California Mental Health Older Adult System of Care Project

Deliverable 4 Report:
Focus Groups

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California Mental Health Older Adult System of Care Project
Focus Group Report: Executive Summary

Overview

The Older Adult System of Care (OASOC) framework puts forth several individual-level values as principles to guide the delivery of mental health services to older adults. Through a series of focus group discussions conducted in English and Spanish, we gathered and documented the first -hand experiences and observations of both older adult consumers and their family members. Analysis of these rich and dynamic group discussions allowed us to examine what these values mean to consumers and their family members, and whether these principles are effectively promoted and addressed through the delivery of mental health and other community-based services and supports. We first document the extent to which the individual- level values of an OASOC are recognized and/or are meaningful in the day-to-day lives of our participants. We then examine their experiences accessing care, and their perceptions of the quality of care received, including the extent to which it is culturally and age-appropriate. Finally, we provide a summary of service gaps that consumers and family members have identified and improvement strategies they recommend.

Background

Since passage of the Mental Health Services Act (MHSA or Act) by California voters in 2004, progress has been made in enhancing behavioral health programs and services designed to meet the needs of those with serious mental illness (SMI). Prior to passage of the MHSA, a great deal of effort was invested in designing a comprehensive and integrated OASOC, similar to the systems developed for both children and adults. This report presents findings from a study designed to address the following primary research question:

i. *What progress has been made at the State and local levels in the past decade toward implementing an integrated and comprehensive system of care for older adults with serious mental health needs?*

Six focus groups were conducted with three different consumer and family member stakeholders: 1) Spanish-speaking older adult consumers of mental health services, 2) Older adult consumers of mental health services who were currently or had previously been homeless, and 3) Family members of older adults who are consumers of mental health services.

The focus groups were one of three primary methods used to address this research question: Key informant interviews with both county and state-level representatives, Focus groups, and Secondary data analysis. The results from two of these methods (i.e., key informant interviews and secondary data analysis) have previously been reported. This report presents the results of the focus groups.

Methods

Focus Groups

This methodological approach was chosen because it provides an effective way to gather, synthesize, and represent the perspectives of consumers and family members. This qualitative method further supports the investigation of contextual factors and processes that may bolster or inhibit the effective delivery of MHSA-funded mental health services to older adults

Development of Focus Group Guides

The content of the focus group guides was informed by the key informant interview guides that were developed through a review of the literature of studies of older adults with mental illness and with consideration of the fundamental concepts included in the OASOC framework. Once finalized, the English language consumer focus group guide (along with the information flyer and the screening and consent script) was translated to Spanish.

The final focus group guides included (as applicable) the following content areas:

- Current use of mental health services
- How consumers learned about or got connected to these services
- How services or programs have been helpful to consumers, to family members
- What challenges consumers have had getting what they need from these services
- How well services respond to who consumers are, to the ethnic, racial, gender, or cultural groups they identify with

•How well do the services they receive respond to their needs as they grow older
•Are consumers participating in other types of services or programs that are helpful?
Suggestions about how to improve the way mental health services are provided to older adults in California

IRB Review and Approval
All draft focus group recruitment and data collection protocol, procedures and documents were submitted to the UCLA Institutional Review Board. Approval for the overall study was granted on February 26, 2016.

Recruitment
Three organizations that serve older adult consumers of mental health services or their family members were identified as venues for the focus groups in 3 of our 6 study counties. Representatives from these organizations were given study information flyers with the locations, dates and times of the focus groups.

Data Collection
Six focus groups were conducted between March 7th and April 12th of 2017. The groups were comprised of a total of 33 consumers and 11 family members. Each group was staffed with a primary facilitator and a note taker. We scheduled a 2-hour window for each focus group. UCLA Center for Health Policy Research Page 3 Actual discussion time averaged a total of 90 minutes, allowing ample time for screening and for participants to take a break.

Focus Group Sample
Consumers: The 33 consumer participants ranged in age from 54 to 85, the average age was 66, and the majority (61%) was female. Approximately half of participants identified as Hispanic/Latino, while 42% were African American, 6% White and 3% identified as Multiracial. English was the preferred language of 52% participants, 18% were Spanish monolingual, and 30% were bilingual (English/Spanish).

Family Members: Seventy-three percent of the 11 family member participants were female. The majority (73%) identified as African-American, while 18% were Multiracial, and 9% Hispanic/Latino. More than a third said they were living with a family member who is a consumer of mental health services, and 36% said the family member needs a caregiver.

Data Analysis
All focus groups were audio-recorded and then transcribed verbatim. The transcripts were then independently coded by two members of the research team in ATLAS.ti, a software program which facilitates the management, organization and analysis of qualitative data. Through this phase of analysis, recurring patterns, emerging themes and outliers in the data were identified.

Findings

The focus groups produced information that both confirmed and supplemented what we learned through the earlier secondary data analyses and key informant interviews conducted for this study. Importantly, the focus groups significantly increased representation of the consumer and family member voice, which strengthened our methodology, while also aligning well with the MHSA commitment to stakeholder involvement in all aspects of MHSA planning and implementation.

The focus group composition by participant type, the specific locations of the focus groups, and the dynamic nature of group discussion and processes all contributed to the discovery of both new and more in-depth content. These data are helpful in addressing our primary research question concerned with the progress made toward implementing an integrated and comprehensive system of care for older adults with serious mental health needs

At the same time, the focus group data provide supplemental information about older adult homelessness, substance use, the role of the family and religion/spirituality in recovery, and the impact of historical and collective trauma experienced by participants, the vast majority of whom are members of racial/ethnic minority groups.

The focus group data also address the research questions concerned with identifying barriers, facilitators, service gaps, and strategies for improving a system of care for older adults. The narratives illuminate what matters most to consumers and family members, including where services work well to support their goals and preferences for care, and where they fall short.

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Individual Values Guiding an Older Adult System of Care

Although participants were not directly asked about the 10 individual values enumerated by the OASOC framework, relevant content came up naturally in the course of the focus group discussions. We were able to identify and document the following ways in which consumers and family members think about and experience these values.

Healthy Aging
Participants across all groups noted the importance of staying active while acknowledging some of the common health conditions associated with aging. They discussed the value of having access to physical health screenings in convenient locations, the importance of taking charge of one's own health, for example, by quitting smoking or eating well.

Recovery and Resilience
Consumer participants described their recovery experiences which typically illustrated tremendous resilience. They discussed the importance of taking individual responsibility, as well as the value of incorporating peers and family role models into their process. Many talked about their recovery as a journey that, for most, was closely connected to religious or spiritual beliefs.

Emphasis on Strengths, Quality of Life, Options and Contributions
Consumer participants shared examples of how they work on identifying and building on their own strengths through participation in peer and support groups. Many also discussed finding strength through prayer.
Quality of Life
In general, we found that the quality of life experienced by consumer participants is associated with how well the other OASOC values have been addressed.

Options
Many consumers spoke about having choices, and how these choices produced hope and empowered them to make their own decisions – for better or for worse.

Contributions
Many consumers talked about the importance of having a sense of purpose, keeping busy and contributing to something meaningful. Examples included engaging in volunteer work, serving as peer mentors, participating in advocacy efforts, and taking time to share their life experiences with younger generations.

Regain Social Roles
Consumer participants illustrate some of the ways in which they have connected with meaningful activities that help them reestablish an identity that moves beyond being marginalized as "just" an older adult, a recovering addict, someone who is recovering from mental illness. Several consumers also described how they have become more engaged in social roles through their participation in mental health services and through activities at the church.

Holistic Approach (Biological/Psychological/Social/Spiritual)
Consumers and family members described a broad range of biological, psychological, social and spiritual needs and noted a number of ways in which these needs were or were not effectively met, both in the context of formal interactions with the public county mental health system and through both formal and informal interactions with a wider network of community resources.

Role of Consumers, Family Members, Caregivers
The role of family and intergenerational supports emerged as a central aspect of the consumer experience. Both consumers and family members discussed how family members may be instrumental in getting consumers to needed care and are often an essential resource for their recovery. Across participants, there was variation in the nature of family member involvement and the quality of these relationships. Family members identified their own unmet needs for caregiver support.

Community Focus & Empowerment
Across all focus groups, the importance of community was emphasized. The types of communities discussed included support group communities, church communities, and neighborhood communities that were defined by a specific geography and shared experience. Participants spoke of many of the challenges that affect the cohesiveness and overall health of their communities including a history of racism and exploitation that has deeply affected individuals, families, and entire communities, often undermining and eroding their trust in government systems. They also spoke of the importance of finding solutions within the community, coming together to address injustices through empowerment and advocacy.

Pathways to Care

The focus groups revealed the different ways in which consumers found their way to mental health services, as well as barriers and facilitators they experienced accessing and staying in care.

Referred by Family and Third Parties

Many participants got connected to mental health services through a family member. Family members talked about the challenges they often faced ensuring that their loved ones accessed the services. Unexpectedly, some consumers were referred to mental health services through third parties, e.g., through a family member's psychiatrist, through a teacher at a family member's elementary school.

Referred by Established Institutions and Programs

Many of the participants found their way to mental health services through established institutions, such as churches, hospitals and clinics. Others were referred by an Alcoholics Anonymous group or through encounters with law enforcement.

Agency Reputation/Word of Mouth

In some cases, the positive reputation of an agency providing services for older adults appeared to increase the probability that consumers would seek out the services they needed. Word of mouth was an important way in which older adults from all groups, including family members, learned about an agency or program and accessed services.

Barriers

The barriers that participants experienced included medical mistrust, lack of African-American mental health providers, cultural beliefs, current societal attitudes and stigma, provider cultural competency, the frequent turnover of providers and trouble accessing government services.

Facilitators

Participants talked at length about the factors that made it easy for them to access care and/or remain in care, including spirituality and volunteering, preferred characteristics of providers, and programmatic features, such as the type and content of program offered, the language of its offering, and who the programs targeted.

Quality of Care

The focus groups were informative with respect to how and why these services helped them as consumers or as family members. Participants discussed three broad categories of services: mental health services, substance abuse services, and aging services.

Mental Health Services

All three participant types (Spanish-speakers, homeless, and family members) described what mental health services they are familiar with or have used. These include individual visits with physicians, psychiatrists, therapists; group therapy; behavioral modification classes; and daytime outpatient programs. Across all participant types, one-on-one interactions with physicians and psychiatrists were perceived as helpful, particularly with issues related to medication management and the management of other physical health challenges. Some of the reasons given for the most successful/useful provider visits were described as those that included bilingual providers who could communicate and explain well, were knowledgeable about available resources (such as crisis lines/suicide prevention programs), had established a personal connection with the consumer, were familiar with their medical/personal history, and could pick up on the consumer's physical and emotional cues regarding sadness, happiness, etc.

Aging Services

All participant types reported using aging services, such as adult day health centers and senior centers, which provided a diverse range of health and wellness programs. The Spanish-speaking participants talked about receiving healthy living advice, and participating in nutrition programs and art classes. Art programs in particular were described as helpful. In the homeless groups, discussions revolved around senior-specific services (55 and over), which included education, anger management, volunteering, and meaningful engagement. These were perceived as helpful in UCLA Center for Health Policy Research Page 7 recovery, because they provide structure to someone's day, as well as a sense of purpose. In the family member groups, the discussion about aging services was more extensive, focusing on both strengths and deficiencies. Services mentioned by family members included crafts and jewelry making classes for seniors, meals on wheels, and Adult Protective Services which was described as a much-needed resource.

Substance Abuse Services

All participant types mentioned experiences with substance abuse services, such as smoking cessation, Alcoholics Anonymous (AA) and Narcotics Anonymous (NA). However, discussion of these services, plus methadone clinics, was more pronounced in the homeless groups. Homeless informants

reported using methadone clinics, NA (regular services and over-55 services), AA, and smoking cessation through behavior modification programs. These programs were credited with giving participants more structure in their day-to-day lives, and providing a venue in which they could open up without fear of backlash.

Integrated Care
Participants from all groups described services and programs that provide integrated services and care. In the Spanish-speaking group, participants mentioned receiving physical and mental health services, such as therapy, blood pressure management, sleep clinics, management of multiple conditions/co-morbidities. These services were often combined with housing, education, and employment support. In particular, one program's support with accessing housing was very much appreciated.

Service Gaps

In addition to explaining how helpful services have been, focus group participants also discussed some of the deficiencies and gaps they have encountered. Their conversations centered around five particular areas where programs fall short: delays in referrals and services, screening and diagnosis failures, misalignment of substance abuse and mental health services, and disparities in access to services and experienced providers. In illustrating these service gaps, participants drew from their own experiences as well as the experiences of family and friends who have been similarly affected.

Improvement Strategies

Participants also made recommendations for future improvements in service availability and delivery. These included the introduction of "community ambassador or mentorship" programs, mental health services that provide more opportunities to socialize, support groups and education programs for family caregivers, recruiting local providers, and being more responsive to older adult specific needs. They articulated the need for these services in their communities, the potential benefits that they could afford, and offered recommendations for how to develop and implement them.

Consumer-identified programs and strategies
Consumer participants mentioned several additional preferred programs/ practices including: UCLA Center for Health Policy Research Page 8 home visits, support groups, crisis hotlines, volunteering, art therapy, and biofeedback. They also talked about strategies for improving mental health services through: partnerships with grassroots community agencies; use of diplomatic, non- stigmatizing language in social marketing campaigns for mental health services; hands-on outreach in the homeless community; frequent follow up phone calls and home visits after physically or emotionally traumatic events; and collaborating with law enforcement and educating officers about the needs of older adults with mental illnesses.

Summary and recommendations

Observations across groups
First, it is important to note that the focus group participants are currently and actively engaged in the mental health delivery system, and therefore their narratives reflect a specific point of view and experience. Most participants are low-income residents of underserved inner city areas and survivors with a lifetime of exposure to abject poverty, drug epidemics, and violence. These raw realities brought forth a depth of insight and truth that the participants shared with us in a most open and compelling manner.
All groups went beyond a narrow discussion of mental health service delivery, bringing in examples of other publicly delivered services, informal community support networks, and observations about sociopolitical and other factors that provided the backdrop to their experiences as consumers or family members of consumers of mental health services.

Finally, both types of consumer participants (i.e., Spanish-speaking and homeless) were generally very positive about the services they are receiving from the host organization (i.e., the focus group venue). While this is a clear limitation of our convenience sampling, the sincerity of gratitude and satisfaction expressed by so many consumers was hard to dismiss as lacking in significance.

Observations within groups
While we found commonalities across groups, there were also some observations within groups that are important to note.

Spanish--speaking consumers: The role of religion was quite central to the identity of many participants and, on average, more emphasized than by other focus group types. References to religions were, for some, closely connected to their process of recovery. Religious participation

was more explicitly connected to the idea of making a contribution through working or volunteering, while also remaining socially engaged as a benefit to oneself and to others. Spanish-speaking participants also tended to take a more collective - "We" vs. "I"- approach to recovery – through family, friends, peers, church, and community. In general, they appeared less identified with the concept of "individual goals" of recovery.

Homeless consumers: While the homeless participants considered church and family as part of their service/support network, their discussions of religion were most strongly connected to recovery from addictions, less about mental illness recovery, per se (which was more the description UCLA Center for Health Policy Research Page 9 provided by the Latino participants). They also more frequently discussed individual level trauma in the context of collective, societal trauma, taking a broader view of systems issues affecting their entire community. This collective view further extended to descriptions of their experiences within the mental health delivery system, which were framed in the context of historical and social factors such as racism, generational poverty, lack of community resources, urban blight, violence, and drug epidemics.

Family members: Family member groups were the most outspoken about deficits in the mental health delivery system and in public services more generally. They took a broader focus with respect to public services than either of the consumer groups. Like the homeless groups, they discussed the lack of resources in the community/ neighborhood that affects delivery and access to care. They also discussed the need for solutions that come from and are implemented from within the community.

Recommendations

In earlier reports produced from this study, we made recommendations based on analyses of secondary data and key informant interviews. Here we make recommendations that are specific to what we learned from the consumers and family members who participated in our focus groups.

Offer information and services from trusted and compassionate sources:

- Create and support more opportunities for consumers and family members to connect with one another; design activities that bring family members and consumers together
- Develop formal services that recognize and support the important role that family members play in consumers' lives, through education and counseling for family members.
- Incorporate family concerns into treatment plans and goal -setting with consumers that includes reunification plans, as appropriate.

Identify and support the religious/spiritual practices and traditions of consumers, both in individual treatment and in group practice and program settings.

Provide more opportunities for one-stop shopping:

- Integrate the delivery of physical health, mental health, and substance use services through co-location and through interdisciplinary teams.
- Increase access and linkages to substance use disorder and recovery programs that are essential to effective mental health services. Once in recovery, ensure that mental health services are available and tailored to also meet consumer needs as recovering addicts.

Conclusion

To improve the delivery of mental health care to older adults, the public mental health service delivery system should aspire to better align itself with the consumer and family member needs and preferences identified in this report. Systems-level delivery processes and programs that are responsive to the expressed needs of older adults and their families can leverage and enhance existing social support networks that already bolster individual-level recovery. We learned from our participants that a sense of community, support from family, and grounding in one's religious/spiritual beliefs all contribute to a sense of purpose and a source of social connection for older adult consumers of mental health services. The lessons learned can be used by counties to improve older adult access to mental health services, to reduce the factors that impede their recovery, and multiply the factors that support their recovery by recognizing the social context in which older adult consumers are situated and addressing the more holistic needs that they have identified.

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Project Overview

The UCLA Center for Health Policy Research received a 2-year contract from the California Mental Health Services Oversight and Accountability Commission (MHSOAC) to assess the progress made in implementing a system of care in California for older adults with serious mental illness (SMI) and to identify methods to further statewide progress in this area.

The assessment methods include examining the extent to which a representative sample of counties have systematically implemented services tailored to meet the distinctive challenges and needs faced by the older adult population, including historically disadvantaged and un/underserved older population subgroups. In addition, the assessment shall consider the extent to which the Mental Health Services Act (MHSA), passed in 2004, has facilitated or bolstered the implementation of a system of care for older adults.

The UCLA Center for Health Policy Research shall also identify and document the challenges and barriers to meeting the unique needs of this population, as well as strategies to surmount these obstacles. In order to support the State's ability to promote improvements in the quality of mental health services for older adults, a series of indicators was developed that focus specifically on older adults and systems of care for older adults. These new indicators will assist future MHSOAC data strengthening and performance monitoring efforts. Lessons learned and resultant policy recommendations for improving older adult mental health programs at the State and local levels shall be developed and presented to the Commission.

A key process in the project was assembling a statewide project advisory committee (PAC) that represents key stakeholders in the area of mental health for older adults. The PAC includes representatives from different geographic regions who are older adult consumers, family members/caregivers of older adults, community-based providers contracted by counties, county program administrators and other relevant county representatives, evaluation experts with experience in older adult systems of care, representatives from relevant stakeholder associations (e.g., those focused on racial/ethnic/demographic minorities, and un/under-served populations), and relevant state-level representatives (e.g., California Department of Aging) who are subject matter experts in the area of program and service delivery for older adults. The final PAC member roster with their affiliation, contact information and stakeholder representation is provided in Appendix A. The PAC provides meaningful stakeholder input for all phases of the study.

Deliverable 4 Overview

This report presents findings from six focus groups conducted with three different participant types: 1) Spanish-speaking older adult consumers of mental health services, 2) Older adult consumers of mental health services who were currently or had previously been homeless, and 3) Family members of older adults who are consumers of mental health services.

As per the terms of our executed contract, the focus groups were one of three methods used to address the research questions related to Specific Aim 1: To assess the progress made in California towards implementing a system of care for older adults with SMI. The three primary methods included:

i) Key informant interviews with both county and state-level representatives,
ii) Focus groups, and
iii) Secondary data analysis.

The results from two of these methods (i.e., key informant interviews and secondary data analysis) have previously been reported (see Deliverable 3). This Deliverable 4 report presents the results of the focus groups.

Our original contract specified that the "theme/content area and participants for each of the focus groups shall be determined based on preliminary findings from key informant interviews across the sampled counties". Based on findings from the key informant interviews, we determined in consultation with our Project Advisory Committee that the project would benefit from additional consumer and family member representation, especially among communities of color. Therefore, we submitted an amendment to the original focus group plan to specifically add two Spanish-language focus groups, two focus groups with homeless or previously homeless consumers, and two focus groups with family members with older adults of persons with mental illness. The amendment was approved by the State on January 10, 2017.

Part 1 of the report presents the focus group findings and Part 2 summarizes/discusses the findings and offers preliminary recommendations based on these findings. As noted throughout the report, appendices are provided as a separate document.

Meaningful Stakeholder Input

To assure meaningful stakeholder input for Deliverable 4, we have utilized our PAC throughout the design and execution of these major project activities. Their contributions have been instrumental to the work summarized in this report, as they have reviewed and provided valuable input on numerous project products, including: focus group recruitment flyers, information sheets, screening scripts, and data collection instruments; and have also assisted with advising recruitment strategies and focus group implementation, including the selection of venues and logistical support. Feedback from the PAC has

been solicited and provided in the course of regularly scheduled PAC meetings (December 9, 2015; May 4, 2016; December 8, 2016, February 22 and 23, 2017) and through individual phone calls and emails exchanged in between formal meetings.

Approach

Our approach to the project, including the work within Deliverable 4, was based on four key principles, which are described below:

1. Use the values and principles laid out during seminal work in California for an Older Adult System of Care (OASOC) (See Figure 1 below)
2. Build on evaluations and reports by leaders and stakeholders in the area of public mental health services for older adults
3. Utilize key stakeholder input and recommendations to shape the design, process and reporting of findings within Deliverable 4
4. Gather information from a wide range of diverse key informants and stakeholders to inform the project

Even prior to the passage of the Mental Health Services Act (MHSA), considerable work had been completed in outlining key components for an Older Adult System of Care (OASOC). As described previously, the project team analyzed several models that were presented and discussed early in the project with the PAC. The framework put forth by the California Mental Health Directors Association (2001, with revision in 2005), was adopted for the project on December 9, 2015. This framework is presented in Figure 1. A system is more than a set of services. It is an **organization of parts/programs** integrated through processes, in order to accomplish its purpose. It has boundaries and a mechanism for decision making in order for the system inputs and outputs to produce a dynamic stability and outcomes **in interaction with its environment**. There is ongoing feedback among these various part/ programs to ensure they are aligned to **accomplish the overall system goal**. The framework below of the OASOC has guided all components of the project, and has been instrumental in guiding the study, including the Focus Group component reported for Deliverable 4.

