

**STATE OF THE STATE IV:
2013-2014
Reducing Disparities in Mental Health
Refugee/Asylees and
Individuals with Intellectual/Developmental Disabilities**

California Mental Health Services Act Multicultural Coalition
A project of the Racial and Ethnic Mental Health Disparities Coalition
Mental Health Association in California

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Acknowledgments

The California Mental Health Services Act Multicultural Coalition (CMMC) would like to express appreciation to the many individuals who contributed to the State of the State IV: 2013-2014 Reducing Disparities in Mental Health report, which brings awareness to the concerns and needs of the Refugee/Asylee communities and Individuals with developmental disabilities and intellectual challenges. This report is one of many deliverables of the CMMC to be submitted to the California Department of Public Health, Office of Health Equity. First and foremost we would like to acknowledge and thank our consultant and key writer, Katherine Elliott, as well as our graduate student intern, Diana Johnson, for their skills and expertise in crafting this report. We would also like to thank CMMC MAC (MHSA Assessment Committee) members Beatrice Lee, Gulshan Yusufzai and Michelle Alcedo, as well as staff Noemi Castro, for coordinating and conducting Key Informant interviews. Finally, we would like to especially acknowledge and thank the nine Key Informants who participated in this study. Through their dedication and tireless work, they have developed a deep understanding of the critical issues. We are grateful for their willingness to share their time and wisdom with us and for lending a voice to these critical issues and their communities. Thank you!

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Executive Summary

The annual “State of the State” Report on Mental Health Disparities is an effort by the California Multicultural Mental Health Services Act Coalition (CMMC) to shed light on current issues that affect mental health for diverse ethnic and cultural communities and Lesbian, Gay, Bisexual, Transgender, Queer and Questioning (LGBTQ) groups in California. In addition, the CMMC seeks to bring awareness to issues that affect groups that experience disproportionate and unfair exposure to adverse social and economic conditions. In this, the fourth “State of the State” report, the CMMC explores the needs and challenges of two groups: Refugee/Asylee communities (RA) and Individuals with developmental disabilities and intellectual challenges (DDIC). This report is a brief qualitative study intended to raise awareness regarding the challenges faced by the communities, the mental health needs, and the existing resources for individuals from these communities. These efforts are part of an ongoing process of connecting and building relationships with un-, under-, and inappropriately served communities throughout the state of California. A further limitation is that this paper did not address the historical overrepresentation of minorities in special education, an issue pertinent to individuals with DDIC. Future research may drill down, examining the inequities in placement in special education specific to minorities within DDIC communities.

Key Findings:

Interviews with four key informants regarding refugee and asylee communities revealed the following key themes related to community needs and challenges, specific health and mental health concerns, assets, and recommendations.

- *Resettlement Difficulties* One of the most prominent themes that emerged from the interviews with key informants was the impact of resettlement difficulties on refugees and asylees. Obtaining employment and financial security, establishing new social networks, and navigating bureaucratic systems are all significant challenges which affect the ability of refugees and asylees to resettle successfully and overcome traumatic experiences suffered prior to resettlement.
- *Cultural and Historical Factors* Experiences prior to resettlement may include extreme deprivation and exposure to intense violence and combat. Some refugee and asylee communities may have histories of political conflict within or between ethnic groups. Still other communities may have widely differing views of health, mental health, and treatments. These factors affect the health, mental health, and well-being of refugees and asylees and affect their willingness to reach out to community members or social service providers for help.
- *Specific Mental Health Problems* For refugee and asylee communities the chief mental health concern is post-traumatic stress disorder. In addition, challenges of resettlement as well as losses related to the flight from their home country may contribute to the development of depression, anxiety, substance abuse, and intimate partner violence.
- *Special Populations* Resettlement may be particularly difficult for women, who often have responsibility for maintaining family functioning both financially and emotionally.

In addition, older adults may experience isolation in resettlement due to loss of community and language barriers.

- *Assets and Recommendations* The resilience and strength of refugees and asylees in the face of extraordinary trauma and loss is a key asset for these communities. Participants recommended utilizing existing community resources such as community leaders and faith based organizations to provide prevention services to refugee and asylee communities. Services should focus on improving awareness of mental illness and treatments as well as providing health promotion for victims of trauma to prevent the onset of mental illness. Finally, improving access to services in the refugee or asylee's primary language was recommended. Key informants suggested that existing resettlement programs should be strengthened as they are understaffed and overburdened.

Key Findings:

Themes that emerged in interviews with five key informants for individuals with developmental disabilities and intellectual challenges (DDIC) included: financial hardship, lack of access to care, specific mental health problems, and concerns for vulnerable groups. Key informants also identified community assets and recommendations for improving conditions for individuals with DDIC.

- *Financial Hardships* Attaining and maintaining financial independence and security are key concerns for individuals with DDIC. There is a dearth of supported employment programs to assist individuals with DDIC. Financial insecurity often leads to homelessness and obtaining subsidized housing for individuals with DDIC is challenging.
- *Lack of Access to Care* Several factors prevent individuals with DDIC from accessing health and mental health services including lack of awareness or knowledge on the part of the individual with DDIC, lack of provider understanding of DDIC issues and reluctance to provide care to individuals with DDIC, reliance on care providers to advocate for health and mental health needs, and provider biases and cultural stigma regarding individuals with DDIC. Recent budget cuts have drastically reduced the availability of social service programs available to individuals with DDIC.
- *Specific Mental Health Problems* Key informants identified a prevalence of depression, anxiety, social isolation, and dementia for individuals with DDIC.
- *Special Populations* Older adults and women with DDIC may face specific challenges. In particular, isolation experienced by older adults with DDIC may be profound. Women may face difficulties with health care as many providers may lack the experience or knowledge necessary to conduct a physical exam with a patient with DDIC. Women with DDIC are also at heightened risk for sexual exploitation and abuse, and may face greater challenges obtaining employment.
- *Assets and Recommendations* The state Regional Center Program, the statewide mandate for services for DDIC instituted by the Lanterman Act, and peer run programs were viewed as a critical resources for individuals with DDIC. Recommendations centered on

improving coordination of care across county mental health departments and Regional Centers and providing education and training to providers to improve care for individuals with DDIC.

Limitations and Summary

Given the scope of the current study, results may not be broadly generalizable to all refugee and asylee communities. In particular, as informants for RA communities were primarily from Northern California, the key themes may not reflect issues relevant to RA communities residing in Southern California or other areas. Similarly, key informants for individuals with DDIC did not address the intersection of identities, and the impact of membership in more than one vulnerable group such as DDIC *and* African American or LGBT. Nonetheless, the current findings provide a starting point for identifying critical issues for RA and individuals with DDIC. Further, they illustrate the importance of conducting ongoing outreach and engagement with communities that are new or that have hitherto been left out of mental health policy setting.

