18 Discussed at length in *The Humpty Dumpty Syndrome*, St. Luke's Health Initiatives, op. cit.
- 19 Although Latinos may share a language, they have roots in different countries with different histories and cultural influences. The bilingual Latino population in Maricopa County is itself diverse, and some of the views expressed by focus group participants may not necessarily reflect the views of all Latino constituencies, which can vary by education, acculturation, English language proficiency, legal status and income. They should be generalized with caution.
- 20 We do not summarize behavioral health services offered through hospitals, primary care clinics, prisons and similar sites, some of which have been discussed in previous SLHI reports.
- 21 Community Information and Referral, 2004 Directory of Human Services and Self-Help Support Groups, Maricopa County, 27th Edition. Agencies or programs may be repeated among the categories directly or indirectly related to behavioral health needs.
- 22 Notice of Intent to Issue Solicitation: Behavioral Health Services Administration for Greater Arizona, Arizona Department of Health Services: Division of Business and Financial Services, May 31, 2004.
- 23 State Health Facts Online, The Henry J. Kaiser Foundation. Data obtained from Kaiser directly, June 22, 2004.
- 24 2002 Occupational Employment and Wage Estimates: 2002 Metropolitan Area Cross-Industry Estimates. U.S. Department of Labor: Bureau of Labor Statistics. www.bls.gov/oes/oes\_dl.htm
- 25 View the complete report at www.unitedhealthfoundation.org.
- 26 Mental Health Prevalence Data: Risk Factor Surveillance System, National Center for Chronic Disease Prevention and Health Promotion: Mental Health Work Group, 2001. www.cdc.gov/mentalhealth/prevalence\_data.htm
- 27 The sampling was designed to be suggestive, and not conclusive. More information is available from SLHI.
- 28 Employee Assistance Professionals Association. www.eapassn.org.
- 29 National Institutes of Health (NIH) news advisory, May 24, 2004. www.nccam.nih.gov/news/2004/052704.htm
- 30 See Resilience: Health in New Key, op. cit.
- 31 Lisa A. Cooper, Neil R. Powe, *Disparities in Patient Experiences, Health Care Process and Outcomes: The Role of Patient-Provider Racial, Ethnic and Language Concordance, John Hopkins University Press, 2004.*

#### **Our Mission**

## To improve the health of people and their communities in Arizona, with an emphasis on helping people in need and building the capacity of communities to help themselves.

The purpose of *Arizona Health Futures* is to unravel an important health policy topic of relevance to Arizonans, provide a general summary of the critical issues, background information and different perspectives on approaches to the topic, tap into the expertise of informed citizens, and suggest strategies for action.

*Arizona Health Futures* is available through our mailing list and also on our web site at **www.slhi.org**. If you would like to receive extra copies or be added to the list, please call 602.385.6500 or email us at info@slhi.org.



Comments and suggestions for future issues, as always, are welcome.

St. Luke's Health Initiatives is a public foundation formed through the sale of the St. Luke's Health System in 1995. Our resources are directed toward service, public education and advocacy that improve access to health care and improve health outcomes for all Arizonans, especially those in need.



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