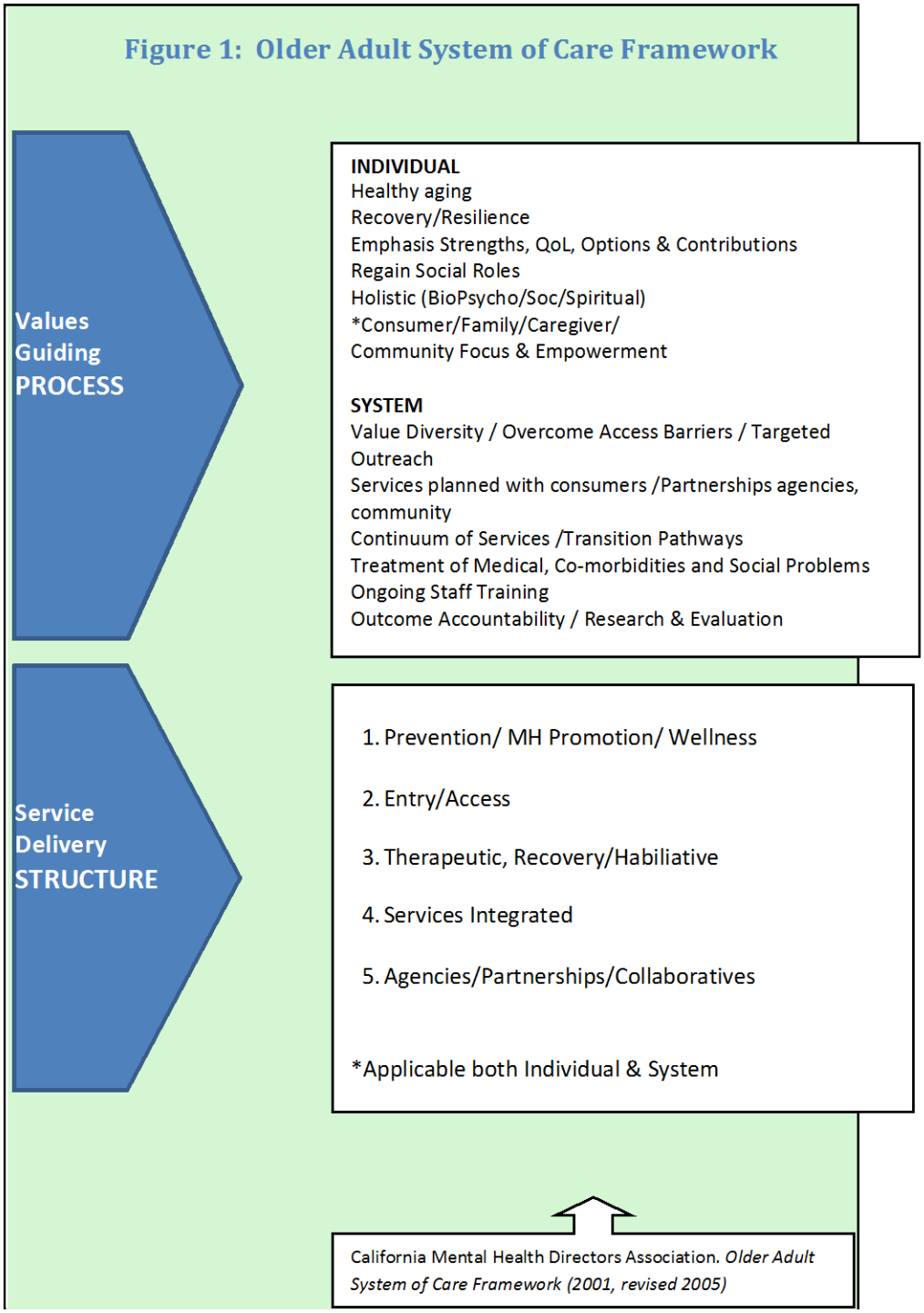
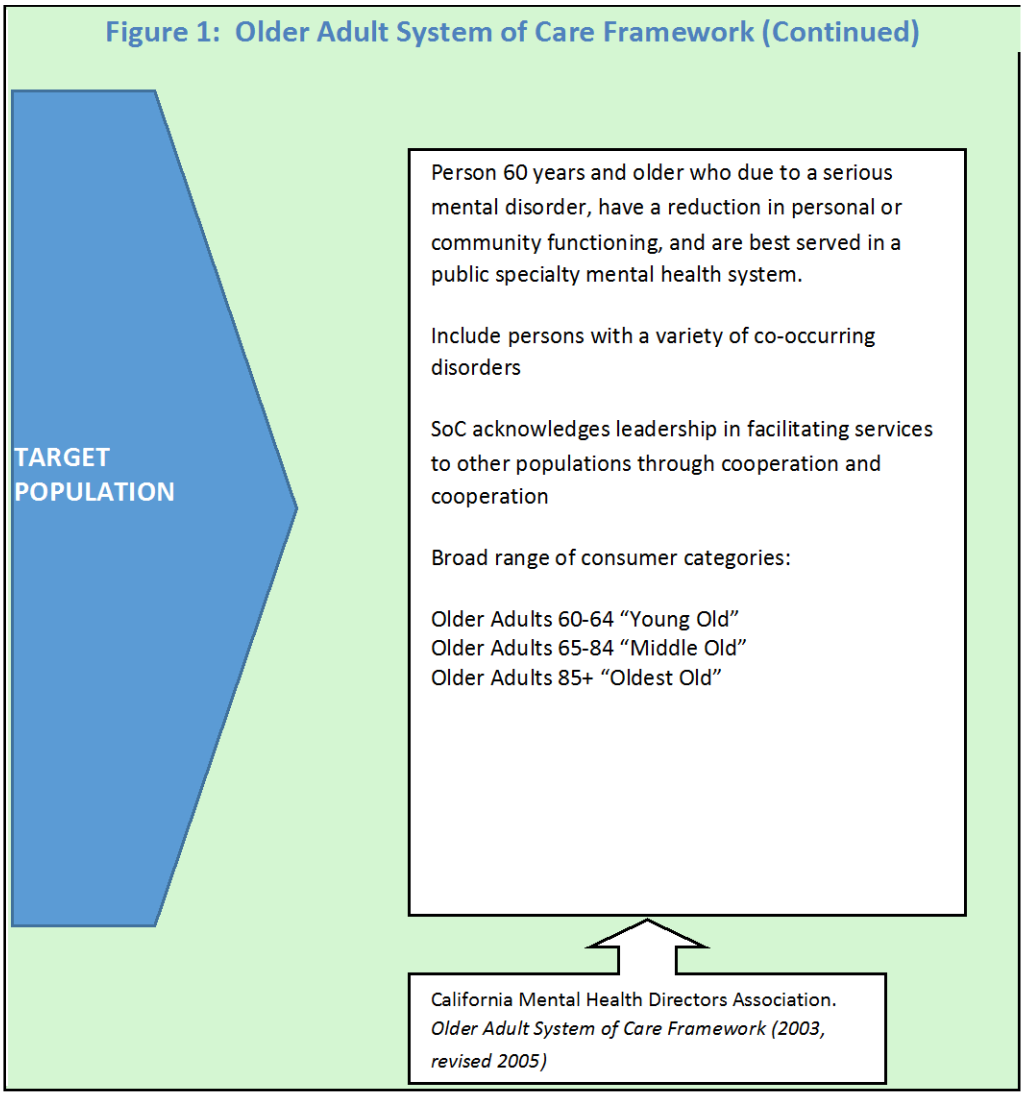


Figure 1: Older Adult System of Care Framework
Values Guiding PROCESS
INDIVIDUAL
Healthy aging
Recovery/Resilience
Emphasis Strengths, QoL, Options & Contributions
Regain Social Roles
Holistic (BioPsycho/Soc/Spiritual)
*Consumer/Family/Caregiver/
Community Focus & Empowerment
SYSTEM
Value Diversity / Overcome Access Barriers / Targeted Outreach
Services planned with consumers /Partnerships agencies, community
Continuum of Services /Transition Pathways
Treatment of Medical, Co-morbidities and Social Problems
Ongoing Staff Training
Outcome Accountability / Research & Evaluation
Service Delivery STRUCTURE
1. Prevention/ MH Promotion/ Wellness
2. Entry/Access
3. Therapeutic, Recovery/Habiliative
4. Services Integrated
5. Agencies/Partnerships/Collaboratives
*Applicable both Individual & System
California Mental Health Directors Association. Older Adult System of Care Framework (2001, revised 2005)



Adapted from the Older Adult System of Care Framework developed by California Mental Health Director's Association (2001, revised 2005)[1]*, the California Mental Health Planning Council "Chapter 6 Planned System of Care for Older Adults"*[2] *and approved by our Project Advisory Committee on December 9, 2015*

Focus Group Data Findings

Background

Since passage of the Mental Health Services Act (MHSA or Act) by California voters in 2004, progress has been made in enhancing behavioral health programs and services designed to meet the needs of those with serious mental illness (SMI) and to expand available services and resources to previously unserved and underserved communities. Prior to passage of the MHSA, a great deal of effort was invested in designing a comprehensive and integrated Older Adult System of Care (OASOC), similar to the systems developed for both children and adults.

Despite progress made over a decade ago to develop this system of care, the extent to which the OASOC has been implemented at the local level across the State is unknown. Similarly, the extent to which the MHSA may have facilitated or bolstered such implementation is unknown. Challenges in implementing a comprehensive and integrated system of care for this population appear to still exist.

Primary Research Question

Establishing a better understanding of what has been done and challenges that have been faced, including those that have been overcome and those that remain, may provide insight regarding strategies for furthering progress in this area across the State, which are primary goals of this research. As such, we posed the following primary research question:

i. *What progress has been made at the State and local levels in the past decade toward implementing an integrated and comprehensive system of care for older adults with serious mental health needs?*

Under this primary query, we posed the following series of sub-questions:

a. *How has, if at all, the MHSA bolstered or facilitated implementation of an Older Adult System of Care?*

b. *What obstacles and barriers have been identified in implementing a comprehensive system of care for older adults at the State and local levels? What strategies have been identified to overcome obstacles and achieve sustained improvement in the older adult system of care? What, if any, challenges have been insurmountable via State and local efforts? What gaps exist in services for older adults with serious mental illness across the state?*

Methods

Focus Groups

The focus groups were one of three methods used to address the research questions related to Specific Aim 1: To assess the progress made in California towards implementing a system of care for older adults with SMI. The three primary methods included:

i) Key informant interviews with both county and state-level representatives,
ii) Focus groups, and
iii) Secondary data analysis.

The qualitative data gathered from the focus groups is intended to build on and complement the data gathered through the i) key informant interviews and iii) secondary data analysis. These three methods, taken together, provide a point of triangulation from which the validity of the findings of each method can be further assessed for concordance or discordance. In addition, findings that are unique to any one method can be evaluated as potential supplementary evidence that expands understanding of the phenomenon of inquiry.

The nature of the focus group format adds richness to information gathering that is achieved through dynamic discussions engaged in by multiple members who share a common characteristic (e.g., older adults with mental illness) and who are asked about a particular topic (e.g., their experiences receiving mental health services). This methodological approach was chosen because as one of the three study methods because it provides an effective way to gather, synthesize, and represent the perspectives of consumers and family members. This qualitative method further supports the investigation of contextual factors and processes that may bolster or inhibit the effective delivery of MHSA-funded mental health services to older adults. Finally, the consumer- engaged approach inherent in focus groups directly reflects one of the hallmarks of the MHSA, i.e., ensuring that there is meaningful stakeholder input in every phase of MHSA's development, implementation, and evaluation of outcomes.

Focus Group Composition

As noted earlier, while consumers were included in the key informant phase of the study, we believed that, to more fully understand and evaluate the consumer experience, we needed additional representation of the consumer voice. We, along with the members of our PAC, were especially concerned about adequately representing the perspective of racial/ethnic minorities and other historically underserved populations who represent a disproportionate share of the population served through the public mental health system. In addition, only a couple of family members were part of the key informant interviews; we included them because we believed that they would offer a unique and informative perspective on how their loved ones were being served through the public mental health system.

Recruitment

We worked closely with members of our PAC and with select key informants to identify appropriate venues in which to reach the desired populations (i.e., Spanish-speaking older adult consumers, homeless or formerly homeless older adult consumers, and family members of older adult consumers with mental illness). Three organizations that serve older adult consumers of mental health services or their family members were identified as venues for the focus groups in 3 of our 6 study counties. Representatives from these organizations were given study information flyers with the locations, dates and times of the focus groups. They handed out information flyers to prospective participants they knew through personal contact with them through their respective organizations and usual organizational activities. To maintain confidentiality, informational flyers were handed to prospective consumer or family member participants in a private setting (e.g., a private office, private room). If a prospective participant was interested in participating, they were invited to call the toll-free number on the flyer, or to show up at the scheduled focus group location and time to meet with members of the research team to get more information. Prospective participants who showed up at the focus group venues were screened on site for eligibility and, if eligible and willing to participate, project staff administered a verbal consent script and gave them a project information sheet.

To review the complete set of English and Spanish recruitment flyers, information sheets, and screening and consent scripts, please see Appendices A-J.

Development of Focus Group Guides

The content of the focus group guides was informed by the key informant interview guides that were developed through a review of the literature of studies of older adults with mental illness and with consideration of the fundamental concepts included in the Older Adult System of Care (OASOC) framework (see pages 4-5) put forth by the California Mental Health Directors Association (2001, with revision in 2005) to ensure that these core philosophies and values were represented. We also identified topic areas and questions that were not covered in depth through key informant interviews and that we believed would be particularly productive in the context of a group discussion. We shared the focus group guides with the Project Advisory Committee (PAC) via email, asking them to review the guides and provide feedback about the relevance of the content included and the appropriateness of the language used. Once finalized, the English language consumer focus group guide (along with the information flyer and the screening and consent script) was translated to Spanish. A Spanish-speaking member of our PAC provided helpful feedback about appropriate language use which we incorporated across these documents. The final versions were submitted and approved as an amendment to our IRB on February 27, 2017.

The final focus group guides included (as applicable) the following content areas:

- Current use of mental health services
- How consumers learned about or got connected to these services

- How services or programs have been helpful to consumers, to family members
- What challenges consumers have had getting what they need from these services
- How well services respond to who consumers are, to the ethnic, racial, gender, or cultural groups they identify with
- How well do the services they receive respond to their needs as they grow older
- Are consumers participating in other types of services or programs that are helpful?
- Suggestions about how to improve the way mental health services are provided to older adults in California

To review the complete set of 3 focus group guides and specific questions within, please see Appendices K-M.

IRB Review and Approval

All draft focus group recruitment and data collection protocol, procedures and documents were submitted to the UCLA Institutional Review Board for approval. Any refinements to these documents as they went through further stakeholder review and pilot testing were submitted to the IRB as an amendment to the original IRB approval. Approval for the overall study was granted on February 26, 2016. Follow up amendments were approved as needed, with the focus group protocol amendment approved on January 12, 2017.

Data Collection

Six focus groups were conducted between March 7 and April 12 of 2017. The groups were comprised of a total of 33 consumers and 11 family members. We scheduled a 2- hour window for each focus group. Each group was staffed with a primary facilitator and a note taker. The actual discussion time averaged a total of 90 minutes, allowing ample time for screening and for participants to take a break.

Consumer Sample

As detailed in Table 1, the 33 consumer participants ranged in age from 54 to 85, with an average age of 66; almost two-thirds (61%) were women. Approximately half of participants identified as Hispanic/Latino, while 42% were African American, 6% White and 3% identified as Multiracial. Less than half of participants (42%) were foreign-born, most of them in Mexico (93%). English was the preferred language of 52% participants, 18% were Spanish monolingual, and 30% were bilingual (English/Spanish). The earliest year when a consumer participant started utilizing mental health services was 1965, and some started in 2017. Insurance coverage among participants was mostly through Medicare (73%) and MediCal (88%). More than half of participants reported a history of homelessness, with an average duration of 2.3 years, ranging between 2 and 10 years. Some participants reported being continuously homeless, whilst others were homeless on and off.

Table 1. Demographic Characteristics of Consumer Participants (N=33)	
Characteristic	
Age (range)	66 (54-85)
Gender (%)	
Male	13 (39)
Female	20 (61)
Race/Ethnicity (%)	
Hispanic/Latino	16 (48)
African-American	14 (42)
White	2 (6)
Multiracial	1 (3)
Foreign-born	
Yes (%)	14 (42)
Years in the U.S. (range)	42 (30-54)
Country of origin (%)	
Mexico	13 (93)
Puerto Rico	1 (7)
Language preference (%)	
English	17 (52)
Spanish	16 (48)
Monolingual (Spanish)	6 (18)
Bilingual (Spanish/English)	10 (30)
Start of mental health service utilization	
Earliest year	1965
Latest year	2017
Insurance (%)	
Medicare	24 (73)
MediCal	29 (88)
History of homelessness	
Yes (%)	20 (61)
Average longest duration in years (range)	2.5 (2-10)

Family Member Sample

Seventy three percent of the 11 family member participants were women (Table 2). More than half (73%) identified as African-American, 18% were Multiracial, and 9% were Hispanic/Latino. More than a third said they were living with a family member who is a consumer of mental health services, and 36% said the family member needs a caregiver. About a third of participants identified as caregivers at the time of the focus group, while almost a third said they were formerly caregivers. The average duration of caregiving was 7.6 years, ranging between one and a half years to 20 years. The earliest year when a family member consumer started utilizing mental health services was 1960, and some started in 2015. More than half of participants reported a history of homelessness for their family member consumer, with an average duration of 4.3 years, ranging between 7 months and 4 years.

Table 2. Demographic Characteristics of Family Member Participants (N=11)

Characteristic		
Gender (%)		
	Male	3 (27)
	Female	8 (73)
Race/Ethnicity (%)		
	Hispanic/Latino	1 (9)
	African-American	8 (73)
	Multiracial	2 (18)
Living with family member consumer		
	Yes (%)	4 (36)
Family member consumer needs caregiver		
	Yes (%)	4 (36)
Participant identifies as caregiver		
	Yes, currently (%)	3 (27)
	Yes, in the past (%)	3 (27)
Duration of caregiving in years (range)		7.6 (1.5-20)
Start of family member consumer mental health services utilization		
	Earliest year	1960
	Latest year	2015
History of homelessness of family member consumer		
	Yes (%)	7 (64)
	Longest duration in years (range)	2.3 (0.58-4)

Data Analysis

All focus groups were audio-recorded (with participants' permission). These audio tapes were then transcribed verbatim. The Spanish language focus groups were translated to English by one of the two bilingual facilitators and then transcribed verbatim. The second Spanish language group facilitator reviewed the English translation and made revisions as appropriate.

The first verbatim focus group transcript was independently hand-coded by 4 members of the research team using the code list developed from analysis of the earlier key informant interviews, which was first revised to reflect content relevant to consumers and family members. The team then convened to review and discuss the coding labels and definitions, eliminating codes that were not useful and adding codes that were needed. Based on the discussion, code definitions were refined and finalized and categories of codes were identified.

Each verbatim transcript was entered into a software program called ATLAS.ti which facilitates the management, organization and analysis of large amounts of qualitative data. These transcripts were then independently coded by two members of the research team, one of whom had participated in the focus group. Through this phase of analysis, recurring patterns, emerging themes and outliers in the data were identified. Output data was generated by selecting specific groupings of codes that represented identified themes. Members of the team developed narratives from these data, which are presented in the next section on findings.

Findings

The Older Adult System of Care (OASOC) framework (see pages 4 -5) puts forth several individual-level values as principles to guide the delivery of mental health services to older adults. Through a series of focus group discussions conducted in English and Spanish, we gathered and documented the first-hand experiences and observations of both older adult consumers and their family members. Analysis of these rich and dynamic group discussions allowed us to examine what these values mean to consumers and their family members, and whether these principles are effectively promoted and addressed through the delivery of mental health and other community-based services and supports. We first document the extent to which the individual- level values of an OASOC are recognized and/or are meaningful in the day-to-day lives of our participants. We then examine their experiences accessing care, and their perceptions of the quality of care received, including the extent to which it is culturally and age-appropriate. Finally, we provide a summary of service gaps that consumers and family members have identified and improvement strategies they recommend.

Individual Values Guiding an Older Adult System of Care

The focus groups gave us the opportunity to learn the extent to which consumers and family members recognize and experience OASOC individual level values which include: healthy aging;

recovery/resilience; emphasis on strengths, quality of life, options and contributions; regain social roles; holistic (bio/psycho/social/spiritual; consumers, family, caregiver; community focus and empowerment.

Healthy Aging

Participants across all groups noted the importance of healthy aging while acknowledging some of the common health conditions associated with aging (e.g., hypertension, diabetes, dementia) that may be challenging to manage, especially in conjunction with mental health concerns.

Staying active

Male: *But I notice as a person get older, their body don't allow them to be active in the way that they were when they was younger.*

Female: *That's true*.

Male: *Of course.*

Male: *And I'm 72 and a lot of things I wished I could do, but I can't do. I do volunteer and I'm called upon sometimes to be of service. But I'm finding for me that I have to learn how to keep myself busy. I have to learn how to do things that I've been – a lot of things I can do that I put off. What you call that when you put…*

Male: *Procrastinate*

Male: *Procrastinate. I procrastinate a lot. And my main thing now is learning how not to procrastinate cuz there's always something to keep me busy. There's always something I can do to help me spiritually and mentally. And one thing I should study more. I should read more. I should gain more knowledge through my ability to read and to listen. But as you get older, your body don't allow you to do things that you could do up until I was say 60 years old, you know. But like now at the age I am, well my muscles won't pick this up, you know. My back started hurting. I started doing this and my back started hurting, so I have to learn how to stay active and be of service in a different manner. I have to allow my higher powers to send me somewhere and work me according to the way that He feels I can do it, you know. I can't go out no longer and solicit jobs, solicit work or volunteer to do anything.*

Facilitator: *No, it's not going to be the right time for everybody to do that, or maybe for anybody.*

Female: *Well I don't know because I just looked at an article on Google and they called them Super Agers. Those people are 60 and 70 years old and their brain functions as good as a 20-year-old. So that's why keeping yourself busy, doing something that means your mind's not going.*

Male: *Yeah, well if it's not my mind it's my body.* [Laughter] *I can't pick up that stuff no more. I can't walk those distances. I can't track myself like I used to. I'm older now and my body just don't cooperate the way I want it to cooperate.*

Female: *I can't go around the corner.* [Laughs]

[Multiple participants, Homeless group]

Making health care convenient

The value of having physical health screenings provided in mental health clinics, senior centers, and at housing sites was noted. Participants also mention that staff supports their efforts to get follow-up care.