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Background and Introduction

In 2004, California voters passed Proposition 63, now known as the Mental Health Services Act (MHSA), which placed a 1% tax on income over one million dollars to fund mental health services, programs, and infrastructure. The MHSA generated funds for the transformation of California's mental health system through the implementation of innovative, comprehensive, family and community driven, culturally competent, and recovery oriented approaches to mental health. As part of this system transformation, the MHSA made an unprecedented investment in programs focused on prevention of mental illness through a funding allocation entitled "Prevention and Early Intervention" (PEI). Embedded within PEI was a groundbreaking project aimed at addressing disparities in mental health for ethnic and cultural minority communities, the California Reducing Disparities Project. The CRDP is a multi-pronged initiative that includes the formation of the California Mental Health Services Act Multicultural Coalition (CMMC), the implementation of a statewide community engagement project intended to gather information on needs of communities and community driven approaches to mental health, and the development of a strategic plan to address disparities based on the findings of community engagement efforts. This report is a part of the work of the CMMC.

The CMMC is a coalition of community providers, community leaders, consumers, and family advocates whose mission is to reduce disparities in mental health for minority communities through advocacy, education, and leadership. The CMMC conducts several activities in pursuit of the goal of reducing disparities, including the implementation of an emerging leaders program and the development of policy statements and advocacy materials. Another key activity of the CMMC is to prepare the "State of the State" annual reports, which provide a snapshot of mental health disparities in the state of California.

The CMMC has focused the annual "State of the State" reports on studies that increase awareness of "invisible" communities: those that have not previously been the topic of statewide research, policy, or service provision. These studies are intended to complement the work conducted by another MHSA funded project administered by the California Department of Public Health, Office of Health Equity: the California Reducing Disparities Project (CRDP) special populations studies. The CRDP effort identified five historically marginalized communities: African American, Asian Pacific Islander, Latino, Lesbian, Gay, Transgender, and Questioning (LGBTQ), and Native American communities. Through a comprehensive community based participatory approach, the CRDP developed five special population reports which identify the needs of these communities and survey community based effective approaches for addressing these needs.

The CMMC sought to complement the CRDP Special Populations Reports by exploring the needs of communities that had not been surveyed. This objective is consistent with the value of multiculturalism and is one of the foundations of the CMMC's work. Further, it addresses the ever-changing social landscape of California communities in its recognition of emerging needs, trends, and groups that face inequitable conditions.

Previous State of the State reports have focused on ethnic and cultural communities such as

Armenian, Russian-speaking, Middle Eastern/Southwest Asian, and the Deaf and Hard of Hearing communities. In the current report, the CMMC ventured outside of this paradigm and surveyed groups that do not represent distinct cultural or ethnic entities - that is they don't have a culture in common. Instead this report focuses on groups that - by virtue of their common experiences - have historically lacked access to health and mental health services, and have faced inequitable social and economic conditions. This departure represents a focus on social justice which, does not diminish the overarching goal of reducing disparities for diverse ethnic and cultural communities and for LGBTQ groups but rather complements it. The current report focuses on the needs and challenges of refugees and asylees (RA) as well as individuals with developmental disabilities and intellectual challenges (DDIC).

Methods and Participants

To gather information on the socio-cultural background, history, mental health needs, cultural strengths and assets, and barriers to care of the two selected communities, the Mental Health Services Act Assessment and Recommendations Committee (MAC) conducted a brief qualitative study. Four key informants were interviewed for the RA community and five key informants provided information for individuals with DDIC, with all interviews lasting approximately 1- 1.5 hours. To recruit key informants, MAC members reached out to others in the CMMC as well as organizations and programs (such as the Regional Centers) and colleagues. Interviewees were contacted by email and by phone and were provided with a description of the study and a copy of the interview questions in advance. Prior to the interviews, the interviewers and researcher discussed the interview protocol and interview techniques to ensure interviewers elaborated on key concepts. During the telephone and face-to-face interviews, the interviewer thanked the participants, briefly described the purpose of the project, the interview, and the benefits of their participation. Each interview took approximately 60 minutes to complete and a note taker took extensive notes. Although previous key informant interviews have been conducted in other languages, for the current study all participants were fluent in English and thus the interviews were conducted in English. Only with the permission of the participants, interview sessions were audio recorded for accuracy. Each participant who agreed to be audiotaped provided a verbal consent. According to Stringer (1999), in qualitative research, it is essential to first build rapport with the participants before engaging in interviews and taping. Therefore, prior to asking the questions related to the study, the interviewer engaged in casual discussion in order to build trust or used open-ended questions that started with "Tell me about your community..."

Interview Questions

The interview questions were designed specifically for the project's purpose, yet broad enough to capture unexpected but related concepts (Strauss & Corbin, 2007). The thirteen open-ended questions were intended to explore the views, opinions, and experiences of communities that have historically been unserved/underserved. These questions were: (1) Tell us about your role in your community. (2) Tell us about your community. (Consider asking about history, geographic distribution, socioeconomic issues, acculturation, etc.). (3) What are some of your community's greatest concerns? (4) What do you think are your community's greatest concerns around mental health? (5) Where do people in your community go for help when they have emotional concerns or are worried about a family member with emotional, relationship, or social

issues? (6) What services or programs are available in your community for social and emotional issues (mental health problems)? (7) What barriers exist to accessing services for your community? (8) What kinds of challenges do women in your community face? (9) What kinds of challenges do older adults in your community face? (10) Are there any other groups within your community that face specific challenges? (11) If we had the opportunity to develop programs and services to prevent or treat mental health problems, what recommendations would you give us to do this? (12) Tell me about strengths or assets of your community. (13) Any additional advice that you have regarding mental health?

Participants

To gather information on the needs, concerns, community assets and recommendations for programming, the MAC committee members interviewed nine key informants: four key informants representing RA communities, and five key informants representing individuals with DDIC. With regard to RA communities, the MAC committee interviewed informants from four community-based organizations, including two Sacramento agencies, one from the Central Valley, and one in the Bay Area. The first Sacramento-based consultant serves refugees and asylees from Eritrea, Iraq, Iran, Burma, South America, Southeast Asia, Moldavia, Ukraine, and other regions of the former Soviet Union. The second informant from Sacramento works as an executive director for a community-based organization that primarily serves veterans, refugees and asylees from Afghanistan, Kyrgyzstan, Iran, Latin America, Romania, and Russian-speaking nations. Key informants also included a consultant with several years of experience in the Central Valley, primarily serving Hmong, Mien, Lao, and other Southeast Asian communities. Finally, the MAC committee consulted with an informant from a Bay Area community-based organization that provides services to a wide array of refugees and asylees including those from Iraq, Iran, Afghanistan, Eritrea, Burma, Bhutan, the Republic of Congo, and Sri Lanka. Key informants for Individuals with DDIC included a Director of Programs, Development, and Communications for an Independent Living Resource Center, a service coordinator for a program that provides art therapy and resources for individuals with DDIC, a coordinator and Chief of one of the 21 statewide Regional Centers, an executive director for a state advocacy organization for DDIC, and a Clinical Director for another one of the 21 Regional Centers.

Data Analysis

Data analysis followed the interview sessions. After transcribing the notes of each interview session, two members of the research team began coding the transcript/notes to identify themes or patterns in the data. Specifically, when analyzing the data, the researchers extracted significant viewpoints and opinions from the transcripts/notes and began looking for categories through a process called open coding, which means forming initial categories of information about the phenomenon being studied by segmenting information (Creswell, 1998). Then using axial coding, the author was able to organize the data in order to obtain a holistic picture of participants' views and opinions. Creswell describes axial coding as a process used to establish themes and patterns in order to build a meaningful story. After the researchers and MAC member read all the individual transcripts/notes marking meanings and themes, each developed a list of possible themes. The group met to discuss the possible themes representing the

participants and stopped when consensus was reached.

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Refugee/Asylee Communities

Definitions:

According to both US and international law, refugees and asylum seekers are defined as individuals who seek refuge from their country of origin due to a well-grounded fear of persecution. According to the 1949 Geneva Convention, this “well-grounded fear” must pertain to five general characteristics: fear of persecution based on race, religion, nationality, membership in a particular social group, or political opinion (CRS Report, 2005). According to Human Rights Education Associates, the primary reasons refugees/asylees leave their countries include war, religious, ethnic, or tribal violence. Refugees and asylees are not able to return to their countries of origin due to threats to their physical safety. In contrast to refugees, asylees typically arrive in the US prior to obtaining legal refugee status.

In addition to refugees and asylees, the California Office of Refugee Health recognizes several other groups of individuals who may be eligible for refugee services. These include Cuban and Haitian Entrants, Victims of Human Trafficking, Amerasians (individuals who were born in Vietnam between 1962 and 1975 fathered by US citizens), and Afghani and Iraqi Special Immigrants (individuals displaced from Afghanistan and Iraq who provided services for the US during times of conflict) (California Office of Refugee Health, 2013).

Of note, there exists a third group of individuals who come to the US fleeing from persecution but do not seek refugee, asylee, or special status. These individuals may continue to be fearful of the disclosing their identity, they may be reluctant to undergo the process of describing and often re-experiencing their trauma (required to obtain refugee/asylee status), or they may be distrustful of the government entities. They comprise a largely invisible group for whom services are virtually non-existent and levels of distress and suffering are high.

This qualitative study seeks to elucidate cross-cutting issues that affect the many refugee/asylee (RA) communities in California. In general, the term RA will be used in this text to refer to all individuals in California who seek refuge from persecution in their home countries including individuals with special status (Cuban and Haitian Entrants, Special Immigrant Visa, or Victims of Human Trafficking) and individuals who have not received special status but reside in the US without documentation. When noted, this study will identify concerns that are unique to groups from specific countries of origin (such as Iraqis or Hmong) or groups with special concerns (such as women, children, or LGBTQ).

Demographic Information:

The United States is one of 17 countries that currently accept refugees and asylees for permanent, rather than temporary settlement and in 2009 the United States accepted more refugees (60,191) than all the other countries combined. Since 1975, 700,000 individuals with designated refugee status have arrived in California (Immigration Policy Center, 2010; RFP Fact Sheet, 2013). Prior to 1990, the greatest influx of refugees came from Southeast Asia: Vietnam, Cambodia, and Laos. Currently, the greatest number of refugees come from

Iran, Southeast Asian, the former Soviet Union, Iraq, and Africa. Other refugee communities residing in California include Bhutanese, Somali, Chinese, Burmese, and Afghani. Large communities of refugees have resettled in Los Angeles, Fresno, Orange County, San Diego, Sacramento, the San Francisco Bay Area, and Merced.

History:

In 1948, in an effort to alleviate the mounting needs of refugees from World War II, the United Nations Universal Declaration of Human Rights (and later, the 1949 Geneva Conventions) cemented refugee and asylee status into international law, declaring that "Everyone has the right to seek and to enjoy in other countries asylum from persecution." Two years later, the UN created the office of the High Commissioner for Refugees, the first international governmental organization to address the displacement and coordination of refugees. The United States prolonged adoption of UN policies, however as the 1950s progressed and the Cold War heightened, the US passed laws to accept refugees from communist and socialist countries. As of 1967 the United Nations Protocol Relating to the Status of Refugees extended refugee status to all nations while also declaring that, "Countries signing the treat[y] agree never to return a refugee to a country where he or she fears persecution" (CRS Report, 2005). The United States ratified this agreement, but continued to accept refugees and asylees from communist nations exclusively (Constitutional Rights Foundation, 2012).

During the late 1960s, American conflict in Vietnam, Cambodia, and Laos broadened the acceptance of those seeking refuge from communist nations. Thus, "From 1946 through 2000, the United States gave legal permanent resident status to 3.5 million refugees, asylees, and other humanitarian entrants. Over half (53%) of all of these refugees and asylees were from three countries: Vietnam (19%), Cuba (18%), and the former Soviet Union (16%)" (CRS Report, 2005).

A turning point arrived in 1980, when the United States finally wrote into law the refugee policies of the Geneva Conventions, expanding refugee status to all persons. At the same time, the Reagan Administration implemented stricter numerical policies with regard to both immigration and the admission of refugees under the 1980 Refugee Act. No official cap was placed on asylees, but refugees were now limited to 50,000 per year in the United States (Constitutional Rights Foundation, 2012).

With the fall of the Soviet Union in 1989, refugees continued to relocate from Eastern Europe, but the ceilings for acceptance began to fluctuate at the discretion of Congress and the President. During the mid-1990s and early 2000s, residents of Bosnia-Herzegovina, Yugoslavia, Cuba, and Ukraine accounted for roughly 55% of all refugees seeking residence in the United States. However, for the first time President Clinton limited protections for asylum seekers through the Illegal Immigrant Reform and Immigrant Responsibility Act of 1996.