Facilitator: *How do you get your physical healthcare needs met?*

Male: *They have programs that come here.*

Facilitator: *Okay. Do they do any health services here on-site like blood pressure screening?*

Female: *Yeah, yeah. They do that. They do all that. It's through the um…*

Female: *Health plan.*

Female: *Well then they have the nurses through the* [name of local university] *and they come here a couple, I think two days a week, nurses in training. They come here and they'll help, they'll do care plans for different seniors.*

Male: *They also have a portable clinic on wheels that comes here.*

Facilitator: *Oh, okay. So you can get health services.*

Male: *Yeah, they do their thing and it's good.*

Male: *Prick your finger…*

Facilitator: *How important is that to you?*

Male: *I like it because I have hypertension. I don't have a cuff. So you come here twice a day and you know I take medicine for my hypertension but you come here twice a day,*

twice a week and have it checked. And you know if it's really too high you know to get—

Female: *Yeah*

Facilitator: *And so you go and make the appointment with your doctor then or does sometimes your case manager help you make appointments?*

Male: *Yeah, they do.*

Female: *If you need help with it they will.*

Male: *They will.*

Male: *If you have a case manager, your case manager's like a hound dog on you.* [Laughter] *I mean, really. They'd be at you.*

[Multiple participants, Homeless group]

Being proactive with one's health

Consumers also discussed the importance of taking charge of one's own health, for example, by quitting smoking. Participants in the homeless group spoke about having access to smoking cessation classes.

Female: *And then they have here Stop Smoking.*

Male: *That's a hard addiction to kick, the cigarettes.*

Others spoke about the importance of being proactive with their health. This consumer describes how she takes pride in remaining physically active and not smoking or using drugs.

Ok well last year I had a stroke and I had no paralysis. I just had a sorta like a wakeup call stroke. And immediately they wanted to put in house people to come take care. And ok like, there's certain things that I'm really, I'm kinda like proud about. Ok like I still ride around on a bicycle. Alright. I live on a third floor walk-up and I go up and down like nobody's business and I'm proud of that.

You know what I mean. I don't smoke cigarettes, you know. I do not do drugs, ok and look, no drug use here, right? I like, I have other problems you know, like, like, mental health. I had to reach out and find a therapist. I had to find a therapist and why I say proactive, it's like, this is for me. If I don't do this, I'm gonna end up homeless again and I'm gonna end up, you know when you get older, you kinda like know your routine.

[Female consumer, Homeless group]

Another consumer who has diabetes talks about listening to his health care providers and being able to get off medication.

> *My feet, they get callouses on 'em but I go to the foot doctor and I… See I can't enjoy walkin. I can't enjoy being home when they hurt. But now I go get a treatment and I feel much better at home. You know what I mean? So like I got diabetes so, although I took medication long enough. I'm off of that. And so now I do it… I'm a diet diabetic, 'cause I've been paying attention to what they say to do. Now I don't have to take it. So like then I feel better about that. I do my readings everyday and I'm right where I need to be. So see that makes me enjoy home much better, me being able to have medical care.*
>
> [Male consumer, Homeless group]

Raising awareness of older adult health issues

One family member participant brought up the importance of educating and raising awareness about the physical and mental health issues that are specific to older adults.

> *Things come in fads and crazes, you know, but educate not just the older adults but then the young people, too, so that they could – they'll know, okay, this is Mr. so-and-so. Because I mean you have folk that are going with dementia, Alzheimer's, and that's a whole 'nother thing and you really gotta know what you're dealing with. So I think education and awareness. Raise awareness so that when we are in the presence of a loved one or a family member, a neighbor that perhaps is older and has a mental condition, we know how to be supportive and considerate of them and I just think that's another way.*
>
> [Female, Family member group]

Recovery and Resilience

Consumer participants described their recovery experiences which, more often than not, illustrated their tremendous capacity for resilience. They discussed the importance of taking individual responsibility, as well as the value of incorporating peers and family role models into their process. Many talked about their recovery as a journey, a process of discovery that for most was closely connected to religious or spiritual beliefs.

Role of individual responsibility

Participants in both the homeless consumer groups and the family member groups discussed the importance of taking individual responsibility in the process of recovery, by making a personal commitment and fully participating.

> *…the thing is, in the end result it's your decision. Everybody's an individual. We all make our own decisions and whatever you do, you have to reap those benefits. I mean you do this,*

that's what's going to happen so you have a choice and unfortunately sometimes we make those choices and then we blame other people but it's your fault because you made the choice. Even talking to the psychiatrist I mean he can suggest. That's all he can do. That's it… It's up to you…And you got to do it. You got to accept it and do it.

[Male consumer, Homeless group]

…and the next thing you know, if that person stayed, the next thing you know that person's getting healthy and strong, he's getting spiritually, his mind is recovering and he grows to the stage where he's able to recognize stuff and seek that what he needs after he's been part of the program. Cuz you gotta hang with it for a while. You just can't just come in and get a ego or get a problem and run away. You gotta stay and you gotta see that it's good for you and you gotta participate. A lot of people won't participate.

[Male consumer, Homeless group]

Some noted that it doesn't help to look back and blame others, stressing the importance of being proactive and taking the lead in one's own life.

Male: *I know my situation and I better do the best I can with that and stop blamin e v e r y b o d y else and pointing over there and pointing everyday with my thumb pointing back at me. You know what I'm sayin? So like…*

Female: *You gotta come out the past—*

Male: *Yeah, a whole lot, a whole lot of things that uh…We gotta make ourselves proactive to do something about it. But I know a lot of times they say, "Don't make no complaints if you ain't gonna do nothin about it." If you ain't goin do nothin about it, don't complain about it.*

[Multiple participants, Homeless group]

Importance of peer and family role models

The Spanish-speaking consumers didn't speak much about an individual recovery process. Instead they tended to speak about their recovery as more collective, a process that typically involved family members, peers, and a connection to their faith.

Facilitator: *It also seems like, correct me if I'm wrong but it seems like you're telling me that it helps when you talk to someone who's had the same experience. Like you told me that some of the* [peer] *specialists have gone through what you've gone through and that that also helps.*

Female: *That too. Of course because you say to yourself, "God willing I will recover too, because look how he's coming to visit me. He's even talking to me about his life so that I see an example of recovery." You can sometimes get lost in your worries.*

[Female consumer, Spanish-speaking group]

…when we go to the women's group, it's like, in the group we have now everyone talks about what they feel, how they slept, what they want to do with their lives. Because some of us, when we want to kill ourselves, we want to go jump off a bridge…and all that. So all this has helped us a lot, the group that we have… All that has helped us a lot, a lot! Because I was one of them, I was going to kill myself, to throw myself from the bridge but I didn't. Many of us have had things like that happen to us. And that's how it went for us… But yes, this is the way that we have recovered, in those groups.

[Female consumer, Spanish-speaking group]

…well yes, it helps us a lot. Yes because we talk, we make comments. It helps a lot. If you took this service away from us, we would truly end up in an asylum.

[Female consumer, Spanish-speaking group]

Several consumers disclosed that other members of their family were also managing mental health issues. One participant shared how observing a family member's recovery inspired her to pursue her own.

Ok I will tell you my pathway. Me and my kid's cousin, his cousin, was coming here everyday for a jail pass. And I used to see him. He got a shop. He used to look raggedy, you know, homeless for real, no teeth in his mouth. Now he got a whole gold set in his mouth, you know. He got his shoes buffed up and he's telling me, "You ought to come down to [name of organization]. *They got it goin on. You can get you some help down there." He kept tellin me that. Do you know I didn't come until he passed, but I got here…I'm sorry he had to pass before I got here, but I know they was doin something for him because he wasn't the same person that I knew, that I lived with, as an addict. He wasn't the same man. He was a different man, a total different man. And you… I mean his face was lit up to where one time all you see is worry, dread, dopish look, skin all dark and dry, where now he's glowin, he's just glowin, beamin all over the place. So when I see people like that I wanna know how they got it and I want it.*

[Female consumer, Homeless group]

Recovery takes time and effort

Both consumers and family members described the process of recovery as a gradual and continuous journey that requires serious effort.

…for me it's like I took off from where I left off at when I started drugs. Like when I came back in like 2012 when my head got back right, I wanted to hear the music I was hearing when I was like before I started drugs. That's the music I liked. Everything I used to do I was feeling that, mentally and everything, you know. And it's like I took off there and it took me a while and I'm still trying to catch up. I haven't caught all the way up yet, you know, because I got a long way to catch up. But I'm catching up …And like what you was

saying also about being clean is more of a job than when I was using because I was used to that for years. I know how to do that. But this clean thing, it's good and I'm doing it, but every day it's a different journey.

[Male consumer, Homeless group]

And what I see is with her going and getting these services and doing these techniques and classes I do see an effort. You know, no one's perfect, but I do see that she is trying. She's doing it on a day by, you know, one day at a time and I do see that there has been success. She's acknowledging that "I have a mental illness. I have a – I am an alcoholic." Where before they would, you know, hide, you know, it would be the classic symptoms of someone who's in mania or something like that. They would be hiding and you know everyone sees it, but you know, if they put on shades and they felt, and turned the light off, they felt that no one could see and the whole neighborhood could testify that something's going on. So it's been a blessing with her attending these particular classes, you know, over a course of time because this did not happen overnight… She's taking responsibility which makes a difference. Cuz if a person is doing something and they don't realize or know that they're doing it then you can't help them.

[Female, Family member group]

Consumer participants noted that lack of awareness or denial of their mental illness and addiction disorders impeded their recovery.

I didn't know I had these problems. My mental problem, I didn't know I had that until I got over here...to modification and behavior. I didn't know what that meant either at that time, you know, until I got in there. I broke every rule there was, you know. I came out the penitentiary into the program, because I didn't want to go back to the penitentiary. And I, like you, came to the conclusion that I was my own self's worst enemy and, if I wanted to stay out of the penitentiary, I had to do something about my drug habit. So I went in there just trying to stay out the penitentiary, but I winded up really finding out who I was and that there was life after death… It's so many things that we don't know about ourselves, because we have kept ourselves in the dark of not being able to grow or to come out of this death we walk in and live in. You know it's like zombies. You know you wake up to get high and you lay down just to face another day of gettin high. But once you get clean, it's a whole different… it's beautiful.

[Female consumer, Homeless group]

Recovery as a spiritual journey

Participants across all groups spoke frequently and passionately about the importance of religion and spirituality in their lives. They also described the role that faith plays in their - or in their family member's – recovery.

Female: *It really helps me to study the bible and share it with others. That is something essential for me, as part of my treatment, my path…*

Male: *Your recovery.*

Female: *… my recovery. And it really helps me spiritually. I do 70 hours of volunteer work a month. It helps to keep me busy and it's a pleasure to give and to receive.*

Facilitator: S*o for you spirituality is a way for you to help yourself?*

Female: *Yes. Yes, in my life.*

Female: *For me it is too. There is no work that is better paid than working for the lord. He's the one in charge of really compensating us a lot. And it's really very good for mental health.*

Facilitator: *For anyone else, is religion important for your mental health? Does religion help you in your mental health?*

Male: *Me too. Me too. Every Sunday I'm at church, I'm at mass, like twice a week I'm in church.* [many others agreed that they are too] *Praying, like she said, working on my spirituality.*

[Multiple participants, Spanish-speaking group]

But and then faith-based Bible studies and prayer groups, I find that this has been a very, very good method for her, that it is really working because for years when a – a person have to accept their own mental illness or their own issue first. If you're in denial then you're defeating, you've already given in. But when you take the steps and you're responsible for and you're trying to do something about it, and make the change, then I think that that's a win-win.

[Female, Family member group]

Many of the homeless consumers described their process of recovery as a spiritual journey. Many of the stories they shared also involved recovery from addiction. One participant described the importance of being at ease with oneself and at peace with one's creator.

When I first came to recovery spiritual health, I remember praying. I was a straight up dope, crack fiend that couldn't live without crack cocaine. And I was smoking 24/7, 7 days a week. And I didn't know what it meant to be in my sane mind. And I remember going, I remember at night trying to go to sleep, but trying to hit that pipe at the same time. And I remember I hated what had became of me because then my whole life had been tore, just been tore out of me. And I remember praying and asking, I said, Oh God, I'm so tired of this. Oh help me, help me, help me. And I must have did that for about three or four months.

And then one night I went and copped some drugs and the police arrested me. [Laughs] *Police arrested me and nailed and sent me to jail. And I'm in back of the car just crying because this had never happened to me before. Ohhhh, and the police turned around and looked at me saying, are you all right?* [Laughter]

So anyway, that was the beginning of my voyage, of my journey. From there, I was put into recovery, mental health programs. And from there, I was taught about the spiritual path that I had to follow if I wanted to get healthy. And so everything else has just been a process of me crying out, wanting to get well and you know, yeah because it wasn't me that, I wasn't desirous of trying to get healthy and whole. I was hurt, but I wasn't making no effort to get healthy because I had heard about programs and stuff, but I was caught. I was just caught up.

And it seemed like a power greater than me entered into my life and said, here's the path, Go. And when I first got on that path, I was so crazy. I didn't know which way to go. I was fighting against everything cuz this wasn't, I hadn't been exposed to any of this. It was all new. But everybody kept talking this talk and these people that had been sick kept appearing up in my life looking good and healthy, telling me what they had did and how their lives had become wonderful again. And they kept promising me this health if I would just follow this path. Just follow this path. And he kept saying, this path is spiritual. [Laughs] *It's spiritual. You know.*

And so you asked about the thing about mental health, I think mental health is just a state of mind where you're at ease with yourself. You have peace with yourself and you got peace with your fellow human beings and you've got peace with your creator. I think it all comes down to being at peace with your creator. See once I became at peace with my creator, I acknowledged Him, and I let Him come into my life, my life got 1,000 percent better. But as long as I was trying to find my own way, trying to identify the paths that I wanted to follow, the lifestyle that I wanted to live, I was crazy as a fruitcake, you know. Crazy as a fruitcake. And sometimes it comes back, you know. It comes back. And I have to say, no. I ain't going that way.

[Male consumer, Homeless group]

Others shared the stories of their spiritual paths, including the importance of being around other healthy people, being open and honest with themselves and others, and having the courage to continue the journey.

Speaking about mental health. I noticed my mental health improved when I became spiritual. As long as I was just in my own mind trying to discover stuff for myself, I really couldn't get anywhere…And I had to learn how to identify what was good for me and what wasn't. I had to learn to say no to certain things and yes to certain things...And I found the best place for me to go is to be around people who are healthy and know the path to follow…

So you know I find that mental health is a spiritual experience. You know, without being open and really wanting to get well and accepting truth – it's about accepting truth about self and what's going on... And then after I accept truth, applying the wisdom and knowledge I get through the truth… So I want to get to that straight and narrow path where I can really become whole and I find out that it's an ongoing process and it's a challenge. I have to be brave, courage and be convicted to take those steps I need to get healthy. And I'm still sick. I'm a sick rascal…But it's a challenge and it's a reward and it's spiritual.

You know sometimes you go down paths and you get so full of joy and happiness, you're on a cloud. But then you go down the same paths and your head be all knocked all up, you know, but you gain. You know you're going forward. So that's, you know, mental health is an ongoing process and wherever you can go and get it, go get it.

[Male consumer, Homeless group]

Participants in the homeless group made a clear distinction between specific religious beliefs and spirituality, per se, describing a path that while spiritual was directed by the *"God of your understanding"*.

Facilitator: *A lot of you have talked about the spirituality, about church and so forth.*

Male: *I need 'em both.*

Facilitator: *Is it built into the programs or do you go out and get that in addition to the programs?*

Male: *Most of the programs don't, they tell you it's the path that's spiritual. They don't choose your God. That's your search. But they do inform you that this is a spiritual path. Your health is on a spiritual path and you must find the God of your understanding or the faith or whatever spiritual path there is for you and you must pursue it. And that's where the challenge is at, you know, is pursuing the spiritual path to understand your God, your creator and whatever you believe. You'll find some people take a big pretty car as their God, you know.*

[Male consumer, Homeless group]

Some consumers referenced a "higher power" or a "power greater than myself" as that which guided their recovery.

They take and find a higher power. If you look at the word higher power, they're going to tell you anything that lift your spirits, that lift you up. In my case music was my higher

power because music soothed me.

[Male consumer, Homeless group]

I came to believe a power greater than myself could restore sanity. I didn't do nothin. It wasn't me because my best effort had got me to the railroad tracks. It was the power, a great power, greater than myself, that brought me to come here and that's when I began to get clean. And I'm not going back because if I believe that god and staying in the will of god and follow his will, I can't go back.

[Male consumer, Homeless group]

Consumers describe how providers and peers understand and support the role of religion or spirituality in their recovery.

Facilitator: *Others of you also mentioned your faith or the church and I wanted to know if your health providers also understand the importance of faith and how it helps you?*

Male: *Oh yes, yes.*

Female: *Yes in my case they know that I'm a Jehovah's Witness and they know that this h e l p s me a lot to serve my neighbor and going to the meetings, help me to help others…Then you have this hope that is so beautiful and it helps us to share it with everyone else. So the doctors and therapists realize that we have that kind of hope because you can't lie about that.*

Female: *For me also, they push me harder to follow my religion because it's only Sundays when I'm doing that… when I'm dedicating myself to god. So I teach the kids and the youth group and it's really important…*

Female: *And that is what they like because they say all the people/providers in mental health should be very close to* [religion]. *Everyone but especially us.*

Facilitator: *Who told you that?*

Female: *They are… what are they? PC, something like that. They are* [peer] *specialists at* [name of program]. *They are the ones that came for us when we were homeless and all that and they were saying, "I also felt that way." They accompany us on our walks and yes, they've told me many times that it really helps me to be very busy with the work of the lord.*

[Multiple consumers, Spanish-speaking group]

Emphasis on Strengths, Quality of Life, Options and Contributions

Strengths

Consumer participants shared examples of how they work on identifying and building on their own strengths. Often times, this recognition is achieved through their participation in peer and support groups.

> *I feel heard. I feel supported. I feel respected. I know that I have a mental condition but* [says own name] *they make me feel like* [says own name] *has many qualities that you couldn't see before. She's a very sociable person. She's a very intelligent person. She's a person who has gifts like writing.*
>
> [Female consumer, Spanish-speaking group]

> *It's that the group has helped me with all of this. It has helped me to not feel as undervalued as I had believed myself to be, that* [says own name] *has many gifts like all human beings, that we all make mistakes like all human beings. Nobody is perfect. And that I have to accept myself, what I've done or what I'm still doing wrong. I'm not perfect. And there is no reason that because of this wrong that I keep beating myself up. I am the person that has criticized myself most of all and I'm the person that should criticize* [says own name] *the least. They have helped me a lot.*
>
> [Female consumer, Spanish-speaking group]

Some consumers spoke about finding their individual strength through prayer.

> Female: *You have to be the best that you can be. You know, this is for you. This is for me. You know and I have to be about my life. And you know, and building up my life, you know. And I can't do it by myself. I need others…Need a strong support. As he said, healthy. You know. Can't do it by myself. When I thought I could, but it was just a ball of confusion. Now that's another place, you know. That was work. I seen everybody go through all these changes, all this work to be sober. to stay sober. That's a job.*
>
> Facilitator: *So where do you get your strength? Where do you feel like you get strength?*
>
> Female: *I pray. I get on my knees every day.*
>
> Facilitator: *You pray.*
>
> Female: *I have to believe in God. You have to have something that you believe in and God is what helps me going day by day.*
>
> [Female consumer, Homeless group]

Quality of life

We don't directly report on quality of life because the focus group data did not yield much that spoke explicitly to this dimension of OASOC individual-level values. That said, we believe that the quality of life experienced by consumer participants is associated with how well the other OASOC values have been addressed and therefore can be inferred from content provided throughout this report.

Options

As noted earlier, many consumers spoke about taking individual responsibility for their recovery. At the same time, they spoke about having choices, how these choices produced hope and empowered them to make their own decisions – for better or for worse.

> Male:…*the thing is, in the end result it's your decision. Everybody's an individual. We all make our own decisions and whatever you do, you have to reap those benefits. I mean you do this, that's what's going to happen so you have a choice and unfortunately sometimes we make those choices and then we blame other people but it's your fault because you made the choice. Even talking to the psychiatrist I mean he can suggest. That's all he can do. That's it.*
>
> Facilitator: *At the end you have to pick up and do –*
>
> Male: *It's up to you…And you got to do it. You got to accept it and do it.*
> Facilitator: *Do you feel like in general you have choices then as you've gone down this path with services, that you've had choices along the way?*
>
> Male: *You always have choices.*
>
> Male: *Yeah.* [Sounds of group agreement]
>
> Male: *You always have choices. I mean you don't get choices, you don't have no hope.*
>
> Male: *You don't have nothing.*
>
> Male: *God gave everybody free will…*
>
> Female: *That's right.*
>
> Male: …*That's the gift that everybody have. You have to just realize it.*
>
> Male: *You just have to make the right choice.*

Male: *You have to realize because you do have a choice. In everything.*

Female: *That's right and then some people may not believe that there's a God and Jesus Christ, but that's my belief. I believe that…*

Male: *If they don't believe that's their choice.*

Female: *…because it works for me.*

Female: *That's their problem.*

Male: *That's their choice.*

Female: *But it works for me.* Female: *It works for me, too.*

Female: *But as long use some of that strength. There's strength around this table right now, you know. But um my spiritual walk and well my life, my life period is so much better.*

[Multiple participants, Homeless group]

Contributions

Many consumers talked about the importance of having a sense of purpose, keeping busy, and contributing to something meaningful. One woman described how the volunteer work she was doing at a church helped her manage her depression and address the sense of loss she was experiencing.

> *My doctor was telling me, "That was the depression that you had." I went to the psychiatric doctor and the heart doctor and he told me, "Your heart is strong." He told me, "But you*
>
> *know what? There is no medicine to take away the pain you feel when you're missing someone, only time." So ok I was accompanied by people from* [name of program]. *So they really recognize my work in the church.*

[Female consumer, Spanish-speaking group]

Consumer participants in all groups talked about the importance of keeping busy, and their awareness of opportunities for engagement in productive activities.

> Male: *And you know what, one more thing I want to say. And what I had to learn now that I am disabled and retired or whatever, I had to learn like to have something to do with my time because that's really a bad thing…*

Female: *Exactly*

Male:…*not having nothing to do all the time. That's why I volunteer here and do what I do. Otherwise I would go crazy.*

Facilitator: *So you mentioned volunteering. Do others at the table volunteer or do certain activities? Are there employment opportunities that come through the center?*

Female: *There's opportunities.*

Facilitator: *Uh-huh. So those are options.*

Female: *If you wanted to go to school they'll help you get in school. If you wanted to go in different programs, if they've got openings they'll get you in there if that's what you want.*

Female: *Me, myself, I want to take a computer class. I don't know computers.*

Male: *They've got opportunities here. I volunteer a lot here. If you're over 55 they've got an agency… where they give senior citizens four hours of work, 20 hours a week. I volunteer a lot. We just went to an encampment and passed out clothing and talked to each of the encampment, the homeless people. I volunteer like a lot there.*

[Multiple participants, Homeless group]

Regain Social Roles

Another value of the OASOC framework stresses the importance of older adults regaining social roles that they may have lost along the way as they have grappled with their mental illness and substance use disorders. Consumers noted the challenges sometimes faced when trying to move beyond a negative identity, often because of others' perceptions of who you are. One consumer gave the following example of a woman who was judged by her past actions.

"There was a young lady that had gotten out of the penitentiary in [city name]. And she had all these things that she couldn't do and she was being described by her past experiences: ex-convict, thief, you done this. And the young woman said, "That was 20 years ago, but you're still describing me, because this is your hard skills, your language. But today, I'm a architect, but I'm not being described as an architect, in your circle…"

[Male consumer, Homeless group]

Reinventing oneself

Consumer participants illustrate some of the ways in which they have connected with meaningful activities that help them reestablish an identity that moves beyond being marginalized as "just" an

older adult, a recovering addict, someone who is recovering from mental illness. One consumer shared how she had worked to reinvent herself to get out of the penitentiary and stay off drugs.

> *I even got my GED. That's something that I was scared of, but I overcame that.* [I had to learn] *how to be a lady, how not to steal. All these things… how I had to take communications classes 'cause the only thing I knew how to talk was street talk and prison talk. I didn't know how to hold a conversation.*
>
> [Female consumer, Homeless group]

Another described how he regained a new outlook on life once he got past his addiction.

> *I figure when I was in my addiction I stopped taking in knowledge. I was too busy chasing the dope, chasing liquor, chasing the pills. So I had no knowledge coming in. So when I came here they gave me a new outlook on life. I didn't know nothing about no Smartphone, or nothin' about social media. I didn't know nothin' so I came in here and they gave me a new outlook on life because I came here with an open mind and my brain started taking back more knowledge after the drugs wore off and I got some addictions.*
>
> [Male consumer, Homeless group]

Regaining roles through church

Several consumers also described the value of the social roles they regain through activities at the church, including the goal of keeping a positive outlook and being helpful to others.

> *Right now I'm very dedicated to the church. I go to two classes at church on Sundays, for the kids, catechism, and for the youth, confirmation. So I keep my mind busy with good ideas. With good ideas, not with holding on to resentment or anything like that. I have forgotten about all that with the therapy that they have given me.*
>
> [Female consumer, Spanish-speaking group]

> *Yes in my case they know that I'm a Jehovah's Witness and they know that this helps me a lot to serve my neighbor and going to the meetings, help me to help others.*
>
> [Female consumer, Spanish- speaking group]

Reducing social isolation

Participants also talked about how mental health services have helped them become more engaged in social roles. In turn, this has helped to reduce the experience of social isolation that is often a byproduct of mental illness, substance abuse, and homelessness.

I also wanted to say that they've helped me a lot in the sense that, when you are sick or if you have panic attacks or depression or strong emotions, when something happens in your family or something happens in the street, you feel isolated. Now I don't. Now I look for help or I look for someone to help me to be able to survive all of this.

[Female consumer, Spanish-speaking group]

That is very important and it's what the therapies hope to maintain. And yes, it's like the lady said. Yes you become isolated and for me, even more, because I was homeless, in the street. To receive… but as if we were friends at [name of program]. *Because they have helped me, like the lady said, to move forward, to not be introverted, to dedicate myself.*

[Female consumer, Spanish-speaking group]

Holistic Approach (Biological /Psychological/Social/Spiritual)

As detailed in the previous sections, consumer participants described a broad range of biological (see: Healthy Aging), psychological (see: Emphasis on Strengths, Options, and Contributions), social (see: Regain Social Roles) and spiritual needs (see: Recovery and Resilience). Consumers and family members also noted a number of ways in which these needs were or were not effectively met, both in the context of formal interactions with the public county mental health system and through both formal and informal interactions with a wider network of community resources, including faith-based organizations, family member, and friends.

Some family members explicitly noted the multifaceted and complex needs of older adults with mental illness. One participant compared these needs to the needs of younger adults, pointing out some of the similarities and the differences.

It seems like a lot of times the person be it an older adult cuz you see, the older adults, their stories or their situations are about the same … you want the support groups or [to know] *have they been diagnosed? Are they receiving care period? … But specifically for older adults, I have seen where persons who were once able to drive are no longer able to drive. And are they able to get out to these clinics or to support groups? And you know whatnot and that's transportation. And that's a stressor. That's a stress factor.*

[Female, Family member group]

Role of Consumers, Family Members, Caregivers

The role of family and intergenerational supports emerged as a central aspect of the consumer experience. Both consumers and family members discussed how family members may be instrumental in getting consumers to needed care and are often an essential resource for their recovery. Across participants, there was variation in the nature of family member involvement and in the quality of these relationships. Some consumers came from families where multiple members had a history of mental illness and substance use disorders. In addition to providing support for

consumers, family members identified their own unmet needs and discussed the important role of intergenerational support.

Mental illness affects the whole family

One participant described the challenges that her family has experienced.

> *It doesn't just affect that individual. It affects the family as well so yes, I have been, myself and my family members, we have been through it even in legal matters, it turned legal and we have really, really been placed under the guillotine many, many, many times. And it was just through preservation and through awareness and knowing what you're dealing with and maneuvering around the loopholes. Again, you can't make a person do something…so my relationship, I have to take care of my health…I had to set creative boundaries and you know for myself, for my own well-being, because when you, especially when you cohabitate with an individual, you never know where they're coming from and what state of mind. I don't put anything past anyone. So I know with based on my personality and I had to really dig deep and be the bigger person and understand. I do have an understanding of what's going on, so I was able to show empathy or support. But I know that I couldn't be directly in her face, per se… And I found out it wasn't what I said. Sometimes it's what I don't say, you know. And I found that that was just as powerful as having, you know, a verbal discussion because some people when they're going through, they'll talk to you for hours, just rambling. Just, they'll go.*
>
> [Female, Family member group]

Family members play a role in getting loved one to services

The following narratives illuminate the dedication of family members and the challenges sometimes experienced getting consumers connected to services.

> Female: *But I do know for a fact that most people go out of their way to get the help for their loved ones. And once they get there and get 'em the place to go, now that's the million dollar question. Getting the individual to walk into the door…That's the challenge.*
>
> Facilitator: *Accepting or being able to go out and get treatment.*
>
> Female: *That's the challenge.*
>
> Facilitator: *So, you're saying there's times, family members often will try to open those doors and get the person in.*

Female: *Oh, absolutely. They'll go out of their way to – where do I go? What do I need to do? What do I need to bring and so forth. And they will tell the person, okay, they must come in on, say for example, Monday morning we open at 8:30 a.m. So make sure they're here before 9 or whatever so they could be – do the paperwork. And that's the hardest thing for the family member. That's the 64 dollar question. Get that loved one to walk through those doors.*

[Female, Family member group]

Well, my brother was homeless, and he lived in his car. And I was going to take him money, go check on him, go look for him, go find him. And this was about a year that this happened. He's so paranoid. He would say to me, lock the door. As I sit and talk, lock the door. Why? Because I keep locks down there so he could see them coming. I said something's wrong. And finally, a year and a half, I said to him, he's not going to make. He, he is, he's falling. We're going to lose him. So that's when we got him into services. Sending him to her house for like two weeks to do some business, and then we got him into services because he's so paranoid. He was so devastated. He couldn't sit. Everybody was coming for him. But that's like confusing people…So he's still homeless. But he has a voucher. So we're looking for him a place. He's homeless, and he sees a doctor. He's not taking his meds. But he's, we're trying to get him off the streets, and maybe he'll…I watched him and he was so paranoid. For three hours, somebody coming after us. I said oh, my God. He's going to die out here. We got to get him off.

[Female, Family member group]

Variation in family member involvement and quality of relationships

Consumers also discussed some of the challenges they experience in their family relationships, including family members who deny or dismiss the consumer's mental health issues.

My daughter just tells me, because I live with one of my daughters, "How did you sleep last night, Mom?" "Well barely at all. Or I slept a very little." But they don't fight with me like they did before. But they were always like, "Ay, these are problems that you want, that you look for, Mom. You!" And it's not true. I try to be strong and I don't want to be sick. But it's impossible - no se puede - it can't be done.

[Female consumer, Spanish-speaking group]

I have had many problems at home with my children. Because they have never understood what I suffer…Never. [Speaking emphatically, from the perspective of her children*]: "Mom, anything can be controlled!" When she was with us, she would say to me, "Bring me your daughter so that I can talk to her." But they were working. But lots of problems, because they don't believe me. But now after so many years it seems that they've accepted it.*

[Female consumer, Spanish-speaking group]

Even though the problems are very serious sometimes within the family…You love them a lot but sometimes you can't change the situation with your family. You shut yourself in.

You don't shut yourself in but you end up focusing on what you can do and what you can't do. How do you say it? This is how far I can go and this is how much I can do. And you leave the rest the all powerful.

[Female consumer, Spanish-speaking group]

I found myself husbandless, homeless and then I had to go stay with my family and that was the most difficult part of my life because, oh my God, even though it was just like seeing my family wasn't there for you at the time you were out.

[Female consumer, Homeless group]

Others disclosed that they had come from a family with a history of mental illness.

In my family, almost everyone needs psychological help. Like me, once I reached an extreme, which was embarrassing, they were telling me… here… ummmmm. I ended up in a psychiatric place. Do you understand me? But for us Latinos, they've thought I was crazy since I was a kid. They thought I was crazy… ah ha… since I was kid.

[Female consumer, Spanish-speaking group]

Yes, my daughter's psychiatrist knows lots of psychiatrists and counselors and all that. The time that she saw me and how badly I was doing, I was crying, crying a lot, that's when they sent me. She talked with the doctor so that he could see me there. So she has knowledge about all the ways.

[Female consumer, Spanish-speaking group]

I have some other siblings in mental health but the programs they're under is not working.

[Female consumer, Homeless group]

As illustrated by the following examples, family members often play a vital role in the recovery process.

In my case, I arrived at the clinic after a breakdown/crisis in a psychiatric hospital and they sent me to [clinic name] *and I was really lucky that everyone realized that my son came and brought me and waited for me. It's a type of support that… no one else could provide. Something like that, no one else can do. And that's my opinion. I don't know how you could find someone who would want to do that.*

[Male consumer, Spanish-speaking group]

My family. I mean they don't have enough to afford me, that's why I'm homeless. I can't live there. But they are behind me. I mean they are behind me. And I mean ever since I've

gotten, I tell you this is my first time being homeless. Ever since I stepped back in California I haven't slept outside one night. And that was since January I haven't slept outside one night.

[Male consumer, Homeless group]

One consumer was asked what other services or programs were important to his well-being (in addition to church, Narcotics Anonymous, the methadone clinic, and case management). He responded as follows:

Family. Very important for me because I torched bridges. I didn't burn 'em. I torched them and so… [laughter from group] *so by me having family brought back to my life, you know, we catching up and I'm opening up more… I didn't tell them what I was doing, I showed them and they kind of like approached me when I was in my addiction slowly coming out of it and I ran off the mouth and I showed them wall to wall so to speak and they approached me and that's how we came back together as family.*

[Male consumer, Homeless group]

Consumers also talked about the importance of having providers who recognize and support the role that their family members play in their recovery.

…they ask us if we have grandchildren, if we have spouses, if we have cousins, nephews and nieces, what relationships we have with them, due to our age. Do they talk to us a lot? Do they barely ever call us? They ask us all that, so that they know and they write it down, they write it down. And the next time they come and visit you, they say, "Last time you said that you were really happy because you were talking to your niece on the phone every day." That is appropriate for our lives, each of us.

[Female consumer, Spanish-speaking group]

Yes, for me yes they understand pretty well, the ones that come, because they even take us to see them. They don't forget. And they ask. They say, "Do you have a lot of family support? Is it very helpful to you? Are they calling you every day to see how you are, if you're well?"…So yes they worry about us, about how our lives are in regards to family.

[Female consumer, Spanish-speaking group]

One consumer spoke about working with her case manager to try to reunite and establish a better relationship with her family.

I know in 2013 I came back to California and wound up homeless that summer, but that's when I got connected to [name of organization] *and my case manager helped me formulate goals so that I could get closer to my family…And as a result my relationship with my family members is stronger than it was three, four years ago.*

[Female consumer, Homeless group]

Family members also need support

Almost all family member participants spoke about needing help in their efforts to provide support for their loved ones. One participant noted that the consumer support groups provided at the county clinics provide a welcome respite for family members.

> Facilitator: *Can you say a little bit more about that, how* [the consumer support group] *helps the family members?*
>
> Female: *It helps the family members because number one, it gives the family member a time to have maybe an hour break…The family member says, oh, at least they'll be gone for two hours today. They're at their meeting. So that's two hours I could just sit down and have a nice cup of coffee…or do whatever I have to do. So at the end of the day the client feels a little better when they get home. They feel a little – not so edgy. They don't feel so edgy because they realize that they are making progress and that they could talk a little better to their loved one, to their family member. That they understand that their family member is not trying to hurt 'em. See that's what they have to – it's hard to get them to understand that. And once they realize that their family member's not trying to hurt them, then that helps them to be on the road to recovery faster, smoother, easy transition.*
>
> [Female, Family member group]

Some family member participants were involved in an organization that supports family members who care for people with mental illness through education and support groups. One family member describes how she has also learned how to help her family member through direct experience, both with her own mental health issues and those of her loved one.

> Facilitator: *So how did you learn that? How did you learn about what you were dealing with or what the other person was dealing with?*
>
> Female: *Well, I again, I am a member of* [name of caregiver organization], *and so having suffered with depression and other posttraumatic stress myself, I know what I have dealt with and I know just from experience, my own personal experience, what it's like. And I know for me, you know, you can't, again, you can't make anyone do anything. Not only was she medicating, she was over-medicating, you know, and I have no control over that. None. If a person wants to drive and they're under whatever influence they're under, I don't have, I have no right. I can't lock 'em in their room. I can't take their personal belonging. So you gotta kind of pray for 'em and hope for the best.*
>
> [Female, Family member group]

Another family member talked about the decades of caregiving she has provided to her mother and further noted the economic disparities that affect the family caregiving experience.

So I've had 40 years' worth of experience, and not being I searched for it, it was because my family members needed it. You know, and I have been there since like 18 years old. I didn't ask for it, it just, there was a language barrier. And so, you know, what am I going to do, say no? No. We need the services. You know, so sometimes as family members who are put in that position, we don't ask for it, we don't like the obligation, we don't like the responsibility. But it's like why am I going to go to social security when I want to, I want to do something else. You know? But that's part of our family and situations that we come to.

You know, some people don't have to do deal with that. They have people who, because of their economic status, they can get other people to help their family members. You know, we don't do that. You know. And also, we take care of our elderly, you know? Sometimes it's a burden. You know, and we don't talk about that. But it's a burden, you know? And I've had different moments recently in the last year because my mother is aging, you know. Mentally, I'm trying to prepare myself because I know she's about to die. But emotionally, I don't even want to think about it. You know? And that's my mental. You know, I don't, I don't have to g o to a therapist for that, but that's my own emotional turmoil that I'm going through…

[Female, Family member group]

Role of intergenerational support

Consumers and family members also discussed how they want to give back to the generations that have either come before or after them. Participants from the homeless group spoke at length about the importance of sharing what they had learned along the difficult road taken to recovery.

You know what, with that being said, and you probably heard me say it before… that if you get 50 and above, 50 years above in age and ain't got nothin good to share with the young people behind you, you threw away your life, 'cause you didn't learn no wisdom. You didn't learn…You didn't learn nothin to share 'em. You know what? So I'm like, I wanna have somethin to share with 'em. And got a little bit of time left and I got a little bit of wisdom but I wanna grow it. 'Cause I wanna share, you know what I mean. And my sharin don't tell. It's not tellin nobody…But showin 'em how I'm doin it. You know because you can't… a lot of people, you can't tell 'em nothing, but you could show 'em better than you could tell them.

[Male consumer, Homeless group]

They discussed the opportunity to take responsibility for the mistakes they had made and to become role models to the younger generation coming up after them.

Female: *And that's how a lot of people… I had a lot of people, and I didn't know this, I had a lot of people watchin me when I got clean. I didn't know these people were watching me… and as they seen me get clean, I seen them, "Well, you doin ok. You know. Can I get in where you at?" And if you 55 and over, help yourself. You know, I welcome--*

Male: *I had that same experience, but I went back to the neighborhood where I… And I was in the liquor store to get somethin and I seen a young girl there that I knew and they all called me out, "Hey. How you doin? Lookin' good." Like that. It's a compliment. You're allowed to get compliments. You one. Them one. We exchanged compliments. So then she got in line and I was behind her. You know what and then all of a sudden she turned around and she said, "Uncle X, You in church or something?" "Yes I am." I sure felt good. She b l e s s e d my heart. She knew I was a dope fiend when I was… runnin around the neighborhood, probably shootin dope. You know and I was just Uncle X, everybody know me, the oldest dope fiend in* [neighborhood name]. *But you know what, something about all that. They have respect for me and I don't know why. But they used to call me the godfather. They treated me like I was. You got where I'm goin with that. But like I'm gonna share some wisdom. I don't wanna tell nobody nothin. I don't want them to see it. 'Cause I could be passin out lip service with my mouth. You know what I mean? And then I find out that when you try to talk good about yourself, people lookin at you and you keep on…and you keep on because you lookin at 'em and they ain't givin.*

Male: A*nd now, that's why the kids – there's so many kids now that's homeless than ever before. If you go walk down the street or walk right in this – matter of fact, walk back here, it's a bunch of kids that's out there on the streets. Because they, they ain't got, they family really wasn't there when they first, when stuff happened. So now they out of the streets trying to make it. We had a problem making it, now they kids, you know, the kids having a problem….*

Male: *Some we need to do, and this what I found out by doing advocacy. We need to take responsibility for the mistakes we made.*

Male: *Exactly. There you go. Right there. That's it.*

Male: *Okay? Then we need to find solutions for today's problems. And that's coming to the table right now in our era. Because see, we got a lot of stuff, when that crack era came through here out there, selling drugs and tearing up all our neighborhoods. And I responsibility.*

Male: *The gangs today. I do too.*

Male: *Hey, I was out there pressing the line on that.*

Male: *Me too.*

[Multiple consumers, Homeless group]

The homeless and family member groups both discussed the need to impart experience, knowledge and life tips to younger generations so that they can avoid the problems/issues they have gone through.

But if each one just teach one, and share what we've learned, and pay it forward, that s h o u l d be free, you know respect is earned. So if we would kind of honor that and not – everything is not about dollars, you know, costs. You seen that people, you know, and then especially if you're suffering with or you're going through a mental issue that you got to medicate or whatever not medicate or, you know, and stay well and cope day to day. So we can have programs that would spark the interest or keep us all interactive, one with the other. I mean they now have the thing where they have like preschoolers with seniors. You know, they're buddy-buddy because it's one of those things and then we want to educate our communities, you know. A lot of times we lead them along.

[Female, Family member group]

Community Focus & Empowerment

Across all focus groups, the importance of community was emphasized. The types of communities discussed included support group communities, church communities, and neighborhood communities that were defined by a specific geography and shared experience, albeit often one of historic and collective trauma.

Support groups as community

The features of a support group community, created within a county mental health clinic, were described as follows:

In our clinic, we have all shared the space together there well. We support each other, one another. For us, it's been wonderful. Yes.

[Female consumer, Spanish-speaking group]

Another consumer discussed the value and sense of community that the support group provides.

We can talk about what it is that I need and what it is that I don't and for me, those people have helped me a lot.

[Male consumer, Spanish-speaking group]

However, these groups don't work for everyone.

We have a wonderful women's group cuz like that's kind of laid back. But you know what? It's good for some people, some people it's not and I'm one of those people it's not good for me. I was going but I wasn't getting nothing out of it. I kept hearing a whole bunch of humbo jumbo that wasn't [for] *me…So I backed out… I know meeting with people's not good for me.*

[Female consumer, Spanish-speaking group]

Those who enjoyed the support groups described a forum that provides structure and a safe place to speak candidly about how you are feeling.

> Female: *It gave me structure. I've got to have some structure in my life until where now I make decisions more clearly because I was off into a fog. When you're all cloudy in your mind then you can't make those decisions. Coming to these classes and coming to* [name of program]*, it gave me some structure in my life.*
>
> Male: *Yeah it did. You can be honest without worrying about no backlash, you know, with the groups that I've come to here. You can say what you really feel, you know, and don't have to worry about what's going to happen once you get away from the beat, especially to the counselors. They don't, as far as I'm concerned they don't – they listen. They don't do anything to come back at you because of something that you might have said that pertained to them, you know, and I like that. That's a good thing.*
>
> Male: [Name of program] *is a citadel of mental health for people that have problems and issues, especially seniors. They specialize in seniors…and they don't discriminate.*
>
> [Multiple participants, Homeless group]

One family member participant noted that the county-administered support groups for consumers also provide value for family members.