Most recently, American policy toward refugees and asylum seekers has continued to reflect levels of political upheaval around the world. In the post-9-11 climate, tensions heightened over accepting refugees that may pose potential security risks. In 2001 the annual cap for

refugees rose to 80,000, but due to lengthy new security measures, 10,000 of these slots remained unfilled (Constitutional Rights Foundation, 2012). The President and Congress continue to meet each year to determine the number of permitted refugees and asylees and the acceptance of both groups parallels current levels of conflict in places such as the Middle East and Africa. As of 2013, the largest numbers of refugees came to the United States from Iran, Southeast Asian, the former Soviet Union, Iraq and Africa (RPP Fact Sheet, 2013).

Literature Review: Health and Mental Health Needs

The research literature focuses on three phases in the refugee process that have a significant impact on health and mental health: the preflight phase, the transit phase, and the resettlement phase. Experiences during these phases vary widely among refugees and thus health and mental health needs may also vary. For example, in the preflight phase, many RA communities have intense and/or prolonged exposure to extreme violence (witnessing the massacre of family members, involuntary participation in combat, etc.) while others do not have direct exposure to conflict-related violence. Thus, depending on their level of involvement in combat situations, some refugees may experience intense post-traumatic psychiatric distress, while others may have relatively low levels of distress (Lustig et al., 2004; Hsu et al., 2004; Asgary 2011).

With respect to experiences in transit, many RA individuals do not come directly from their country of origin and instead spend varying amounts of time in temporary residence in refugee camps. In some camps, RA individuals may experience deprivation - limited access to food, health services, sanitation, and education- as well as violence and exploitation. They may arrive in the US with numerous health problems and/or psychological trauma and many may be fearful or lack trust in government systems. Further, some asylum seekers experience sexual assault, physical assault, and exploitation in the journey to the US. Several studies have documented the prevalence of traumatic experiences for individuals crossing the border to the US from Mexico (e.g. Eschbach et al., 1999). In addition, some RAs are held in detention facilities for extended periods of time while their cases are adjudicated. These individuals may suffer an array of physical and psychological problems including anxiety and depression, post-traumatic stress, and physical injuries.

Experiences of resettlement may vary widely for RA communities. RAs who have higher levels of education, exposure to Western culture and systems, and English language skills may be able to adapt to life in the US relatively easily. They may obtain employment and become integrated into new communities. For RAs without these experiences and skills, common tasks such as going to a bank or taking a bus may be unfamiliar and daunting. Finding employment, learning English, and forging new social networks may seem like impossible tasks to these individuals. These difficulties may lead to feelings of shame, isolation, hopelessness, loneliness and depression.

Despite these differences, many mental health and physical health problems are common across RA communities. In particular, post-traumatic stress disorder (PTSD) as well as post-traumatic symptoms (nightmares, agitation), depression, and anxiety are highly prevalent. In addition, panic attacks, adjustment disorder, and somatization (or the physical expression of mental health concerns) are common. Documented rates of psychiatric diagnoses range from 10-40% for

PTSD and 5-15% for depression. In children rates are higher; PTSD diagnoses are found in 50-90% of RA children and depression is found in 6-40% (Refugee Health Technical Assistance Center, 2011). As noted above, factors that increase the risk for the development of mental illness include stress and trauma (delays in obtaining legal refugee status, stays in detention facilities, and a greater number and intensity of traumatic experiences) and resettlement difficulties (unemployment, limited language proficiency, isolation, difficulty navigating unfamiliar systems, grief, and poverty).

Special Populations: Vulnerable groups such as women, children, and LGBTQ individuals may experience particular challenges. For example, many women and children experience physical and sexual abuse preflight and during transit. They may sustain significant physical trauma, and require medical care and reproductive health interventions.

For children, separation from caregivers may occur at any point during the displacement. This separation may greatly exacerbate the experience of trauma. Furthermore, a number of children and youth arrive in the US as unaccompanied minors and lack documentation. They may have experienced violence, torture, exploitation, combat, and deprivation. Often these minors are held in detention facilities for varying and sometimes lengthy stays while their case is adjudicated. Children may miss years of school. Given the prevalence of trauma and the lack of any family or social support, these children and youth are at particular risk for the development of mental health problems (Lustig et al., 2004).

LGBT individuals who seek refuge due to their sexual orientation or gender identity may experience continued persecution or fear of persecution even after arriving in the US. For example, they may worry that government entities from their country of origin will pursue them in the US and persecute them further. In addition, they may experience continued rejection from their community in the US. They often lack the support of family and community and are reluctant to disclose their sexual orientation or gender identity. This situation leads to extreme isolation and fear (Shidlo & Ahola, 2012).

Findings for Refugee/Asylee Communities:

Four key informant interviews were conducted with individuals who have experience working with refugee and asylee communities. When asked about the needs and challenges for RA communities, key informants identified difficulties in resettlement, specific health and mental health needs, cultural and historical influences, and a general lack of resources. Participants also discussed strengths and assets of their communities as well as recommendations for improving conditions for RA groups.

Resettlement Difficulties

One of the most common themes raised across interviews was the prevalence and profound impact of resettlement difficulties on RA. Most notably, poverty and financial insecurity was experienced by a majority of RA and was described as deeply oppressive. RA are eligible for cash assistance programs that are available to US citizens (such as CalWORKS, MediCal). For those who may not have access to these programs because they do not have children, 8 months of

cash aid is provided as well as employment assistance. However, according to key informants, 8 months of aid is not enough to ensure financial stability and many RAs find themselves destitute after aid is discontinued. Despite employment assistance programs, many are unable to secure stable employment. One key informant stated,

“They must find rapid employment. They are helped, but even when they are depending on the public safety net or put in their first jobs its not enough to make ends meet. The greatest concern, they are always worried that they are not going to pay the rent. That persists for many years.”

Limited English proficiency is a significant barrier to obtaining work. While many resettlement agencies provide English language lessons, attaining the level of proficiency in English sufficient to enable employment is an almost impossible task. As one key informant described, “the existence is truly hand to mouth, month to month.”

Furthermore, many RA have difficulty with navigating systems and bureaucracy in the US. Whether coming directly from a country of origin in which an agrarian lifestyle is common, or a refugee camp where there was very little access to social services or education, many RAs may have very little exposure to Western systems. According to one key informant,

“Often times I’m told I don’t need counseling I need a good job, I need help and support, how to navigate this complex place which is America. We’re coming from collectivist cultures, state run cultures, where theses streets are navigable, we don’t have enough guidance, we’re lost.”