> *…and they* [the consumers] *thrive on that. They look forward to coming to those meetings at the facilities when they go to see their clinicians or their psychologists because they have a chance to get out of the house and talk to other people that's going through what they're going through and I find that to be very beneficial for the person that's experiencing and it helps the family members too*.
>
> [Female, Family member group]

Support found in the larger community

Some consumers also talked about the wealth of support they experience in the larger geographic community.

> Facilitator: *You said something that was interesting to me. You said, "You can't even turn around, without finding services." Something like that?*
>
> Female: *Yes. Wherever you go. Many times people have even stopped me on the trolley and they start chatting with me about my problems. I also tell them about mine and we end up almost like friends. Wherever you go. Wherever you go there are people that are suffering. Wherever you go they need help. You help them and they help you. Even people that you have nothing to do with.*
>
> [Female consumer, Spanish-speaking group]

Effects of collective and generational trauma

Participants spoke of the many challenges that affect the cohesiveness and overall health of their communities. A significant portion of the discussion with both homeless consumers and family members focused on larger systems issues that affect the context in which they or their loved ones are receiving services. Participants spoke of the historical and sociopolitical context that has deeply affected individuals, families, and entire communities.

> *Okay. I was just speaking as far as me being a black male. And I find out um, I suffer various too because of what was done to the people before me. And so, the older adults, you know, they came up and all them tests that they took and the stuff that was shot up in them and the stories that was told, and I, and I, and it, it acts – man, I can't see, I can't, because they actually pulled out a tooth that didn't, didn't need to be pulled out. So me dealing with doctors, dealing with doctors is an issue that we have due to our, what happened in the p a s t . And then we was told and there's some things that happened to us. So actually talking to a therapist, a lot of therapists don't be looking like us.*
>
> [Male, Family member group]

> *And so, I really know like that is a problem, there is a lack of them here in our community. And I'm really active in our community. And so, I understand too how the slave syndrome has came down and affected us. And so, I understand about the Tuskegee Airmen project and all of those things. I understand that. I understand about all of the PTSD that isn't, all of the undiagnosed people in our community unaware about the PTSD that's in our c o m m u n i t y of lack of income or having a loved one die or just the gun shots. I understand a l l of that because that's all of the level of advocacy that I do.*
>
> [Female, Family member group]

This collective trauma is especially pronounced in communities of color - where a history of exploitation has undermined and eroded trust in public systems and people in positions of power, including doctors.

> Male: *Also with some of the psychotropics too, we all know they play um, you know, try this out on this, change a chromosome, get a kick back, get me temple. So I mean I've looked into a lot of this stuff. And we question what they're giving us, and we question what it's going to do to us. Because just with the opioid epidemic with the OxyContin, man, it's an epidemic, and they still got them going – I mean these people are going in there for pain, and they coming out straight addicts. And a lot of times, until it hits to suburbia or their people, you know, up there they got the rich and the poor. Until it starts getting epidemic, just like when the crack epidemic came through here…*
>
> Female: *You know, you just really hit right on.*

Male: *Yeah, I'm going to go with it. I'm know this. Yeah. Yeah. Until it hits into where these doctors, it happens to their sons and their stuff, then they don't want to start putting into the mental health. You know, it's just them down there so we're not going to worry about.*

Male: *We're going to test it over there.*

Male: *Yeah, yeah. Yeah.*

Male: *We're going to test it on them.*

Male: *And when it backfires and it's starts… Because with those OxyContin, it's an epidemic. And I don't even see how these doctors can put this stuff out. I mean all it is, is synthetic heroin.*

Female: *Mm-hmm. Well, I have clients that are on methadone as well, and benzodiazepine does not mix with methadone. And I have to remind the doctor, because if I disagree with um, a certain diagnosis or whatever, the doctor has to listen more or less to my opinion as well. We work together as a team. And I have to remind the doctor, this person's on methadone. He sometimes I believe is like he's forgetting because he's looking at ching ching in those prescriptions. And I said doctor, I disagree with this. And he goes oh, I forgot.*

Male: *So who got to pay for it?*

Male: *He must have been taking some too* [group laughter].

[Multiple participants, Family member group]

Disparities in local community resources

Participants spoke about how they live within a system that seems to forget them, that doesn't include them in the equation when they are cutting up slices of the economic pie.

Male: *The system is already cut out not for us. If you really look at it.*

Female: *What is for us?*

Female: *Exactly.*

Male: *Us, Us. The people that's in this community. It's not for us because it's not. If it was for us, we would have the stuff that we needed. If you go outside our community, they got it. When I was in* [name of city] *and so forth, they had everything we need. I come over to* [name of city] *they don't have all that stuff, the peer groups, the stuff, they don't have all that. And if you look around the community in different, different places, they don't have a*

place where a person, like you said, a social, a social place where we can go to.They got it in different areas. So that's why I'm talking about the system forgets us. And I'm not talking about the color. I'm talking about the people with economics.

Male: *The economics. Yes. That's all it is.*

Male: *It's all about keeping us down. You know, and it already messed us up because they separated our families. If we had more family, we might have more connection of keeping it together.*

[Multiple participants, Family member group]

One participant further observed how the interests of corporate America compete with community needs.

And one of the things that the psychiatrist said was it's hard for him to help the black people because corporate America pushes back when they want to help they people. And so, that's why they can't, they can't really help you because they, it's so many rules, and then they see all of the black people going to want to go right here to [name of therapist participant]. *So corporate America…*

[Female, Family member group]

Community members helping each other

In addition to enumerating many of the challenges facing their communities, participants also spoke of the importance of coming together to address injustices through empowerment and advocacy.

Female: *Well one of the things…, and you know this already is, if you feel that your services are not being met or that your rights have been taken away or they're disrespecting you. You know there is power in the pain. You already know that you and your other people that are in your group, if you guys are witnessing these types of injustices you know that you should be writing, you should be writing letters asking for some type of – give me some*

type of answer as to why. If something happened to you…

Female: *We've been doing that.*

Female: *Oh, good.*

[Multiple participants, Family member group]

Female: *So I believe in where I'm at today, I'm in a good place because I'm just trying to help the individual at their time of need.*

Male: *Meet them at the need.*

Female: *And there's older people that need their SSI and for some reason they're not getting it. I'm an advocate for them. I'm making sure they get it because now I'm getting the words out, whose is it, she's coming down there, we need to hurry up and… They need housing, so I'm hooking up people with the housing. It's networking. I believe that as a community we all need to work together as best we can.*

Male: *There you go. Exactly. Mm-hmm.*

[Multiple participants, Family member group]

One family member participant who is also a community advocate spoke about the importance of working together, to make things better for the *whole community*.

> *And so, I don't do it just for me, I do it for me, my family, and my whole community. And so, being able to just be able to hold myself back when I'm saying it's not black people here in our community because I'm working with the department to say, give me the numbers to tell me how many African Americans are really working here. Um, I'm glad that you're in the drug treatment centers there. They want to put all the housing there. Like every – what downtown. But once again, in downtown is where all the services go. They want to put all about here? And* [name of city], *there's different levels of – and not just in* [name of city], *everywhere in service area one through eight, excluding six, there's different levels of clinics. There's different levels of all kinds of things. It's not here... Everybody know that's what it is that I do, and I speak, I stand on like how do I be able to help our community uplift or whatever. And it's about advocacy. And so, that's how I know about the* [place name] *because anything that's good in this community, I know about.*

[Female, Family member group]

Putting responsibility on people in positions of power

Others spoke about the need to put pressure on those with decision-making power.

> *You got to put, you got to put the responsibility on the people who have the power to make changes. So I know that you're thinking oh, they don't listen… Yes, they do. They do. They have to because things are very transitioning right now. And I mean transitioning, not necessarily for the best. And I understand very much what you're talking about…So I'm just saying don't, don't let them get away with, you know, allowing you to feel like that, that you don't have any power, that you don't have any rights or you can't go and that they'll listen to what you're saying.*

[Female, Family member group]

However, others pointed out that people in positions of power often abuse it.

Male: *I get that, and I understand about going to the… I worked downtown at one time too. And I do the housing and whatever. ..And I seen that how they have a big thing, like homeless is a big deal now. So what they'll do is um …they have to, it's questions that they ask a person to help, to assist them in getting housing. And what it was basically made for is to help those that they feel that's going to die out there on the streets. I was working somewhere before it became big, right? So they needed to find some people. Say if you find a few people. And what they did, where they put the people, they showed up from the ground up, put them in a house, I mean took they pictures. Dusty, alright, picture. Like this. Those that's in power.*

And then everybody think that they doing a good job. A lot of those people that they put in them places don't even stay in them places no more, no follow up. But they got the recommendations that they was doing they job. And that's how they, that's how I seen, ever since that, that was five or six years, and ever since I been doing different things, I'm seeing how they play that game. They'll go get somebody, and they'll put some, you know, that they seem like they really helping the system.

Male: *Excuse my language, but they call it poverty pimping.*

Male: *Oh, that's what it – poverty pimping. Yeah, okay, that's what it is then, poverty pimping. And then they show somebody. And the persons happy because they different from what they is. You know? And they good, they work, I mean they do a few shows or they show them a few times and the better and ask them a few questions…*

Male: *And make money off it – poverty pimping.*

Male: *And make money off of it. But they really not doing nothing. They not. The, overall, everybody, and then when it comes down to it, they not doing the aftercare that's needed…A lot of people that's been on the street, they don't, they have a fear of being inside. That's what I found out. So you got to learn how to work with them. But all they want is a picture to help them people get candidate, to get reelected, you know?*

Female: *Exactly.*

[Multiple participants, Family member group]

Solutions from within the community

Participants also discussed how public agencies and academic institutions exploit the resources they get to do their work, to implement their programs, yet don't lend any support to the community members who are essential to their success.

And the thing is, and no disrespect [addressing the facilitator and researchers in the room], *our community is going to listen to us in the end than you guys coming in here. I'm*

dealing with public health right now on some youth summit issues. And they're coming down, and I mean they got some meal tickets. I mean a couple million dollars up there. And they come in there and they get all our ideas from us, and they getting a paycheck. And I'm going to meetings two hours, four hours a week, and I'm driving from [city name], *you know, every day with my gas, and I can't even get 20 dollars for gas. You know? And with, and just like the guy from public health, he told me straight up, he had some stuff to do, some passing out flyers at the parole buildings and stuff like that, you know, because we're getting out the penitentiaries and we not knowing. And he says man,* [name], *here, can you go do it for me because they're going to accept you before they accept me. Because they know I'm down there talking to them every day. You know, so that's the only reason I'm saying that. And, and, I, this is what I hate to see. They come to tables on meetings, and the moneys there, the things are there, but this is as far as it goes, around this table.*

[Male, Family member group]

Pathways to Care

The focus groups revealed the different ways in which clients found their way to mental health services. These pathways to care can be grouped as referrals (individual and institutional) and word of mouth/agency reputation.

Referred by family and third parties

Many participants began receiving mental health services at the behest of a family member. A

Spanish-speaking participant reported that her sister brought her to the program where she now receives services. She said, *"I found out about that spot* [in the program] *from my sister. She figured out which one was closest to me and brought me. She brought me there."* Sometimes family members were adamant that their loved one receive mental health services.

In the family member focus groups participants were asked, "When you were talking about the clinic and family members getting to the clinic and getting the counseling, how did [you] find out about the clinic?" In response to this line of questioning, family members talked about going out of their way to identify and secure services for their loved ones and about the challenge of ensuring that their loved ones accessed the services. One woman told the group, *"I do know for a fact that most people go out of their way to get the help for their loved ones."*

Another woman summarized the group's views:

> *The first thing* [family members] *want to do is find a place where their loved one could go get treatment… And once that's established, then the family member sometimes will go out of their way to go to the place to talk to somebody and they will give them the phone number or the times that they could bring the person to come in.*

This same participant then acknowledged the challenges associated with obtaining services for loved ones: *"The hardest challenge is to get that person into that clinic. That's the hardest challenge."* This challenge was echoed by another woman who said, *"Now that's the million dollar question: getting the individual to walk into the door* [to receive mental health services]*."*

Unexpectedly, some older adult consumers in the Spanish-speaking group were referred to mental health services through third parties. By "third parties" we mean individuals who are not relatives and who happened to meet the older adult in question and recognized their need for help. For example, a woman told us that she would bring her sister to the psychiatrist. On one of those occasions, she said, *"The psychiatrist saw that I really wasn't doing well. So she told me, 'I'm going to call a clinic.'"* After that, *"they sent me to the clinic that we are at* [now] *and from there the doctor sent me in an ambulance to a home… and I was there for 15 days…. That was 20 years ago."* One of the men also shared that he was referred to mental health services at a time when he was not seeking such services. He shared that he went to pick up his nephew from elementary school and the teacher there referred him to services.

> *I was going to pick up some of my nephews… in second grade…. When I went there I was really nervous and not well. And* [the teacher] *recommended the place where we are now. I really wasn't doing well. It wasn't controlled.*

In these cases, a third party (a psychiatrist and a teacher) intervened when they believed that older adult in question was in need of services.

Referred by established institutions and programs

Many of the participants that found their way to mental health services did so through established institutions, such as churches and hospitals. A female Spanish-speaking participant reported that, *"The priests and the pastors, when they see that someone is really nervous or stressed, they say, 'Go look for psychological help.' There are people have looked for help through the churches."* Other participants agreed that churches were sometimes an avenue for learning about services. Across all groups, many participants found out about the services through hospitals. One of the Spanish-speaking participants reported that a hospital…

> *…recommended that I look for a clinic where I could attend meetings. So they recommended that I go there* [program for older adults]. *That's the way I ended up there…* [The program] *gave me a psychiatrist, and I went from the psychiatrist to the women's group. And that's the way that things went there. But it all happened there.*

Being referred by hospitals or clinics to programs for older adults was common. In some cases, consumers found out about services through other programs. When asked how they found out about mental health services for older adults, a Spanish-speaking woman replied, *"Through Alcoholics Anonymous. I was in Alcoholics Anonymous because I was an alcoholic for many years…. It helped me a lot. It was the first place that helped me."* Another Spanish-speaking woman learned

about the program for older adults through another program that offered her services but ended up closing down. When the program ended it sent all its client files to the local program for older adults. The point to notice here is the apparently seamless transition this woman experienced moving from one program to another. She did not report any disruption in services. If anything, she reported an improvement in the quantity and quality of services she now receives.

Legal institutions appeared to play a role both for older adults using mental health services and for their family members. Some participants shared that their pathway to mental health services came about because of their encounter with law enforcement. A Homeless male participant told the group that...

> *...one night I went and copped some drugs and the police arrested me.* [Laughs] *And I'm in back of the car just crying because this had never happened to me before... The police turned around and looked at me saying, 'Are you all right?'* [Laughter] *That was the beginning of my voyage, of my journey. From there, I was put into recovery, mental health programs.*

Another homeless male participant also shared a similar story:

> *I came out the penitentiary into the* [recovery] *program, because I didn't want to go back to the penitentiary. And I... came to the conclusion that I was my own self's worst enemy, and if I wanted to stay out of the penitentiary I had to do something about my drug habit. So I went* [into the program] *just trying to stay out the penitentiary.*

Legal institutions affected family members, too. A family member reported that because of the legal system, her loved one eventually started receiving the services she needed. She shared that...

> *...When you're dealing with adults you can't make them do anything.... I believe and I'm almost certain there was something* [that] *happened and there was a court mandate that brought* [her loved one to the program]*... kind of turned her around and made her face whatever it is that's going on.... It was a mandate... I do believe* [that] *without that mandate, we would still be going through all the things that we've gone through.*

Agency reputation/word of mouth

In some cases, the positive reputation of an agency providing services for older adults appeared to increase the probability that these adults would seek out the services they needed. Some participants' observations of the agency's clients shaped their perception of that agency. One of the Homeless women told us that...

> ... [Agency X's client] *used to look raggedy, you know, homeless for real, no teeth in his mouth. Now he got a whole gold set in his mouth, you know. He got his shoes buffed up and he's telling me, 'You ought to come down to* [Agency X]. *They got it goin' on. You can get you some help down there.' He kept tellin me that.*

A male Homeless participant made the same point. He said, *"Why* [Agency X] *get the numbers? Why people come to their gate? Cuz they have something to offer…. That's why people come through the doors. There's something to offer."*

Word of mouth was an important way in which older adults from all groups, including family members, learned about an agency or program and accessed services. When asked how they found out than an agency had something to offer, many responded *"word of mouth."* One Homeless participant summed it up best when he said:

> *I don't go by a neon sign…. If you're telling me you're seeing the change that* [a client of Agency X] *made in his life I may go down there and talk to him to see if it* [works] *for me. Word of mouth is the best advertisement on the planet.*

Another homeless participant corroborated this account. He said that he talked to *"various people"* when he was *"homeless, moving around, walking on the streets."* For him, word of mouth meant that, *"when you get into one program, somebody will tell you* [that] *maybe you should check this* [program] *out and maybe they'll recommend* [a program]*."* In other cases, people from a particular program may *"recommend and direct you somewhere else."*

The reputation of an agency and their services affects how older adults perceive their own chances of accessing the services they need. An older Spanish-speaking male complained to the group that:

> [Program Y] *told me that they were going to give me Medicare… And I went and talked to them… nothing. I don't have Medicare…. They were going to come to my house to see me, so that I wouldn't have to go everywhere alone, because I'm alone a lot. And the medicine makes me sick. It makes me dizzy. And they've never come to my house. One time, that's it…. It was a total lie.*

When asked what suggestions he would make, the participant responded that, *"When someone suggests something… they reject you…. So our suggestions are pointless."* Whether his concerns are well-founded is beside the point: as a member of the community he contributes to the perception of the agency from which he receives services.

Barriers

Participants in all groups talked about barriers to accessing care and staying in care. Their concerns focused on: medical mistrust; lack of African-American mental health providers; cultural beliefs, societal attitudes, and stigma; provider cultural competency; the frequent turnover of providers; and accessing government services.

Medical Mistrust

Medical mistrust resulting from a history of anti-black racism in the U.S. came up in two of the focus groups as a barrier to accessing and remaining in care.

> *And then also with the older, 60 and older, you got to understand, they were coming off*

the cotton fields…So they sure not going to be that apt to go in there to the white doc, that they just, you know… And that might be it…. Even myself, I question things with the medication and the pharma companies nowadays.

[Male, Family member group]

I was just speaking as far as me being a black male. And I find out um, I suffer various too because of what was done to the people before me. And so, the older adults, you know, they came up and all them tests that they took and the stuff that was shot up in them and the stories that was told, and I, and I, and it, it acts – man, I can't see, I can't, because they actually pulled out a tooth that didn't, didn't need to be pulled out. So me dealing with doctors, dealing with doctors is an issue that we have due to our, what happened in the past. And then we was told and there's some things that happened to us. So actually talking to a therapist, a lot of therapists don't be looking like us.

[Male, Family member group]

Lack of African American mental health providers

Family member study participants expressed how the dearth of African American mental health professionals affected them. The race/ethnicity of mental health providers mattered because racial concordance vouched for the provider's capacity to understand them as clients.

One of the African American women explained it this way. First, she thought that consumers of mental health services were people who *"know exactly what they want and if they're talking with their clinician they'll be very clear as to what it is that they want or don't want."* She talked about her and her friends' experiences of wanting the clinician *"to be someone that looks like them."* And she explains why this matters: *"I don't think that they really understand what I'm saying, so therefore they don't know what I'm going through…. I don't think they understand what I'm experiencing. I want someone that looks just like me."* For her, and clients like her, having a mental health specialist who *"looks just like me"* was more than just about racial concordance: it signaled to her that the provider would *"really understand what* [she is] *saying"* and therefore really understand what she is going through.

One of the family member participants captured the thrust of the conversation when she said:

I really [want] to go and confront the [county department of mental health] *and say we don't have no African American psychologists or therapists or clinicians right here in our community… that is a problem, there is a lack of them here in our community.*

Other participants agreed, saying *"a lot of therapists don't be looking like us."* And even though they recognize that there *are* African American therapists, they view them as *"one out of a*

million," which means that they are *"going somewhere that's… uncomfortable."* At the same time, some participants recognized that merely having an African American therapist would not solve the challenges they had with mental health services. The following exchange brings this observation into sharp relief:

> Male: *And sometimes when you do get the black ones [therapist], they act funny though."*
>
> Female: *"Mm-hmmm."* [Agreeing]
>
> Male: *"Some of them act super funny… you go in there with the intentions, "Ok* [the therapist is] *my race… you're going to help me out a little bit. And they tend to end up worse than, you know, the other people."*
>
> Male: *"Yeah, judging and everything…"*
>
> Male: *"You know what I'm saying? Like for reals! You're going to leave me like that?"*

In short, although participants expressed a need for more African American therapists, they also acknowledged that mere race concordance did not guarantee that their mental health needs would be met.

Cultural beliefs, societal attitudes, and stigma

The Spanish-speaking consumer focus group commented that Latinos, as a group, may have difficulty accepting their illness and therefor difficult receiving services.

> *Well, in the past, we Latinos didn't want to accept that we were sick…. Since the days of the Indians, speaking as a Mexican, like me*."
>
> [Female consumer, Spanish-speaking group]

> *In my family, almost everyone needs psychological help. Like me, once I reached an extreme, which was embarrassing, they were telling me… here… ummmmm. I ended up in a psychiatric place. Do you understand me?*
>
> [Female consumer, Spanish-speaking group]

When asked if services were appropriate for Latina's a female consumer responded, "*Yes they are, but it's difficult for us to want to accept it".*

A couple of participants in the family member focus group agreed that there is less respect for older adults now compared to "back in the day" that makes accessing services particularly challenging. There is additional burden for older adults with mental illness. Stated by one female participant

"*People don't respect each other as they did a time ago and there's just certain decent common courtesies, you know. So our older adults are faced with, you know, riding the train standing up, you know, they might have just had their eyes dilated. You know you have a lot going on. And then to be suffering with or going through a mental issue is not easy".*

According to participants the challenges that come with aging and mental illness is further compounded by stigma. " *It's a very difficult task left unnoticed or undiagnosed or untreated, you know, for them to have to, so then you get ostracized and then people are you know calling you 5150 all the time, you know, name calling and shaming which we're trying to erase all that*".

> *Mental illness…I mean that's why one of the things that we've really been trying to do now is educate our law enforcements, our faith-based communities, just raising awareness about mental illness because it's so – it's a stigma and it's a stereotype and you tell me what mental illness looks like. I want to know. Half the people you go come in contact with suffers with some form of mental illness whether they want to acknowledge it or not.*
>
> [Female, Family member group]

Provider cultural competency

Family members also shared the observation that there is a lack of cultural appropriateness among providers. Specifically, they perceive inadequacies among providers who lacked cultural and/or professional experience, were much younger in age, or did not understand the concerns of specific racial/ethnic groups.

Participants in the Spanish-speaking focus group commented about challenges receiving services from providers who attempt to speak in their non-native language.

> *But what I don't like are the doctors that, when I first started, I began for 5 years with Dr… Ay I don't remember his name. Ah ha. And I knew his background. Then they changed doctors and an Arab came. I could barely understand him...*
>
> [Female consumer, Spanish-speaking group]

> *Then later a gringo came, right? But he barely spoke Spanish. Yeah, he spoke Spanish but I didn't understand him very well. And now he's going to leave. So that's the problem that I have.*
>
> [Female consumer, Spanish-speaking group]

One female family member discussed the challenge of her older adult loved one being served by a young provider. She voiced concern that the provider's age may affect her capacity for generational cultural competence and discourage her family member from getting services. More generally, focus group participants seemed most concerned about whether their loved ones would be able to connect with, and be understood by, a young provider.

> *…but I can't take my mom to see someone that's fresh out of college because they don't even understand…her, her culture. I mean especially if that…Because like, for me it's a problem….So I think sometimes though, because even I experienced or I feel that when I go get treatment and it's a young person, I just – is they giving me something out the damn book? Because I'm not even in the book. And so, if, if I'm taking my mother and if somebody still fresh out of college and the likelihood of them understanding her culture, the community, and all of the things who she is, if it's not a match, it's not even going to be match for her to even go back because the trust – she's not even going to trust them enough to even talk to them*.
>
> [Female, Family member group]

Yet the skepticism of providers who are young, lack the relevant life experience, or only know "book stuff" was not shared by all the participants. Some of them articulated the solution to this barrier. When the female participant voiced her reluctance about seeing a young provider or to taking her mother to a young provider, another participant retorted, *"You know what? No, no. You're wrong to misjudge those young kids"* and other participants agreed with this statement. The participant went on to say, *"You need to give them an opportunity. I mean you really need to trust that."* Later, when another participant voiced similar concerns about a young provider, someone else in the group responded, *"Wait, I want to back up on that. You know why? Don't get that twisted. That college student may* [have] *had a mother or a father or whatever that had the knowledge, and they just got the degree."* In other words, some of the participants recognized that although some of the providers may not have experience dealing with mental health issues, they may have other personal experiences dealing with these issues in their families, and this was good enough. Still, this was not the final level of analysis by the participants. Someone took the discussion one step further, and said:

> *It's not if* [the providers] *come out of college or if* [they] *have a family member* [with mental illness]*. The people that work in mental health have to have the heart, and if their heart is not open for these people, I don't care what degree you have…* [and] *it don't matter how young you is, you have to have that heart, that giving, loving heart that takes yourself out of it, and you want to be a person, a giver instead of a taker.*

The conversation around this topic ultimately points to the importance of having providers who know how to connect with their clients. Part of this includes understanding that for some, age and relevant life experiences may be barriers to establishing an effective therapeutic relationship.

Provider turnover

Many participants expressed how frustrated they were every time their provider changed, for whatever reason. They were unhappy because it took time to establish trust with a provider, and having to build trust with a new provider struck many as tiresome. A male homeless participant focused on the importance of trust to their ability to improve their mental health. He said:

> *You're going over stuff over and over again* [with a new provider, and] *you're not making no progress. You're telling the same story over and over and over again and you get stuck there until you find somebody you're comfortable with. That's real important, find someone you're comfortable with.*

He was not alone in this experience. Someone else from the Spanish-speaking group shared:

> *Everything went really well* [with the first worker]. *But afterwards, because she left, another one came and then another and then another and for me it was really difficult to adapt, to keep adapting to each of them. That didn't help me at all. Not at all.*

Another homeless woman shared how at this point she has had *"two therapists and two psychiatrists,"* and for her, *"it interrupts the whole flow."* By *"flow"* she was referring to her comfort. She shared, *"I got comfortable with this lady and I would love going seeing her… and then she left. So that took, like wow."* And she had a similar experience with her psychiatrist. For her, the relationships with her psychiatrist *"was like a marriage."* But that also ended. She concluded by saying, *"So now I have two different ones and it's hard for me to get comfortable with them."*

The frustration with switching providers was not limited to mental health services. A Spanish-speaking woman shared:

> *We had Dr. X. She was a very good doctor but she had to go… she did a lot with us because she was very good. She left and then they gave us another one. And then, 'Non compliant, non compliant.'* [Mimicking the new doctor] *He was very serious, that guy.* [laughs]*"*

Apparently, that was not the end of the changes to her provider. She continued:

> *Then they changed doctors and an Arab came. I could barely understand him. Then later a gringo came, right? But he barely spoke Spanish. Yeah, he spoke Spanish but I didn't understand him very well. And now he's going to leave.* [group laughter] *So that's the problem that I have.*

Accessing government services

Many participants found the government bureaucracy daunting and off-putting. Although this may not be surprising, this perception may influence the effort participants put into trying to access services for themselves. Frustrations grew out of their own experiences, as well as from observing the experiences of friends and other people they knew who tried to access services. In some cases, participants did not feel welcome in programs designed for older adults. A male homeless participant reported, *"I was uncomfortable* [because] *I was looked down on. Already judged."* Another participant believed that advertised services were not really available or that it was difficult to access them. She said:

> *I don't think the county is doing enough. I think that it's all textbook. It's all on paper…. They say they provide particular services,* [but there] *are none. You can apply till you're blue in the face…*

This participant was recounting the experiences of people she knew.

> *I know a lot of individuals that find themselves… displaced and they need shelter and a lot of facilities say* [that] *they have emergency housing and they do not deal with you. They'll tell you about a piece of* [paper] *– fill this out.*

The perception that services either did not exist or were difficult to access was not limited to housing. People reported similar views about mental health services. One participant believed that the mental health department *"has so many resources,"* but when they seek out these services, he is told, *"Oh, well, we don't have the class and we don't have it."* He said that based on those interactions one would believe *"*[it's like there is] *nothin' out there."* But he believes there are resources. According to him, *"I see a gang of resources so why y'all can't get none? And it's just like they don't care cuz when we tell 'em, it's like they laugh. They go in the back. We can hear them talk about us…"*

A female participant also reported difficulty accessing resources. She said that when she tried to access services:

> *I got the royal runaround. So I don't find that the county is doing enough. They say* [they offer services], *but then to qualify for these* [services] *you have to be in a – you almost have to be on life support to get services…*

The feeling of being given the *"runaround"* was not unique to that participant. Another participant mentioned that she was becoming aware of her growing need for services from the county, but she also knows that, *"You cannot just walk in a county building and get services. They're going to have you fill out a bunch of paperwork. They're going to have you wait two or three days…"* But worse than the bureaucracy, this participant believed that the providers did not really care about her. She said, *"and they could care less. I mean I know people right now who are getting ready to be on the street, but before they go to the county offices they already know they're not going to do anything."* That is, their friends are not even going to try accessing services through the county *"because of past failures"* by county. Part of the failure had to do with the amount of time they had to wait to receive services.

One participant shared the experience of her friend:

> [My friend] *just says, 'It don't work for me… every time something happens and these situations* [needing services] *come up, it's always the same thing when we go to* [the county]. *It's five or six months* [waiting period].*' And she's just like, 'Forget it. Just forget it.'*

The worse outcome, it seems, is for community members to lose faith in government's ability to provide them with the services they need in in a timely fashion.

Facilitators

Participants talked at length about the factors that made it easy for them to access care and/or remain in care. The topics that participants talked about included the following categories: spirituality and volunteering, preferred characteristics of providers, and programmatic features.

Spirituality and volunteering

As noted earlier, many older adults believed that spirituality and religion aided their journey toward mental health. Although the participants did not explicitly state this, it appeared that, for some, spiritual and religious commitments opened up opportunities to become involved in the community, to keep busy, and to obtain social support for their mental health challenges.

Making sure that they did not have too much idle time was important to many. As one of the men noted, *"I had to learn… to have something to do with my time because [it's a] really a bad thing not having nothing to do…. That's why I volunteer here and do what I do. Otherwise I would go crazy."* Other participants agreed with him.

Sometimes consumers' religious and volunteer activities intersected. As one woman described it:

> *I quietly went and signed up to the Catholic ministry…. Now I'm hardly ever at home, always running around for church errands. But it helps me a lot because it fulfills me… and I'm very happy. I'm doing very well there. And yes, it has helped me* [with my anxiety]. *Anxiety is at the center of everything and attacks me in every way.*

For her, volunteering at the church helped her to deal with her anxiety. A male participant shared how volunteering contributed to his mental health and spirituality. He said, *"I do volunteer and I'm called upon sometimes to be of service. But I'm finding for me that I have to learn how to keep myself busy…. There's always something I can do to help me spiritually and mentally."*

For others, volunteering tapped into their altruistic motives and kept them busy. One of the participants said:

> *I'm a volunteer there and I like it because I like to be busy during the day. I open the door for the clients. I let them in. I let them out. And yes I have to get a coupon to get food there, but that doesn't matter to me. But I love going there and volunteering.*

Another participant talked about the value of having opportunities to volunteer available to older adults. He said, *"If you're over 55, they've got an agency…where they give senior citizens four hours of*

work, 20 hours a week. I volunteer a lot. We just went to an encampment and passed out clothing and talked to… the homeless people."

Preferred characteristics of providers

The participants talked at length about the features of their providers (including physicians, group therapy facilitators, and case-managers) that made it easier for them to access or stay in care. The characteristics the participants talked about are grouped under the following headings: personal qualities of the provider, type of provider, and the motivational impact of the services they provided.

Personal qualities

A key theme that emerged across all focus groups was having mental health providers who were patient and empathetic. One woman talked about how much she appreciated the patience her providers showed her. She believed that her mental illness could be difficult for others to deal with. Her story is worth quoting at length.

> *I'm very grateful because* [my doctor] *had a lot of patience. I was vomiting a lot and she had patience with me going to the bathroom, being in there. Everything's really good still. The doctors… the nurse,* [had] *a lot of patience with me... Everything is really good for me and I'm progressing because before I cried a lot. And the birds would make me nervous because I would tell myself that they were making fun of me.* [The group laughed.] *Yes, and they were laughing a lot and I'm very grateful to [a county worker?] because she had a lot of patience. Thank you.*
>
> [Female, Spanish-speaking group]

According to this participant, her providers' *"patience"* not just with her mental health challenges but also with her physical challenges, helped her to move from a mental state in which she believed that the birds were *"making fun of* [her]*"* to one where *"everything is really good."* Older adults appreciate providers who are empathetic and know how to put them at ease.

Another female participant talked about the comfort she had developed with both her therapist and psychiatrist. It was at the point where *"they don't have to say a thing. You just walk in the office and you just feel that comfort. You just feel it."* She went on to say:

> *They open their mouth… and it was just inviting the way they carried themselves and the body language... and it was just easy. I just fell in love with this one lady. She was just so smooth to talk to. I just loved her…*

Gender

Surprisingly, the gender of the provider was mentioned only once, by a male participant. He was happy to have had a woman therapist. He said that he was *"the only male out of six sisters"* and that he was raised by *"my grandma, my auntie and mother."* As a result, he felt comfortable talking to a *"woman more than to a man."* He shared, *"I tried [therapy] here with a man and I wasn't feeling it. So*

I knew they had to find me a therapist that was a woman." The experience of this participant points to the fact that although gender concordance may be important for some consumers, each consumer's experience with previous therapists, type of mental illness, and family history should all be considered when thinking about the gender of the provider.

Peer/Model

Many participants talked about the importance of working with someone who had similar experiences to their own. This was especially important for people with a history of substance use disorders. One of the women in the groups talked about why it mattered to her to talk with people who had had similar experiences to hers. She said, *"They are the ones that came for us when we were homeless… and they were saying, 'I also felt that way.'"* Besides being empathetic, these staff played a more important role: they modeled for her what her life could be like. Seeing these models triggered this thought in her: *"You say to yourself, "God willing I will recover too, because look how he's coming to visit me. He's even talking to me about his life so that I see an example of recovery."*

One of the women explained that someone with a history of addiction would be able to relate better to clients. She said, *"All of the trouble, the homelessness, the addiction and all of that, they can relate to you and you can relate to them."* As discussed in an earlier section, feeling comfortable with the provider was something participants wanted from their providers. They wanted someone who could relate *"instead of someone just having a book knowledge"* because *"you can tell as soon as you walk in book knowledge from real knowledge."*

Picking up on this theme, one of the participants talked about the advantages of having a case manager with a history of drug addiction. This type of case manager *"can take me down roads that she knows where I've been… because she's been there and I love her. I can talk about anything and she can relate to me."* Other participants agreed with her. The importance of working with someone with a similar history as hers was so important that she would refuse to work with someone who did not have a history of addiction. She said, "I refuse to go to a group with somebody running the group that's not an addict."

For people with a history of substance use disorder, talking to a peer was a first step toward obtaining mental health services from a professional. One of the men elaborated on this when he said, *"When you come out of that addiction, and you're not ready to go to professional people, you know you* [can] *go to another addict…. that's your therapy."* He believed it was easier to talk to another addict first because *"you're not ashamed"* because that addict *"probably did the same thing."* For this participant, talking with an addict first prepared people to talk with a therapist afterward because talking with another addict is *"therapy by itself, until you get ready, get your head clear to go talk to a professional"* because in the end, *"an addict [can] help an addict stay clean."*

Motivational impact of the provider

Participants seemed most enthusiastic with providers who found ways to motivate them and keep them engaged. One of the women in the Spanish-speaking group told us that through the mental health services she received, she learned *"a lot to value my life, my time, how to use it, using it to help*

others [to] *see that you can be at the bottom, but no matter how big your problem is, there is a solution."* She credits her providers: *"The therapists and the doctors, the doctor that I was placed with, have helped me a lot."* Another women shared a similar experience. She told us that she felt *"motivated by the fact that they go to* [her] *house."* She likes that they ask her, *"How you're feeling? Which medicines do you take? How is your life? How do you feel? Are you ok spiritually?"* because doing so makes her feel that *"they push me."* Her view of the therapists is that *"they motivate me."* In the end, motivating clients ultimately impacts their mental health.

One woman liked her providers because *"They listen to me. I feel heard. I feel supported. I feel respected."* Although she knows that she has *"mental condition,"* she said that the services that she receives *"make me feel like [I have] many qualities that you couldn't see before,"* that *"she's a very sociable person. She's a very intelligent person. She's a person who has gifts like writing. I still to this day write."*

Programmatic facilitators

Below we describe programmatic features that facilitated access to services, such as type and content of program offered, the language of its offering, language, and who the programs targeted.

Language

For older adults from Latino communities, the availability of services in Spanish facilitated their ability to access services. A male participant said about his agency: "I think they help Latinos there a lot because practically everyone speaks Spanish. Almost 80%, let's say, of the clinic personnel speaks Spanish. So that's really good." The services offered were in both Spanish and English. According to him, "It helps. It helps a lot." More importantly, even clients who chose to access English language programs felt welcomed. One of the Latina women of the groups accessed programs in both languages. She said of her and her friends, "We're in a Spanish group and they speak to us in Spanish. They listen to us in Spanish." What stands in her experience, however, is this: "We participate in Spanish and I don't speak a lot of English, but I'm in an English group. And when I don't understand, I can ask and they assist me. Never, 'Oh, next question or next person.' No." She was not alone in this experience. Another woman shared that, "What helps me is that… I speak Spanish and English, *broken English and broken Spanish b u t* I have been to many places where they speak both languages." Besides providing programs in English, the agency has created an environment where clients with "broken English" felt comfortable accessing the other available programs.

Program Aim

Participants talked about very specific features of programs that they felt worked for them. One of the things that worked for them was developing plans. A female participant said, "We make plans. [Individuals] have their own personal plan." When asked who helped clients develop their plans, she answered "a team" that included the case manager and anyone else who was willing to help.

What worked for participants are programs that helped them to organize their lives. One of the

women shared that the program "gave me structure." Having this new structure in her life mattered to her because "now I make decisions more clearly because I was off into a fog. When you're all cloudy in your mind then you can't make those decisions [about life]." According to her, "coming to these classes… gave me some structure in my life."

Offerings for family members

Several participants across all group types mentioned certain programs that offer support groups and training for family members of consumers. Below, one Spanish-speaking participant describes a support group for grandparents of children with certain behavioral disorders, while one female participant in the family members group describes a training program.

> *Yes I go to a program but it's for my grandson. So on Tuesday mornings we also meet, we also talk about everything that happens to us and everything. It's like the other group I go to but it's to know… it's for grandparents. I'm going there also.*
>
> [Female, Spanish-speaking group]

> *Yes, there are programs like that. There are programs like that. They have 'em. They have* [program name] *through* [organization name] *with the family members. The family members come and they take the training – 12-week program for the family member of a loved one with a mental illness. They prefer not to have the one with the mental illness in there because it's for the family member so they could ask questions. They wouldn't feel comfortable asking a lot of questions if their loved one, say for example their husband had a problem and he was the reason they're taking this family to family. Well the wife wouldn't feel comfortable talking openly if he's sitting next to her.*
>
> [Female, Family member group]

One male participant in the homeless group describes small regular event where family members are welcome to attend.

> *Well we have a lot of different like little events here. You know. They can come to any of those. They can come every day at 12:00 if they chose to because at 12:00 we have lunch.*
>
> *[Male consumer, Homeless group].*

Other programs encourage family members to become involved in the treatment plan of the consumer by, for instance, offering logistical support.

> *They say that family support is really good for all of your problems. That if you need transportation, there was a time that I couldn't drive, my brother, my daughter and my son, they all brought me and picked me up and thank god I'm doing pretty well. Umm… yeah… family support is really important. In my case, I arrived at the clinic after a breakdown/crisis in a psychiatric hospital and they sent me to [clinic name] and I was*

really lucky that everyone realized that my son came and brought me and waited for me. It's a type of support that… no one else could provide. Something like that, no one else can do. And that's my opinion. I don't know how you could find someone who would want to do that.

[Male consumer, Spanish-speaking group]

Yes, for me yes they understand pretty well, the ones that come, because they even take us to see them. They don't forget. And they ask. They say, "Do you have a lot of family support? Is it very helpful to you? Are they calling you every day to see how you are, if you're well?" So yes they worry about us, about how our lives are in regards to family.

[Female consumer, Spanish-speaking group]

Support Groups

Programs with a support group component were lauded by consumers for several reasons, including the value of having a venue where they could share and discuss their health issues, feelings, and experiences, a process of engagement which ultimately contributed to boosting a sense of self-respect and self-worth. Group therapy facilitated learning from peers and their experiences, and sharing without fear of repercussions or disapproval from family. The groups also helped older adult consumers who have felt isolated: the group discussions are perceived as motivational, acknowledging self-worth, reaffirming the value of life, and the value of individual contributions to life and family.

I believe that this is the most important thing. They have convinced me not to leave the group. We can talk about what it is that I need and what it is that I don't. And for me, those people have helped me a lot.

[Male consumer, Spanish-speaking group]

Listening to other people helps us, hearing phrases. There's one that I heard. I don't know when, but I heard it and it got to me. It goes, "When you have a concern or a disease, don't worry so much, because it will pass. And when you have contentment or happiness, as small as it is, enjoy it is much as you can. Because it will also pass. Nothing is forever." The last two weeks I've had a lot of stress. I've had problems, but I carry that phrase with me constantly, "This will pass." That's how I've been getting through the last two days.

[Female consumer, Spanish-speaking group]

I would go into meetings and meetings I don't do too good, especially talking. Can't tell it now, huh? [Laughter] I wouldn't say anything. But I would listen to other people and get strength from them, you know, until I can stand on my own two feet and go for myself and that strength, that strength that I needed, you know.

[Female consumer, Homeless group]

Family members describe these group activities as a forum for sharing one's story, which is helpful, especially when consumers are surrounded by people who look just like them, and have had similar life experiences.

> *But the clients get a chance to talk about what they are experiencing and they get a chance to see other people in the room that's going through the same thing that they're going through so then it lets them know that they're not alone. So this makes them feel a little better. Because sometimes you'll hear them say, "Oh I thought I was the only one going through this." But once you meet other people, everybody have almost the same issues which it's a common denominator where they could talk together something they all have in common. So I like that. They do have that available and they thrive on that. They look forward to coming to those meetings at the facilities when they go to see their clinicians or their psychologists because they have a chance to get out of the house and talk to other people that's going through what they're going through and I find that to be very beneficial for the person that's experiencing and it helps the family members, too.*

One Stop Shop

> *[Female, Family member group]*
> *A key facilitator in receipt of services was the coordination and provision of integrated care in one location. This was particularly pronounced for participants in the homeless group.*
>
> *This is the one stop center for my health, transportation, dental, medical, education, college, private education*
>
> [Male consumer, Homeless group]
>
> *Yeah this is the one stop cause see I'm gonna tell you, people don't wanna have to run across town to get this over here and run over to this to get that. They want it where, especially people our age, you know, getting older. We don't want to have to go searchin'.*
>
> [Female consumer, Homeless group]

Participants who did not experience a centralized service provision, explained that they would prefer to have it because it would save time both for them as consumers and for the providers.