Obtaining a bank account, taking the bus, going to the doctor, paying rent, enrolling their children in school may be foreign activities for many RA. One key informant stated that many RA need assistance with activities that may seem basic to living in the US,

“They have incomplete information. How to pay taxes, and what are they? What is a rental contract, when some of these folks have never been in a contract before?”

For RA that are highly educated, the challenges may be different. For example, many refugees from Iraq are highly educated; they may have been accomplished doctors or lawyers in their countries of origin. For them, the challenge is adjusting to new financial and social circumstances in which they are often unable to use their skills and education and must resort to low paying, unskilled labor. As one interviewee explained,

“RAs with previous professional degrees or experience from abroad have high expectations upon arrival and may feel genuine anguish to learn that their skills may not be directly transferrable or require re-certification. This is especially true for high level professionals from Afghanistan and Iraq who are resettled through the Special Immigrant Visa program (SIV) who worked for the US military directly or on contract in the home country to provide well paid interpretation, IT, or logistical support on the ground to US government forces. Disappointment may be bitter and anxiety high over how to support a family on a meager income in the US.”

Resettlement also brings significant social isolation to many RA. Some RA may be accustomed to having contact with others who speak their language and share their culture on a daily basis. Finding others who share their culture and language and establishing social networks in the US may be difficult for RA. According to one informant,

“This is especially hard when the safety net runs out or fails and there is no family to call upon. Cultural norms may preclude behavior such as requesting a loan from a non-family member, even in dire circumstances.”

The circumstances of flight may also prevent many from reaching out to others in the community. For example, those who come to the US because they aided the US in political conflict may be considered traitors by their community members. Individuals who represent members of a tribe or ethnic group that is at war with another may be reluctant to interact with opposing group members in the US. Individuals who seek refuge due to their sexual orientation or gender identity may fear continued persecution by community members in the US.

Individuals who are resettled alone face significant social isolation and are further challenged by lack of family or community supports. In some cultures, unmarried men are not often invited to family homes in which unmarried women are present. All of these factors, as well as a dearth of established communities may prevent RA from forming relationships with communities in the US and may deepen the sense of isolation. As one interviewee explained,

“Single male RAs who come and do not have any family or community tie in place suffer from extreme isolation and the mental health difficulties that come from severe gender imbalance in daily life. Often, there are no mothers, sisters, aunts, wives, cousins to soften daily life. In addition, men may have to take on roles and tasks traditionally found in the realm of females in many areas of the world such as cooking and cleaning and met task out amongst other male roommates who also are also suffering from the gender imbalance socially.”

Cultural and Historical Factors

Key informants emphasized the importance of contextual factors such as culture and history in understanding the needs of RA communities. As noted above, the experiences of RA prior to resettlement may vary widely. Some individuals may have aided the US in political conflict against their own countries. In some communities such as the Khmer, community members may have turned against each other in the course of political conflict. Membership in rival political factions may create significant animosity between groups even after resettlement. Still other communities such as the Bhutanese may have caste systems which dictate the ways in which community members interact. These historical factors may affect individuals' adjustment upon arrival in the US, their willingness to seek health or mental health care, and their ability to reach out to others in their community for support.

Furthermore, cultural views regarding health, mental health, gender roles, and sexual orientation and gender identity may vary widely and have a critical impact on the adjustment and help-seeking behaviors. For example, in some communities such as the Hmong, mental illness may suggest that an individual's spirit has been taken, and traditional rituals must be performed to restore health. Some cultures may find procedures such as surgery objectionable, as they affect the integrity of the spirit. Western treatments may seem ineffective and many may be reluctant to comply with care regimens. One participant speaking of his experiences as a Hmong immigrant said,

“Unfortunately the Western health care system believes in developing a relationship with the primary care doctor...In our community that's not how it works. We go straight to the Shaman and deal with the illness until it becomes so severe that the person goes to the ER.”

Stigma regarding mental illness is common among RA communities and often mental illness is hidden. Particularly in small RA communities, issues of confidentiality may be paramount as the existence of a mental illness within a family may influence the way that family is treated. As one participant shared,

“Because these communities are very small, an individual that's having a very serious mental health issue. . . may not divulge it to their own community member in an interpreter type situation because they're afraid. The communities are so small they may be afraid that their own community member will store that in their memory bank and hold it against them.”

Key informants also noted that bias on the part of Western medical systems may adversely affect RA's willingness to access services. Specifically, the distress experienced by RA may be viewed by care providers as pathological. Key informants suggested that too often RA individuals experiencing normal distress and adjustment difficulties are “over-medicalized,” assigned diagnoses, and provided with psychiatric treatments. One key informant suggested,

“We over-medicalize their distress. They see themselves as normal people in extraordinary circumstances. ‘I need a job, a good dignified sense of identity. I need a future, to give a good future to my children’.”

Specific Health and Mental Health Problems

Post-traumatic stress disorder (PTSD) emerged as the most common mental health problem for RA communities. For those who have first-hand experience of violence - have been injured themselves or witnessed family and friends being hurt or killed - symptoms of PTSD (such as reexperiencing the events, avoidance of things, people, or places that remind the individual of the trauma, nervousness or agitation) may be severe. One key informant noted,

“The trauma that we experienced in the war, the Khmer community has more severe issues given that traumatic experience destroyed a lot of social and relationship bonds because the community turned against itself. You couldn't trust your own family. That has translated to here.”

Difficulty managing distress over trauma leads many to engage in alcohol or substance abuse to relieve the psychic pain. One informant suggested,

“Because a lot of problems never get addressed from the get go, and these populations have lots of horrible, horrible traumas, there’s lots of alcoholism. Alcoholism is as persistent as it is for a population that never gets their mental health issues addressed. That leads to domestic violence against women in the families.”

Depression and anxiety also emerged as critical issues as did intimate partner violence and substance abuse/alcoholism. Mental health problems are exacerbated by adverse social conditions experienced by RA including poverty, financial stability, loss of family, loss of profession, and social isolation.

Access to Care and Lack of Resources

For RA communities, access to social services including health and mental health care is limited. One key informant described the specific limitations of the services available to newly-arrived RA stating,

“All new RAs undergo mandated Refugee Health Screening (RHS) within the first 30 days of arrival which includes a built-in mental health assessment tool for individuals who are 16 years and above. During this first and possible singular encounter with a practitioner in a sterile clinical setting, new arrivals may not divulge traumatic events. RHS sites may not be equipped to coordinate referrals into behavioral health care and/or the services currently on offer within the community may not match the needs of trauma survivors. Best practices would build a licensed psychiatrist with specialty training in trauma care to deliver a separate mental health assessment as well as deliver services which match the needs on-site so as to ensure that patients know where to return for care.”