> *Save time with the individual. Instead of going over again and again for two different people.*
>
> [Male consumer, Homeless group]

Home Services

Home services were a program facilitator, especially for the Spanish-speaking participants. They perceived home-based services as helpful, especially when they also provided support with

navigating bureaucratic paperwork, and ensured that clients were stable, could manage on their own, and had a support network available. They further observed that home services were not only convenient but that home visits communicated a sense of trust. The fact that a social worker, therapist, or nurse was willing and prepared to come into someone's home was seen as a sign that they trust that person, that they are comfortable being around them in their home environment.

> *I also feel that they have helped me a lot, at least for a short time, two years, to get to what the Americans call recovery. Recovery. But it was very much because of their help, their presence. You feel motivated by the fact that they go to your house, that they ask you how you're feeling. "Which medicines do you take? How is your life? How do you feel? Are you ok spiritually?" They push me. They motivate me. It's very important for those of us that are mentally ill to turn to god, very important. Any religion you want, but that is very important. To know that and to be grateful for them, because they come see us in our homes.*
>
> [Female consumer, Spanish-speaking group]

> *Well they are really comfortable with us. They always come. I mean they're really comfortable with us because they come to our homes. And they call us on the phone to find out if we're going to be there to receive them. Right? Because sometimes they come and we aren't there and they leave their card in the door, the card with where to go and they leave it outside. This helps a lot for Latinos with mental illnesses. I consider myself Latina, just like everyone else here. So they help us a lot because the medicine that they give us is pretty good. You just have to follow the advice from the therapy because, if you don't do your part, it doesn't go away, it doesn't go away. So it's really good and really practical knowing that they are coming to your house.*
>
> [Female consumer, Spanish-speaking group]

Quality of Care

The focus groups were informative with respect to the types of services that participants used, as well as how and why these services helped them as consumers or as family members. Participants discussed three broad categories of services: mental health services, aging services, and substance abuse services. Although we report these services separately, we note that there is overlap between them, especially for programs that aim to meet multiple needs of the clients they serve.

Mental health services

All three participant types (Spanish-speakers, homeless, and family members) described mental health services that they are familiar with or have used. These include individual visits with physicians, psychiatrists, therapists; group therapy; behavioral modification classes; and daytime outpatient programs. Across all participant types, one-on-one interactions with physicians and

psychiatrists were perceived as helpful, particularly with issues related to medication management and the management of other physical health challenges (i.e., co- morbidities). Descriptions of the most successful/useful physician visits included bilingual physicians who could communicate and explain well, were knowledgeable about available resources (such as crisis lines/suicide prevention programs), had established a personal connection with the consumer, were familiar with their medical/personal history, and could pick up on the consumer's physical and emotional cues regarding sadness, happiness, etc.

Spanish-speaking consumers

Among Spanish-speaking participants, one program was often mentioned, and described as a multi-faceted program that offered integrated care and services. The program's support group component was lauded by consumers for several reasons, including the value of having a venue where they could share and discuss their health issues, feelings, and experiences, a process of engagement which ultimately contributed to boosting a sense of self-respect and self-worth.

Group therapy facilitated learning from peers and their experiences, and sharing without fear of repercussions or disapproval from family. The groups also helped older adult consumers who have felt isolated: the group discussions are perceived as motivational, acknowledging self- worth, reaffirming the value of life, and the value of individual contributions to life and family. In addition to support groups, other programs described as helpful included a women's support group, a caregiver grandparents' group, English and Spanish groups, and an integrative wellness center.

The Spanish-speaking participants perceived home-based services as helpful, especially when they also provided support with navigating bureaucratic paperwork, and ensured that clients were stable, could manage on their own, and had a support network available. They further observed that home services were not only convenient but that home visits communicated a sense of trust. The fact that a social worker, therapist, or nurse was willing and prepared to come into someone's home was seen as a sign that they trust that person, that they are comfortable being around them in their home environment.

Homeless consumers

Homeless participants mentioned several programs and services they have used. These include a community health center, group therapy, and women's groups, all of which have contributed to consumers' sense of self-respect, with a focus on individual strengths. Some of the services described were new, whilst others had been around and utilized over the long-term. Group therapy was especially highly regarded, in particular when therapists were approachable, friendly, and good listeners. Participants observed that when therapists came across as caring, it was easier for them to establish a rapport, and earn the trust of consumers. Group sessions were perceived as safe spaces, which facilitated sharing of information without fear of backlash, repercussions, or hostility.

Similar to participants in the Spanish-speaking groups, visits with case managers, psychiatrists and therapists were cited by homeless participants as a source of help, particularly with medication management and other physical health challenges. Participants embraced services planned through shared decision-making, which involved them in setting goals.

It's something we developed together. Goals, we set goals and then what are the steps involved to meet the goals. My medication has been stable for the last year. Prior to that we were going up and down on it, but it's been pretty stable the last year. I also see a psychiatrist every two to three months through [program name].

[Female consumer, Homeless group]

I found out some things that I didn't realize was happening, you know. I just counted my, I guess it's depression, I just counted it as life. Life things. But I would explain that it was really depression. He medicated me and it helped me. So, and it helps.

[Male consumer, Homeless group]

However, some homeless participants emphasized some of the deficiencies in access to and availability of physicians, psychiatrists, and psychologists. In particular, they talked about how high turnover affected them. Some participants did not enjoy having to recount their life story and issues for every new clinician assigned to them, whilst others were more accommodating.

I just want to just say, like me, I, like you say, I have changed therapists and psychologists at least three times. I like them. But I came to a conclusion after the first time, I know it's a turnover sort of job here. So at any time I know it's going to happen, but I realized once I did it one time and spilled myself, I was able to do it with whoever came in because I'm there now and it was good. But I also and let me say something real quick about the case management thing. But me, see case management here, it's like at [program name] *it has nothing to do with my mental health thing. It's all about my other life. My mental health, I mean my mental health with my psychologist and my therapist, that's separate from my case manager.*

[Male consumer, Homeless group]

Family members

Family members described their loved ones' receipt of mental health services such as group therapy and behavior modification. They discussed how group activities provide a helpful forum in which their family members can share their story and feel supported, especially when surrounded by people who look just like them, and have had similar life experiences. They also explained how behavior modification has enabled their loved ones to take responsibility and control of their recovery, teaching them about their emotional triggers and how to manage them. Family members also pointed out that staff compassion is crucial, because consumers are often fearful of being judged.

Aging services

All participant types reported using aging services, such as adult day health centers and senior

centers, which provided a diverse range of health and wellness programs. The Spanish-speaking participants talked about receiving healthy living advice, and participating in nutrition programs and art classes. Art programs in particular were described as helpful.

> *I noticed that it calmed me a lot and relaxed me a lot. And I started to think things, not bad things, good things. Which colors was I going to mix? Which color was I going to use? My mind was focused on what I was doing or on what I'm still doing, because I still go there.*
>
> [Female consumer, Spanish-speaking group]

In the homeless groups, discussions revolved around senior-specific services (55 and over), which included education, anger management, volunteering, and meaningful engagement. These were perceived as helpful in recovery, because they provide structure to someone's day, as well as a sense of purpose.

In the family member groups, the discussion about aging services was more extensive, focusing on both strengths and deficiencies. Services mentioned by family members included crafts and jewelry-making classes for seniors, meals on wheels, and Adult Protective Services (APS). APS was described as a much-needed resource, and some participants expressed concern and hope that these services would be continued. However, much of the conversation centered on the long wait times and bureaucratic burdens their loved ones experienced when trying to access services, financial burdens incurred (e.g., high co-pays), long distances traveled to reach service providers, discontinuation of services due to lack of funding, as well as the insufficiency of services in the specific geographic areas where consumers resided.

> *I would just like to see again that action speaks louder than words. So I would hope that, you know, down the road that if certain things are available for older adults, not to make it so complicated. You know, because people are not gonna, everyone's not going to want to give their social security number and all this documentation for something that is – if it's for older adults I'm just saying, we all may not look our age* [laughs] *but, you know, just let the programs exist. You know, we want to eat better, you know eat better, exercise and have those types of programs that embrace the older adults. You know you can create all kind of buddies community-wise.*
>
> [Female, Family member group]

Substance abuse services

All participant types mentioned experiences with substance abuse services, such as smoking cessation, Alcoholics Anonymous (AA) and Narcotics Anonymous (NA). However, discussion of these services, plus methadone clinics, was more pronounced in the homeless groups.

Homeless informants reported using methadone clinics, NA (regular services and over-55 services), AA, and smoking cessation through behavior modification programs. These programs

were credited with giving participants more structure in their day-to-day lives, and providing a venue in which they could open up without fear of backlash. One participant described participating in a substance use group designed for older adults.

> *We went to over-55 group and it ran differently than a regular AA or NA meeting. It was a whole different approach but they've got the similar steps, but it's not ran the same. Big difference. It's way different.*
>
> [Male consumer, Homeless group]

In some cases, these substance abuse programs served as pathways to further mental and physical health care, including counseling.

> *My first contact* [with] *mental health here in California came in a drug program that I was involved in at Milestone and that was my beginning of my mental health involvement or exposure.*
>
> [Male consumer, Homeless group]

> *I not only get my therapies here, I also been branched out to the* [clinic name] *to where that I think once you get in the doctor in the* [clinic name]*, you're gonna get paid more attention to, rather than going over to [hospital name] and wait on them. 'Cause* [hospital name] *is a trauma center, everybody know that. If you ain't 'bout dead, you ain't gonna get nothin. You know and you going get on the back list where you gotta wait six months to a year just to get in and see if your finger broke, you know, that kind of stuff. So I think being connected with someone or some program have a lot of advantages to people surviving, such as myself, because had I not… had a door not been open here, I'd probably be dead or still out there on the sidewalk. Because I had no idea that people was in here ready to help me if I come ask for it. But I didn't know how to ask.*
>
> [Female consumer, Homeless group]

For participants who have experienced homelessness and/or SUD, there is a preference for peer therapists, i.e., people who have experienced similar types of problems or addictions. They tend to have higher credibility than regular therapists.

However, some participants discussed that this approach can be difficult at times, especially when peer advisors themselves suffer a relapse. Others outline problematic or otherwise inadequate substance abuse services and practices.

> *It's not like, it's not like we come here as seniors and we literally get help. I mean real help to where my siblings are, they're known and they're addicts. They're put in addictive surroundings and they're being left to their own devices without really getting the proper care, such as seeing a therapist and the therapist addressing the addicted behavior as well as the mental capacity. And I see people being neglected and misused and abused when it*

comes to independent living because all they want to do is put you in a place. And it doesn't matter if the people are taking proper care of you or not. I've done seen this and I've done work for people that does that with seniors. And they're not getting everything they need. But again they're being paid to take care of these people and they're not doing it.

[Female consumer, Homeless group]

Integrated care

Participants from all groups described services and programs that provide integrated services and care. In the Spanish-speaking group, participants mentioned receiving physical and mental health services, such as therapy, blood pressure management, sleep clinics, management of multiple conditions/co-morbidities. These services were often combined with housing, education, and employment support. In particular, one program's support with accessing housing was very much appreciated by informants.

And that's how I know, because I was homeless. They have taken really good care of me. They're there whenever I need them. They've given me a lot of therapy. They've talked to me about housing, if I want to change where my relatives are living. Because I'm on my own. I never got married. I'm on my own. They have helped me a lot. Whenever I need something I call them on the phone and they help me. They even take my blood pressure. It's very important because my blood pressure goes up and down. It's a blood pressure disease that I have. So I've received a lot from [program name]. *I'm very grateful to them*

[Female consumer, Spanish-speaking group].

Homeless group participants provided examples of access to primary care and health screenings, podiatric, dental and eye care, although some pointed to the insensitivity of certain providers, and long wait times for specialist visits. They also mentioned integrated care that was overseen by case managers, who were described as caring and nurturing. Across all groups participants reiterated the need to consider people holistically, and better account for their health, housing, food, and transportation needs. Better outreach to older adults was also recommended, as participants noted that older adults with mental illness underutilize health services across the board.

Service Gaps

Across all focus group types, participants identified gaps in mental health service coverage. They offered their impressions of the various factors that contributed to these gaps and the subsequent effects that they have on consumers. Their conversations centered around five particular areas where programs fall short: delays in referrals and services, screening and diagnosis failures, misalignment of substance abuse and mental health services, and disparities in access to services and experienced providers. In illustrating these service gaps, participants drew from their own experiences as well as the experiences of family and friends who have been similarly affected.

Delays in referrals and services

Several of the participants found the process of utilizing county services frustrating and often futile. One participant explained that, although her loved one had already been diagnosed and referred to county services, she was subjected to inordinately long wait times for appointments. The participant partially attributed this problem to the fact that she and her family member live in an underserved community.

> *…one of the things that we experience in this community is, um, when she is feeling her diagnosis or any of that, when she go to* [place name]*, it's going to take five or six months for them to see her. So by that time she's been self-medicating and she ain't even thinking about it. And so the, the point of, it has to be not as much of a long period in order for someone, if they are feeling these things, that you shouldn't tell me okay, come in, I'll do the paperwork and come back in three, I mean five or six months… And so she, she just says, it, it worked for you. It don't work for me. And so every time something happens and these situations come up, it's always the same thing when we go to* [place name]. *It's five or six months. And she's just like forget it. Just forget it.*
>
> [Female, Family member group]

Participants were also dissatisfied with the level of bureaucracy that they encounter when visiting county facilities. They find the application process frustrating, due to confusion about eligibility documentation and the stress of being asked to wait for many hours. One participant shared this experience:

> *They'll tell you about a piece of—fill this out. If you know next Friday that you're going to need a roof over your head and you go to a county facility, you start out at 8:00 in the morning. You sit there all day. You can't really eat, you know, you're not going to the restroom cuz you're trying to hear your name and you're nervous and you try to have whatever documentation they may need and they're so busy requesting your social security card, your birth certificate, your credit report, and all this other stuff… so I have found that the county, all they're doing is putting it on paper and moving the money around from district to district. They're not doing what they say because I personally had an incident… and needed housing or needed emergency funds or food or I mean legitimate reasons… and I got the royal runaround. So I don't find that the county is doing enough. They say it, but then to qualify for these things you have to be in a—you almost have to be on life support to get services… and if you don't have money when you're on life support they're going to pull the plug.*
>
> [Female, Family member group]

Miscommunication about Medicare eligibility is another factor that contributes to disparities in coverage. One participant explained that he had been assured in error that Medicare would cover services, which he ultimately never received because they were denied.

They told me they were going to give me Medicare… And I went and I talked to them… nothing. I don't have Medicare. They told me they were going to give it to me. Nothing. They were going to come to my house and see me, so that I wouldn't have to go everywhere alone, because I'm alone a lot. And the medicine makes me sick. It makes me dizzy. And they've never come to my house… And they were going to give me Medicare and nothing. It was a total lie.

[Male consumer, Spanish-speaking group]

One participant remarked that sometimes administrators are so preoccupied with correctly billing Medicare and Medicaid claims that they don't respond appropriately to consumers' needs.

When I called a place and told them that I wanted to kill myself, they asked me a bunch of questions, 'MediCal or Medicare?' It's all they ask about…

[Female consumer, Spanish-speaking group]

Another participant observed that there is little recourse for consumers who are dissatisfied with county services. She found that complaints filed over the phone receive very little attention and had subsequently made it a policy to file all of her complaints in person, to avoid being dismissed by disgruntled and disingenuous employees.

If you've got a complaint against a service they ought to take the complaint more serious because some people are doing a job it's a job to them. They do their eight hours. If you talk to someone on the phone, they can tell you anything… they can tell you a lie on the Phone.

[Female consumer, Homeless group]

These unpleasant experiences with county services have left a lasting impression on the participants, their family members and their friends. Some believe applying for county services to be a fruitless endeavor, and this perception may be a deterrent for eligible consumers who need services. One of the family member participants mentioned that she has acquaintances who have chosen not to apply for services for this reason.

I know people right now who are getting ready to be on the street, but before they go to the county offices, they already know they aren't going to do anything… because of past failures… They're living in cars… They're living in garages and whatnot. Sleeping over in other peoples' homes and stuff, whatever they gotta do.

[Female, Family member group]

In their discussion of service gaps due to delays, extended wait times, and denial of eligibility, the participants drew from experiences with multiple county services, from mental health care to housing to financial assistance. Very few of them distinguished between mental health programs and other types of services. Many mental health consumers suffer from housing insecurity and

financial hardship and therefore have needs for other types of county-provided services.

Screening and diagnosis failures

Another service gap that some participants identified was that consumers are often diagnosed well after the onset of their mental illness. They discussed the complex nature of mental illness and the barriers that inhibit mental health consumers from seeking services themselves. Some mentioned the prevalence of risk factors for post-traumatic- stress-disorder in underserved areas, such as domestic abuse or gang-related violence. One participant observed that those who are affected by mental illness may not be able to readily distinguish the fact that the symptoms that they are experiencing are the result of a disease.

> *…a lot of these individuals probably do have a mental illness but they're not even diagnosed… They don't even know. Until they go and take certain classes they don't know the face of the symptoms or what happens when you're bipolar or when you have schizophrenia or post-traumatic stress. They don't even know what they're experiencing. Now a mother and/or a father whose children are taken away, you tell me that they're not depressed or they have fleeting thoughts and they're affected.*
>
> [Female, Family group]

Several of the Spanish participants shared that they first received mental health services after suffering nervous breakdowns. One participant describes this experience and explains some of the psychological barriers that inhibited her from seeking treatment before reaching a crisis.

> *I found out because, I didn't want to accept that I had mental problems no matter how many crazy things I did and umm… I had… a breakdown… I spent many years avoiding it, because I was in denial.*
>
> [Female consumer, Spanish-speaking group]

One problem that arises when people with mental illness are diagnosed late is that their pathway to recovery may become more burdensome. Those who go for extended periods of time without receiving services suffer from their condition and the social alienation that their condition causes. Often times the trauma associated with these events lead up to an involuntary psychiatric hold. One participant described this situation.

> *And then to be suffering with or going through a mental issue is not easy. It's not easy. It's a very difficult task left unnoticed or undiagnosed or untreated, you know, for them to have to, so then you get ostracized and then you have people calling you 5150 all the time, you know, name-calling and shaming which we're trying to erase all that. Because like I said, you're going to find with the days we're living in there's going to be a lot more people dealing with some form of post-traumatic stress, depression, suicidal tendencies…*
>
> [Female, Family group]

Involuntary psychiatric holds are not the only consequence when mental illness goes undiagnosed and untreated. Participants noted that consumers with a history of mental illness are also more susceptible to substance use disorders. Individuals with mental illness, who abuse drugs, are also prone to criminal activity, such as drug dealing or stealing, which often lands them in prison. One of the homeless participants recounted his pathway to recovery, which he reached by way of the penitentiary.

> *My mental problem I didn't know I had until I got over here to modification and behavior. I didn't know what that meant either at the time, you know, until I got in there. I broke every rule there was, you know. I came out the penitentiary into the program, because I didn't want to go back to the penitentiary. And I, like you, came to the conclusion that I was my own self's worst enemy and, if I wanted to stay out of the penitentiary, I had to do something about my drug habit.*
>
> [Male consumer, Homeless group]

Misalignment of substance abuse and mental health services

Across all focus groups, participants mentioned how critical it is to provide mental health and substance abuse services to the aging, homeless population. One participant offered several examples of ways in which homeless population is underserved and expressed concern about how ubiquitous this problem is.

> *I would like to add that I worry a lot about the homeless people. Because the majority of them have emotional problems. And I worry a lot about if there is something that could be done with them… Because they aren't homeless because they want to be there. A lot of them have problems with alcoholism and addiction in* [city name] *and* [city name] *or anywhere. I don't know if there's anything that can be done… But some of them are really old.*
>
> [Female consumer, Spanish-speaking group]

Participants from the homeless focus groups, many of whom had a history of substance abuse brought further insight into this situation. They discussed a variety of problems that they have observed, due to inappropriate or ineffective substance use disorder and recovery services. A frequent obstacle that they have encountered is when recovering addicts, who are working as counselors, suffer relapses. While substance use recovery programs strive to find counselors who consumers can relate to because they are in recovery themselves, sometimes these counselors succumb to their addictions and abandon their charges.

Another issue that occurs in drug rehabilitation programs is failure to appropriately respond when consumers themselves relapse. One participant observed an acquaintance relapse while in recovery and was disappointed to find that the recovery program still allowed him to graduate.

> *It's like real slack, real slack. I know this guy who went to a program in* [city name] *and he relapsed and he was the type of person when he relapses, you know, it's not just that he relapses. He does robberies and… all the behaviors come back, right, boom. He was in that program and he relapsed and they graduated him anyhow.*
>
> [Female consumer, Homeless group]

One family member, who works in health care, addressed the role of providers and how they must modify their approaches with patients who suffer from substance abuse disorders. She has observed some providers fail to take into consideration whether or not a patient is taking methadone or has a history of drug abuse, before prescribing certain medications. She mentioned that doctors are at times quick to prescribe opiates to methadone patients, despite the fact that it is unethical and ill advised.

The homeless participants described their experiences with methadone treatment at length. While many felt that it was a useful step toward recovery, others agreed that it was insufficient in regards to treating the mental health problems that often accompany addiction. One male participant from the homeless group observed that many drug recovery programs treat methadone as a substitute for therapy and do not provide the holistic care that a full recovery requires.

> *… that kinda bothers me because I been there and I see a lot of, a lot of things missing… It's the care… and just the whole nine yards. There's a whole lot missing because people are not getting what they're supposed to get out of this. You know, the medicine, the methadone does one thing but they don't have people there actually equipped to do what the therapists do.*
>
> [Male consumer, Homeless group]

Disparities in access to services and experienced providers

Another hurdle that the participants reported was limited access to mental health clinics, services, and experienced providers. Many report traveling several miles out of their own neighborhoods in order to receive necessary treatment.

> *I would like there to be doctors closer to home… my home or a closer clinic. I live in [city name]. I have to go to* [city name].
>
> [Female consumer, Spanish-speaking group]

Participants in the family member and homeless consumer focus groups, which were conducted in urban and predominantly African American neighborhoods, observed that access to services in their neighborhoods is not equitable. Several participants mentioned that there were certain geographic areas where services were abundant, while they felt that their local communities were being neglected. Two African American family members, one male and one female, expressed this frustration.

… we look to go downtown, but they right here. Everything we, they don't deal with, we don't deal with what's right here. We go upward and go deal with it. It's right here.