After initial screenings, key informants also stressed the difficulties of obtaining additional services for RA clients. There are few resources which connect RA with more long-term systems of care. Interviewees also emphasized that there are very few services offered through community-based organizations and CBOs are understaffed and overworked. One key informant suggested,

“[Organization name] has been working in its sixth year providing free counseling services and has not received funding. People volunteer.... services and programs are few and not enough for what is needed.”

One problem contributing to this lack of resources is that RA often speak languages of lesser dispersion such as Tigrinya, Amharic, Somali, or Iu Mien. Finding providers or even interpreters that speak these languages is often challenging and many rely on telephonic interpreting services. Sometimes communities are so small that interpreters may have a social relationship with clients and clients may be unwilling to discuss relevant personal information with the interpreter present. Key informants also noted that some communities are able to quickly identify leaders

and establish infrastructures that are instrumental in bringing services to their communities. However, even communities that are most effective in this regard face a significant lag time in the receipt of services. Further, these community run organizations and leaders often must contend with extremely high levels of need.

Special Populations

Informants described the specific concerns of particular subgroups as well. Families, youth, women, aging adults, and the LGBTQ community experience challenges that intersect with many of the aforementioned concerns. Families struggle with acculturation and intergenerational conflicts as the children of refugees and asylees tend to acculturate and adopt English at much faster rates. At the same time, young adults and children face identity issues as they enter American schools and feel pressured to acculturate, which also leads to family conflict.

In addition, according to interviewees, there has been a recent increase in the prevalence of unaccompanied minors among the refugee and asylee community. One key informant provided the following information with regard to the specific issues facing children within the RA community:

There are two categories of children under special concern both of whom may require mental health supports. First are those who are resettled as unaccompanied refugee minor children through the Office of Refugee Resettlement in tandem with resettlement agencies. UNHCR officials cannot identify any living kin to take over guardianship in the camp. Upon resettlement, such children are not eligible for legal adoption in the event that a missing displaced parent or relative is eventually found. Supportive mechanisms are put in place similar to those for emancipated foster youth, so that children will be able to be self-sufficient at the legal adult age of 18 years. Even with the best placement, such children may suffer from the perpetual insecurities inherent of worrying over missing relatives as well as culture shock if placed alone with an American family or individual who may not be entirely familiar with the language or cultural customs of the child.

The second population of concern has quickly come to the forefront over the past three years: unaccompanied minor children from Central America. In addition to deprivation and lack of safety during transit, this population is especially vulnerable to rape as well as human trafficking.

Unaccompanied Minor Children used to fall under the care of USCIS, but have since been folded into two programs within the Office of Refugee Resettlement Programs: The Unaccompanied Minor Refugee Program (URM) and the Unaccompanied Alien Children Program (UAC). Federal funding for general ORR Programs cannot keep pace with the human tide of unaccompanied minor children. This year the number is expected to exceed 90,000 child arrivals. (Chisthti and Hipsman, 2014)

Often these minors are held in detention facilities for varying and sometimes lengthy stays while their case is adjudicated. Shelter and essentials such as schooling are provided, but the system is under vast strain to identify relatives and adjudicate cases properly. Mental and physical health services are critical. Additionally, even if a relative

in the US is identified, the relative may choose to reject a child. This happens in cases where the child has knowingly been victimized, such as female children who may be pregnant as a result of the victimization which occurred in transit. In addition, children who are raped in transit may contract HIV from the perpetrator and have an additional new set of stigmas to combat.

With regard to women, refugee and asylee families are forced to adjust to resettlement in ways that sometimes conflict with established gender roles. Due to financial challenges, many women into the community enter the workforce for the first time, a change that causes familial tensions. Other interviewees stated that at times women take on a disproportionate amount of the difficulties of resettlement. According to one informant,

“[Women] face a lot; they are the center of the house. If they have a higher degree they have to go out and look for a job. They have kids, they have to be connected to the schools and the language. We have a lot of problems with women who suffer from mental health issues.”

Older adults in the RA community represent an additional population with specific needs and challenges. Informants stressed social isolation as the most common issue specific to older adults. Before resettlement, many older adults maintain large networks of social support and a strong sense of identity and purpose. The concerns of this population are further exacerbated by issues such as financial hardship and difficulty navigating systems in the US. One informant from the Bay Area articulated these multi-layered obstacles stating,

“[Refugees] are coming from cultural that are very intertwined on a daily if not hourly basis. They have the ability to step outside their house and chat with someone. We really don’t have that here... The neighborhoods are not safe; they are in their apartments where they don’t know anyone. They are afraid to use the bus and go to the store. They are coming from countries where they had something to do and a sense of being.”

Lastly, another key informant provided the following information with regard to LGBTQ individuals within RA communities:

Due to current cultural beliefs at home or government sanction and criminalization of non-heterosexual activity, LGBTQ individuals may face persecution, victimization, and/or incarceration. Family members may feel compelled to uphold cultural norm due to the stigma and publically reject their own LGBTQ family members. If an LGBTQ family member is beaten, for example, the family may condone the beating publically or in private. Sexual orientation may continue to be hidden even in US due to fear and asylees may not disclose this as the reason for asylum request. Special clinic hours to serve this population (such as Transgender Tuesday evening in San Francisco clinic) may lend themselves best to delivery of tandem mental health supports for this population. Clinicians may not otherwise be familiar with the special needs of this population, (mentally or physically), especially RA with a traumatic backgrounds.

Assets:

Refugees and asylees maintain a number of impressive strengths when faced with the obstacles of resettlement. Informants underscored individual and community resiliency as well as the establishment of community-based organizations, businesses and other infrastructures that provide support for these communities. Refugees and asylees lose both their social and economic systems of support upon resettlement, but interviewees emphasized their enduring commitment to helping others and establishing new networks. As one informant articulated,

“I’m in awe of people that leave everything behind, how remarkable the individuals are...they are remarkably resilient individuals and are very giving of whatever resources they have when they see somebody they need.”

Contacts also discussed the strength of faith-based and spiritual organizations among refugees and asylees, an asset to be utilized in the establishment of mental health services. According to one participant,

“The spirituality and religion of many communities... those who have a strong spiritual core, they believe that no matter what happens there is goodness in the universe. So we should look research wise more into that personal resilience and strength and partner with religious leaders in that sense, look at was is strong with spirituality and religion to support the mental well being.”

Recommendations:

Informants from the refugee and asylee community identified numerous recommendations with a focus on community-based support, prevention and early intervention services, and language/interpretation services. Participants frequently underscored the importance of established community networks, suggesting that religious leaders, healers, and other faith-based institutions be incorporated into mental health services. When such members become trained in mental health or offer referrals to mental health agencies, refugees and asylees are able to gain information and guidance from someone with established trust in the community. For example, an informant from the Hmong community recommended utilizing shamans as part of a larger network of mental health support stating,

“So when a person comes to them the shaman will listen to them and will say that they will do the ritual but also they should go to the doctor. It creates a referral process that is a natural conduit for people from our culture to the health care system.”

Interviewees also recommended increasing the support provided to existing community-based organizations. As one informant noted,

“We would like to see a shift in the resources from strictly mental to healthy, psychosocial interventions. Partnering with social service agencies. Giving more resources to community-based organizations. How they struggle to guide their people with little or no sources. In a culture of shame, which is typical outside the western [model], they lose face in front of their community members because they don’t have resources.”

Participants also emphasized the need for early intervention and suggested referring refugees and asylees to various social service agencies immediately upon resettlement. Informants stressed that mental health needs cannot be disconnected from broader issues of resettlement such as socio-economic stability. To increase early intervention in the realm of mental health treatment, participants also recommended the use of lay health workers. Lay health workers expand the availability of mental health services, are lower in cost, and provide an opportunity for community members to receive training in mental health services. As one informant explained,

“What we need more is health and mental health education. As well as places for them to process these things outside or before that. The prevention and early intervention approach is really cost-effective. Individuals may not need to be licensed. As well as it is a place for folks to come back to when they are done with their clinical services.”

Moreover, emphasis was placed on establishing language resources more specific to refugee and asylee populations. Informants described the languages of refugees and asylees as “languages of lesser dispersion,” which presents additional barriers to obtaining interpretation services. Some interviewees suggested using nationwide interpretation agencies via phone and video to alleviate this problem.

Individuals with Intellectual Disabilities

Definitions:

The terms Intellectual Disability, Developmental Disability, and Mental Retardation have been used to refer to this subgroup of individuals with delays in cognitive functioning, for this report we will use the term “Individuals with developmental disabilities and intellectual challenges.”

The definitions of these terms are of critical significance as it determines eligibility for Regional Center Services through the Lanterman Act (described below). As of 2009, approximately 225,000 people in California were identified as having a developmental disability (ARCA, 2009). According W&I code 4512(a) & 4512(l) of the Lanterman Act, individuals with DDIC meet the following criteria:

- "Developmental disability" means a disability that originates before an individual attains 18 years of age continues, or can be expected to continue, indefinitely; and constitutes a substantial disability for that individual.
- As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include intellectual disability, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with an intellectual disability, but shall not include other handicapping conditions that are solely physical in nature.
- "Substantial disability" means the existence of significant functional limitations in three or more of the following areas of major life activity, as determined by a regional center, and as appropriate to the age of the person:
 - (1) Self-care.

- (2) Receptive and expressive language.
- (3) Learning.
- (4) Mobility.
- (5) Self-direction.
- (6) Capacity for independent living.
- (7) Economic self-sufficiency.

Demographics:

The overall prevalence of DDIC in the US is estimated at 1.5 to 2.5% (Bethesda Institute, 2012). The California Department of Developmental Services (CDDS) provides statistics on the population of individuals with DDIC for years up to 2007 (at this time, data collection methods changed). According to the CDDS, California served approximately 190,000 individuals with DDIC through the public system in 2007 (CDDS, 2011). The majority of individuals had mental retardation (75%) and a significant proportion (19%) were diagnosed with autism spectrum disorders. In fact, the CDDS reports that the number of individuals in the system diagnosed with autism grew 321 percent (8,781 to 36,952) from 1997 to 2007. According to the CDDS in California non-Latino Whites represented the largest group served through CDDS (39%), with Latinos representing the second largest group (33%). African Americans represented approximately 10%, Asians were 6%, Filipinos were 2%, Native Americans .4% and Pacific Islanders, .2% of the population. The majority of individuals with DDIC lived in family homes (90%) or community supported living (8%).

History:

The state of California began formally responding to the needs of the developmental disabled community during the 1960s. In 1964 parents from the community urged the state legislature to form a subcommittee to study the lack of available services. At the time, approximately 13,500 people with developmental disabilities resided in four overcrowded state hospitals in California. Thus, in 1969 the Lanterman Act was passed, legislation that mandated the establishment of community-based regional centers for the DDIC community. In 1973 Lanterman expanded the bill beyond “mental retardation,” mandating that regional centers “serve people with cerebral palsy, epilepsy, autism and other neurological handicapping conditions closely related to mental retardation.” In 1976, under its new name, the Lanterman Developmental Disabilities Services Act established “the right to treatment and habilitation services for persons with developmental disabilities” and the number of regional centers in the state grew to 21 (ARCA, 2001). Most significantly, the Lanterman Act required that community agencies be the primary sites of response, thus mandating the state to contract with community agencies to ensure accessibility for all persons in need. In an effort to extend the outreach of regional centers, the legislature also passed the 1993 California Early Intervention Services Act, which qualified infants and toddlers from birth to 36 months to receive services (The SCAN Foundation, 2013).

Over the past three decades, the initial goals of the Lanterman Act have been stifled by significant budget constraints throughout California. In 1991 national recession eroded the budgets of regional centers across the state, forcing longstanding centers such as the Stockton

Developmental Center and Camarillo State Hospital and Developmental Center to close. According to the Scan Foundation, “The cuts imposed on regional centers in the early 1990s were never restored. Regional centers are overwhelmed with unfunded mandates, rising expectations of consumers and their families, and the inability to retain an adequate number of employees.” Moreover, in recent years the state budget has faced similar constraints and in 2012 the General Fund to DDS saw a decrease of \$200 million. This long trajectory of budget cuts has caused restrictions in new admissions, lessening options for consumers, and increased insurance billing. Nevertheless, the state’s system of regional centers continues to endure.