[Male, Family member group]

But once again, in downtown [city name] *is where all the services go. They want to put all the drug treatment centers there. They want to put all the housing there. Like every—what about here?... It's not here. It's not in* [neighborhood name].

[Female, Family member group]

A Latina family member made a recommendation for addressing the disparities that are affecting her neighborhood.

I believe you should have, next to a house of worship and a supermarket, you should have a facility in the neighborhood where somebody walking and going to church and going to the supermarket, and they're just walking and get walking services for mental health… Resources. Like a central location in the neighborhood. They'll put it over there, where they have to go six miles to get it. You know, have it in the neighborhood. And have people there and build them that work around a central hub. They need homelessness, they need resources for mental health…

[Female, Family member group]

Another disparity that the participants identified is that the providers to whom they or their loved ones are referred are often young and inexperienced. One family member explained that, when her mother is sent to a provider that is young and recognizably a recent college graduate, she is uncomfortable and unable to engage. She observed that inexperienced providers are frequently sent to the highest-needs areas, where they are unprepared to address the issues that consumers face.

Participants from both the family member and homeless focus groups identified the need for providers that have "lived experience." They felt that it was important for consumers to be able to relate to their providers and for their providers to have some of the wisdom that comes with age and firsthand knowledge of the therapeutic practices that best serve at-risk patients. One of these practices involves fostering an open discourse by treating therapy as an experience that both the consumer and provider can learn from. One family member, who is a therapist herself, described a strategy that she uses when working with homeless individuals.

As far as myself, I'm a therapist and I do work with all ages right now. I'm working with the homeless of various ages. And um, what I'm learning through this is when they come in and sit down, all they need is someone to talk to… I'd be asking them questions… Because I tell them: 'Each one, teach one'. Just because I sit on the other side of the desk, I'm open to learn

[Female, Family member group]

Improvement Strategies

In addition to discussing gaps in services, participants were asked to make recommendations for future improvement in service availability and delivery. They identified programs that they felt were successful and made various suggestions for how to introduce new resources to their communities or modify existing ones. While several of the Spanish-speaking and homeless participants listed the existing programs that they preferred, the family members spent more time exploring the development of potential innovations in mental health services for older adults. Specific strategies that they discussed at length included: the introduction of "community ambassador or mentorship" programs, mental health services that provide more opportunities to socialize, support groups and education programs for family caregivers, recruiting local providers, and being more responsive to older adult specific needs. They articulated the need for these services in their communities, the potential benefits that they could afford, and offered recommendations for how to develop and implement them.

Community ambassadors and mentors

As noted earlier, one of the major barriers that participants identified was providers who lacked the life experience and/or cultural competence to work with vulnerable populations. Several felt that providers from their own communities, who shared similar cultural or ethnic backgrounds, would be more effective. In addition to advocating for peer support services, some family member participants suggested the need for a "community ambassador" program that would position liaisons from the community to conduct outreach and promote mental health services. One family member offered strategies for organizing such a program and even expressed interest in spearheading it.

> *And now we're saying this is a big issue… to get some ambassadors going. And I think you guys got some good ones right around the table, where um, we can work together, network together, and go back to our different neighborhoods and communities… Because like we said we're just one, two, three, four, five, six, seven, eight people at one table from all over the place. We need to start educating our community, you know? If we want to break this chain… We have to start educating, especially our mental health because we have a stigma behind it… And the thing is and no disrespect, our community is going to listen to us in the end,* [more] *than you guys coming in here.*
>
> [Male, Family member group]

One specific outreach method that family members recommended for the ambassador program was partnering with community organizations and businesses to provide education, referrals and services to consumers. They observed that some older adults are averse to seeking treatment for both physical and mental health, and that promotional efforts implemented by clinics may not be reaching their target audiences. One participant reflected on the promise of a colon cancer screening program that had successfully utilized local barber shops for recruitment. She suggested adapting these strategies.

> *And I'm thinking how do you reach older adults because them are the ones that don't utilize health services. They don't utilize the doctor, they don't utilize no kind of facility.*

And so I think about, um, a few years ago when they were doing, um, I think it was colon cancer screening, they did it right here on [street name]. *Like in every barber shop right here, they had all the people right here because they knew the older adults weren't going into the doctor's office. But they going to go get a haircut. And so, when you saying how do we reach these people, how do we… You have to be able to use some people of their own culture and it has to be people from the community that they know and trust.*

[Female, Family member group]

One suggestion that was raised during the homeless focus groups was a mentorship program between older adults and youth. Several of them participants felt that their experiences with mental illness substance abuse and recovery could be utilized to help deter young people who were headed down a similar path.

We always talk to the younger generation.

[Female consumer, Homeless group]

It comes naturally for some of us to be able to, once you get your life in order, you know, it's such a wonderful, beautiful thing to know that you can be clean and sober and live like normal people… But today I wanna save these young people… We really shouldn't be here but we are… It's something we got to do. We got to do this because, if we was left here for no other reason, it was to bring up… the others that don't have a chance.

[Female consumer, Homeless group]

Opportunities to socialize

Another observation from family member participants was that many of the programs that their loved ones participated in didn't organize activities that involved socializing with others. One family member felt that opportunities to socialize would be a great benefit to her mother, who spends a significant amount of time at home and suffers from social isolation.

I think a good recommendation is socializing and engagement… my mom… just doesn't have anyone to even interact with… she doesn't have no one for her to even socialize with. And I think that if you just, if there was more socializing engagement then a lot of things could get better because she would have someone—just like kids. We send them to school and they learning different things. And she, at 60 years old, you'd think her just sitting in the house isn't a healthy situation either… And so that's one of the things that I wish mental health would do for older adults, is just be able to do some kind of socializing engaging…

Why can't they bring the older adults and take them to the beach? Or some kind of form of activity for them to do as a group to connect them with other people so they can socialize?

[Female, Family member group]

Some of the participants found that spirituality serves to counteract social isolation. One participant chose to begin volunteering at church, after succumbing to pressure from her daughter to get out of the house.

My daughter is always pestering me, 'Go! You have so much time to go somewhere. Go visit the elderly,' to go here and there… So I quietly went and signed up at the Catholic ministry… Now I'm hardly ever at home, always running around for church errands. But it helps me a lot because it fulfills me.

[Female consumer, Spanish-speaking group]

Another participant explained how he uses church activities as a tool to modify his own antisocial behavior.

A lot of times I avoid people. You know what I mean?... But I found that it's easier for me to have a relationship and attempt to know them. That's easier for me. It's so hard for me to avoid them… That's too hard on me and I'm the one causin the problem. So I'm gonna attempt to know somebody around here, you know what I mean? And I'm doing that everywhere, especially in church. You know what I mean? I don't avoid people.

[Male consumer, Homeless group]

While several participants across all groups discussed the opportunities to socialize at faith based organizations, they made little mention of social activities provided by mental health services. Clinical services, even support groups, do not always allow space for socializing. Furthermore, some consumers may associate support groups with uncomfortable conversations and emotional intensity. One Spanish-speaking participant suggested that support group facilitators try to close their discussions on a lighter note, by utilizing jokes and music.

I've always had the idea that the groups, if they last one hour, two hours, three hours, and they sometimes talk about nice things but a lot of the time they talk about negative things, so at the end why don't they give us fifteen minutes where there are jokes or songs or something that makes us laugh, that puts us in a good mood?

[Female consumer, Spanish-speaking group]

Music was a recurrent theme in the family members' discussions of strategies for encouraging socialization.

And whatever culture, you can put whatever type of music… music is the key.

[Female, Family member group]

And it helps with their walking, their circulation, their motor skills. And maybe if you put on music it might make them move and do something with a group of other people that they won't necessarily do in your house.

[Female, Family member group]

Like let them, not just BB King, but if we could a soul um, a soul train or something from the '70s, that kind of music I be seeing them on the bus. They've had their, the music going and they playing Al Green and the whole bus is rocking…

[Female, Family member group]

The family members felt that utilizing music and other amusing activities would serve to motivate their loved ones to get out of the house, exercise and engage with others. One participant offered several suggestions.

… you can't make 'em do anything, so we have to find ways how do you draw them in, you know, I mean 'cause you can't force them to do it… So that's where you, now you see all the different fitness crazes, the zumbas and the… swimming, the exercise in the chairs and you know they have certain dances and bingo and casinos. But I mean, it's more to it. This component, it brings them together, it gives them an outlet…

[Female, Family member group]

One of the family member groups engaged in a particularly rich discussion, during which they identified various possibilities for activities and outings that older adults might enjoy. A few of the highlights include trips to beaches, museums, recreational centers and thrift stores, dances and social hours with music, bowling, swimming, exercise, art or foreign language classes, mentorship programs with youth and communal meals.

Services for family caregivers

Across all focus groups, the participants discussed the influence of family and the critical role that it can play in recovery. Several of the consumers had family caregivers or relied heavily on family members for assistance and emotional support.

…If you need transportation, there was a time that I couldn't drive, my brother, my daughter and my son, they all brought me and picked me up and thank god I'm doing pretty well… yeah, family support is really important… In my case, I arrived at the clinic after a

breakdown in a psychiatric hospital and they sent me to [clinic name] and I was really lucky that everyone realized that my son came and brought me and waited for me. It's a type of support that no one else could provide. Something like that, no one else can do.

[Male consumer, Spanish-speaking group]

In discussing their loved ones' needs, several of the family member participants found themselves describing their own needs as well. Being able to discuss the burden of caring for an older adult with a mental illness in a safe space with others who understood these challenges appeared to have therapeutic effects on some of the participants. One male participant even suggested that they reconvene and start their own support group for family members.

I think all of us have a responsibility, that are sitting here, as much as we want to help them, we also need to come to a group and support one another… And that's what I'm getting out of this too, that maybe we all could exchange numbers somehow at the end of it or whatever and we all need it, I mean our own support group to… Like um, when you put somebody in for drug addiction or something, you also got the family members that are affected by it. And we need more groups so that we can come to the table and let our hair down, you know and talk about whatever.

[Male, Family member group]

In addition to identifying the need for emotional support, some of the family members expressed a desire for more information about their loved ones' diagnoses and how best to care for them. They also expressed the need for better education throughout their communities about caring for older adults with mental illness.

… we need to know, we need to be educated on what may be going on with our elders, with our grandparents or our loved ones.

[Female, Family member group]

Finally, family members outlined the need for programs to address the societal stigma associated with mental illness and aging. One participant commented on the county's role in reducing stigma.

The county is very up-front and open about the stigma and they always want to reduce the stigma, remove the stigma and let the clients know that you're not alone and don't be ashamed. And they do, [County X] *does an excellent job of removing the stigma. They have programs where they have different training programs for the clients.*

[Female, Family member group]

Recruit local providers

Another notable suggestion was that service providers be recruited locally, so that consumers can

be served by members of their own community rather than by outsiders. This would improve health services utilization in certain racial/ethnic populations because consumers would feel their providers understand them and their communities, understand their life story and the problems they deal with.

> *And we need more grassroot, nonprofit organizations instead of just giving it to these big corporations. We need inhouse. We need inhouse. And I'm finding that out, I worked, you know, like I said, in a lot of community agencies from mentoring, to gang intervention, to this, to that, to 12-step programs, to… And that's what it is. We need more grassroot, more where we care, where it's us. And even with us Hispanic, we're starting to break the color lines within now because we're starting to understand we have the same issues.*
>
> [Male, Family member group]

Be more responsive to the specific needs of older adults

Finally, one family member participant spoke about the need to be responsive to older adult specific needs. Specifically, she suggests that such responsiveness comes mostly when older adults are being supported and served by those who are most familiar to them, and most trusted. The closer one is to an older adult, the more familiarity there is with their routines, their habits, their preferences, and their needs. This in turn facilitates consumer compliance with treatment.

> *With mental disorders, if you're taking the medication, the proper medication, they're stabilized. And eventually, like what I do is try to wean them off in a sense to where they can cope. But when you're dealing with older people, they're sometimes stuck in their own ways, where you can't tell them anything. But the more time you spend around with someone, you can um, they can build a trust and maybe they'll listen. But I think more groups, groups, groups, groups, groups, groups, groups, groups!*
>
> [Female, Family member group]

Consumer- identified programs and strategies

Across all six focus groups, the participants mentioned a wide array of programs and strategies that they found to be particularly effective or successful, including:

- Home visits
- Support groups
- Crisis hotlines
- Volunteering
- Art therapy
- Biofeedback
- Alcoholics Anonymous and Narcotics Anonymous

- Spiritual guidance and faith-based organizations
- Sleep clinics
- Healthy relationships classes
- Financial management services (ie. automatic bill paying)
- Integrated services (ie. centers where consumers can receive medical, dental, mental health, housing, transportation, employment and other services all at the same location)

Participants also made recommendations for enhancing existing county services. Specifically, they advocated for:

- More partnerships with grassroots community agencies
- Use of diplomatic, non-stigmatizing language in social marketing campaigns for mental health services
- Hands-on outreach in the homeless community
- Frequent follow-up phone calls and home visits after physically or emotionally traumatic events
- Collaborating with law enforcement and educating officers about the needs of older adults with mental illnesses

Focus Group Findings: Summary and Recommendations

The focus groups produced information that both confirmed and supplemented what we learned through the earlier secondary data analyses and key informant interviews conducted for this study. Importantly, the focus groups significantly increased representation of the consumer and family member voice, which strengthened our methodology, while also aligning well with the MHSA commitment to stakeholder involvement in all aspects of MHSA planning and implementation.

The focus group composition by participant type, the specific locations of the focus groups, and the dynamic nature of group discussion and processes all contributed to the discovery of both new and more in-depth content. These data are helpful in addressing our primary research question concerned with the progress made toward implementing an integrated and comprehensive system of care for older adults with serious mental health needs. While changes over time cannot be explicitly measured with these focus group data, the older adult participants are effectively a living representation of time passed living with mental illness. All focus group participants are older adult consumers or family members of older adult consumers who are currently being served through the public county mental health system. As participants reflect on their experiences over time, the narratives are much more than "point in time" data, and illustrate a life course perspective and experience by virtue of the older adult's recovery and survival.

In addition to assessing progress in the development of a system of care vis á vis the "lived experience" of older adults and their families, the focus group data also provide supplemental

information about certain topics for which the earlier methods yielded limited data, including homelessness, substance use, the role of the family and religion/spirituality in recovery, and the impact of historical and collective trauma experienced by participants, the vast majority of whom are members of racial/ethnic minority groups.

The focus group data also address the research questions concerned with identifying barriers, facilitators, service gaps, and strategies for improving a system of care for older adults. The narratives illuminate what matters most to consumers and family members, including where services work well to support their goals and preferences for care, and where they fall short. The participants provide personal and compelling "real-life" examples that articulate the need to account for the broader social context in the delivery of services, and highlight the numerous barriers and facilitators they experience when accessing care. Finally, the focus group participants offer thoughtful strategies and recommendations for improving the mental health service delivery system to better accommodate the specific needs of older adults.

Observations across Groups

First, it is important to note that the focus group participants are currently and actively engaged in the mental health delivery system, and therefore their narratives reflect a specific point of view and experience. Most participants are low-income residents of underserved inner city areas and survivors with a lifetime of exposure to abject poverty, drug epidemics, and violence. These raw realities brought forth a depth of insight and truth that the participants shared with us in a most open and compelling manner.

Overall, we found that participants were very articulate, quite candid, and possessed a wisdom born of experience. They shared histories of both individual and collective trauma: individual trauma in the form of dysfunctional families, violence, addiction, incarceration, and collective trauma as evidenced by the sociopolitical context in the underserved communities in which they live, particularly as minority group members who have experienced generations of exploitation and neglect by the system. We were repeatedly reminded of the importance of keeping the whole life stories and broader social context in mind: it really matters and has shaped each consumer's experience, often in profound ways.

All groups went beyond a narrow discussion of mental health service delivery, bringing in examples of other publicly delivered services, informal community support networks, and observations about sociopolitical and other factors that provided the backdrop to their experiences as consumers or family members of consumers of mental health services. Participants don't think or live in silos of service delivery – their perspective is holistic in the same way that the OASOC is intended to be. As such, much can be learned from tracing their pathways to care, and considering the factors that they identify as barriers or facilitators to care.

Finally, both types of consumer participants (i.e., Spanish-speaking and homeless) were generally

very positive about the services they are receiving from the host organization (i.e., the focus group venue). While this is a clear limitation of our convenience sampling, the sincerity of gratitude and satisfaction expressed by so many consumers was hard to dismiss as lacking in significance.

Observations within Groups

While we found commonalities *across* groups, there were also some observations *within* groups that are important to note. Interestingly, the views expressed by consumer and family member participants were usually in concordance with each other. There were very few instances of outright disagreement. Conversely, there were numerous instances when one participant began a particular narrative or contributed a specific opinion that triggered a cascade of other responses. In addition to offering words and nods of agreement, others joined the conversation to provide illustrative examples, add nuance, or further explore different dimensions of the same topic.

Spanish-speaking consumers

The role of religion was quite central to the identity of many of the Spanish-speaking consumers and, on average, more emphasized than by other focus group types. For some, references to religion were closely connected to the consumer's process of recovery. Religious participation was more explicitly connected by the Spanish-speaking consumers to the idea of making a contribution through working or volunteering, while also remaining socially engaged as a benefit to oneself and to others. Spanish-speaking participants also tended to take a more collective "We" vs. "I" approach to recovery – through family, friends, peers, church, and community. In general, they appeared less identified with the concept of "individual goals" of recovery and many struggled with some of the questions posed, in particular, those that had to do with individual goals of care and whether their providers understand what is important to them.

The role of family in connecting consumers to care and supporting their recovery was also quite central to our discussions with Spanish-speaking consumers. They spoke about the importance of providers who recognize and encourage this aspect of social support. Some also discussed family as a part of the mental illness (i.e., others in the family suffer, strife and trauma - difficulties associated with family). In addition to - or in the absence of - family, other social groups where consumers could safely share experience of mental illness, substance use, homelessness (e.g., at church or in the community) were also highly valued.

Homeless consumers

While the homeless participants also considered church and family as part of their service/support network, their discussions of religion were most strongly connected to recovery from addictions, less about mental illness recovery, per se (which was more the description provided by the Latino participants). They also more frequently discussed individual level trauma in the context of collective, societal trauma, taking a broader view of systems issues affecting their entire community. This collective view further extended to descriptions of their experiences within the mental health delivery system, which were framed in the context of historical and social factors such as racism,

generational poverty, lack of community resources, urban blight, violence, and drug epidemics. At the same time, the homeless participants observed the role of personal responsibility, especially when discussing substance use and addiction.

Family members

Family member groups were the most outspoken about deficits in the mental health delivery system and in public services more generally. They took a broader focus in their discussion of public services than either of the consumer groups, going beyond the mental health delivery system to include social services, housing, and other county services. Like the homeless groups, they discussed the lack of resources in the community/neighborhood that affects delivery and access to care. They also discussed the need for solutions that come from and are implemented from within the community. including providers who come from the community, who "look like them" and will understand them better and be more responsive.

Recommendations

In earlier reports produced from this study, we made recommendations based on analyses of secondary data and key informant interviews. Here we make recommendations that are specific to what we learned from the consumers and family members who participated in our focus groups.

Offer information and services from trusted and compassionate sources

- Engage local medical, social, and legal institutions, as well as churches and social services and other community-based programs, to play a key role in disseminating information about mental health services for older adults.

- Reduce the bureaucratic barriers that discourage consumers and family members from seeking access to care. Work toward an entry system that is straightforward and simple for consumers and their family members to navigate and reduces the duplication of application processes and paperwork.

- Recruit, employ, and train providers about older adult mental health services who are from the local community and know how to connect with consumers, who show *"heart"* and convey their concern to consumers who are older than they are or come from different backgrounds and life experiences.

Support the role of family and/or spirituality in recovery

- Create and support more opportunities for consumers and family members to connect with one another; design activities that bring family members and consumers together.

- Develop formal services that recognize and support the important role that family members play in consumers' lives, through education and counseling for family members.

- Incorporate family concerns into treatment plans and goal-setting with consumers that includes reunification plans, as appropriate.

- Identify and support the religious/spiritual practices and traditions of consumers, both in individual treatment and in group practice and program settings.

Provide more opportunities for one-stop shopping

- Integrate the delivery of physical health, mental health, and substance use services through co-location and through interdisciplinary teams.

- Increase access and linkages to substance use disorder and recovery programs that are essential to effective mental health services. Once in recovery, ensure that mental health services are available and tailored to also meet consumer needs as recovering addicts.

Conclusion

To learn more about how older adult consumers and family members are currently being served by the MHSA and public county mental health system in California, we conducted a series of six focus groups with: 1) Spanish-speaking older adult consumers, 2) older adult consumers who were currently or had previously been homeless, and 3) family members of older adult consumers of mental health services. In the course of these rich and in-depth discussions, participants highlighted the importance of being part of a broadly defined "community" that provides opportunities for social engagement through support or peer groups, identification with a specific and local geography or neighborhood, and/or through church or other faith-based activities.

Participants also talked at length about the important roles that family and religion/spirituality play in their (or their family member's) process of recovery from mental illness and substance use disorders. Family members (whether biological or chosen) were often instrumental to the consumer's entry to care, providing the information and encouragement that consumers needed to seek out and access available services. They were also central to the consumer's continued recovery as they provided ongoing support and sometimes served as role models, often across generational divides. Similarly, participants emphasized that their religious/spiritual beliefs provided an essential source of strength and fulfillment along the path to recovery.

To improve the delivery of mental health care to older adults, the public mental health service delivery system should aspire to better align itself with the consumer and family member needs

and preferences identified in this report. Systems-level delivery processes and programs that are responsive to the expressed needs of older adults and their families can leverage and enhance existing social support networks that already bolster individual-level recovery. We learned from our participants that a sense of community, support from family, and grounding in one's religious/spiritual beliefs all contribute to a sense of purpose and a source of social connection for older adult consumers of mental health services. The lessons learned can be used by counties to improve older adult access to mental health services. The consumer and family member "voice" shared through these focus groups suggests ways to reduce the factors that impede their recovery, and multiply the factors that support their recovery by recognizing the social context in which older adult consumers are situated and to address the more holistic needs that they have identified.