Literature Review: Health and Mental Health Needs

Individuals with DDIC experience greater rates of mental health problems. According to a recent literature review, children and adolescents have overall point prevalence of psychiatric illness of 36%, with the most commonly diagnosed conditions being conduct disorder (20%), emotional disorders including depression and anxiety (12%), and Attention Deficit Hyperactivity Disorder (ADHD; 8%)(Emerson & Hatton, 2007). Similarly, adults with DDIC had relatively high rates of mental illness; point prevalence was found to be 40% (Cooper et al., 2007). The most common diagnoses for adults were problem behaviors (22%) and affective disorders (depression, anxiety; 6%). In addition, adults with Down’s Syndrome had high rates of dementia (Cooper, 2007). Furthermore, studies suggest that regardless of diagnosis, adults with DDIC are disproportionately prescribed psychiatric medications. For example, one study reported that even among a population of DDIC adults without psychiatric diagnoses, as many as 36% were prescribed psychotropic medications (Krahn et al, 2006.).

Prevalence data must be interpreted with caution given difficulties diagnosing mental health problems for individuals with DDIC. Many clinicians may not have the experience or understanding of DDIC needed to communicate effectively and appropriately with these clients. Understanding the ways in which the individual with DDIC conveys information and gathering collateral information from other care providers may be critical in developing an accurate diagnosis and treatment plan. In addition, individuals with DDIC may not have an understanding or awareness of mental health symptoms and treatment options. They often rely on care providers to identify mental health and health needs and assist them in obtaining appropriate care. Disparities in access to health and mental health care are significant for DDIC (Krahn et al. 2006).

Individuals with DDIC may experience disproportionate exposure to conditions that increase the risk for the development of mental health problems. Studies indicate that individuals with DDIC are more likely to experience adverse life events, poverty, and poor family functioning (Emerson & Hatton, 2007). Furthermore, social isolation, vulnerability to abuse, and residential conditions that discourage inactivity may increase risk for the development of health and mental health problems (Krahn et al., 2006). People living with special needs have had lifelong struggles since by definition all people with Intellectual Disabilities, Pervasive Developmental Disorders (PDD), Autism Spectrum Disorder (ASD) and other Developmental Disabilities are diagnosed by mental health and psychiatric professionals by the age of 18. Further, most adolescents with ID, PDD and ASD experience marked social deficits that lead to feelings of self-consciousness, increased loneliness and social anxiety, and poorer quality of friendships than their typically developing

peers (Bauminger & Kasari, 2000; Bellini, 2004). These adolescents may not understand how to partake in social situations in which to learn and practice social skills, negatively impacting their ability to develop quality friendships. Services that address these issues need to be implemented soon after diagnosis so that the child or adolescent can master these social deficits before they become lifelong problems.

Finally, individuals with DDIC often have poorer physical health. Dental problems, obesity, and respiratory problems are common in adults with DDIC as are vision and hearing impairments (Krahn et al., 2006). Individuals with DDIC are not only less likely to receive treatment for physical health conditions, but are also less likely to access health promotion and prevention programs (Krahn et al., 2006).

Findings for Individuals with Developmental disabilities and intellectual challenges

For individuals with DDIC, financial hardship and barriers to care were the most common concerns identified across participants. Key informants also identified key community and state assets as well as recommendations for improving conditions for individuals with DDIC.

Financial Hardship

The most prominent theme that emerged across all interviews with key informants for individuals with DDIC was financial instability. Key informants stressed the difficulty of attaining and maintaining financial independence for individuals with DDIC. Although programs exist which provide supported employment, there are not enough of these programs to meet the level of need. One participant stated,

“From an economic empowerment standpoint, jobs are few and far between. People with disabilities are disproportionately unemployed compared to the rest of the population.”

Some individuals with DDIC may receive help from family, others may rely on federal and state funding for individuals with disabilities. Regardless of the source of income, a large portion of individuals with DDIC experience financial insecurity that may lead to poverty and homelessness. Those who rely on public housing may have difficulty finding housing as facilities may be reluctant to rent to an individual with DDIC or with mental health problems. Thus, key informants noted that many individuals with DDIC end up homeless and living in shelters. According to one key informant,

“The overarching problem, the basic need is housing. What is the appropriate housing? What is available for someone who has special needs?”

Barriers to Care

One of the greatest concerns mentioned by key informants was the lack of coordinated services for individuals with DDIC. In particular, key informants noted that Regional Center services are often not integrated with services from county mental health departments. When mental health

providers receive referrals for individuals with DDIC, they often refer them back to the Regional Center, with the assumption that these services will be provided. However, Regional Centers do not provide mental health services and thus must rely on county mental health departments. According to key informants, both county mental health departments and Regional Centers lack awareness regarding the scope of each organization's work such that clients often get shifted back and forth, never receiving needed mental health care.

Furthermore, many county mental health providers may be ill-equipped to manage the special needs of individuals with DDIC and thus reluctant to accept these referrals. Clinicians are often unfamiliar with the special needs of individuals with DDIC and may feel uncertain regarding how best to provide care. Further, it is often difficult to untangle symptoms in order to make a diagnosis. According to key informants,

“There is this myth that people with DDIC don't have mental illness, that all of their behavior is attributable to the DDIC. If there is an acknowledgement of the MH problem, trying to get them into mental health or substance abuse programs is almost impossible.”

Furthermore, key informants noted that some clinicians may believe that individuals with DDIC are unable to benefit from psychotherapy because of cognitive limitations.

“There's a bias against people with developmental mental disabilities in terms of their ability to benefit from substance abuse treatment and to a large degree from mental health treatment as well.”

Lack of access to care may be particularly egregious in crisis situations when it is necessary to find an emergency psychiatric placement. Thus the lack of a coordinated system results in low levels of access to mental health care for individuals with DDIC and high rates of untreated mental illness.

Cultural biases and stigma may further contribute to lack of access to care. Key informants suggested that some cultures view disabilities as shameful. In these cultures, families may be unwilling to seek help for family members with DDIC. One key informant reported,

“We do a lot of cultural outreach especially in the Chinese community. What has been expressed to us . . . [are] the cultural taboos about disabilities. You're not supposed to have a disability.”

Thus, stigma regarding DDIC is compounded with stigma often associated with mental illness.

Finally, limitations related to cognitive functioning may prevent individuals with DDIC from advocating for themselves effectively and obtaining needed care. They may be unable to accurately or effectively communicate their symptoms. Individuals with DDIC may lack awareness regarding mental health symptoms, treatments, and how to obtain services. One key informant noted,

“I have a disability so I know what its like to have barriers. Things like how to get yourself up on time to get ready, helping people figure out about health care. What are they eligible for.”

Finally, all key informants mentioned recent funding cuts that have resulted in the drastic curtailing of programs and reduced availability of services to individuals with DDIC. According to interviewees, budget cuts have led to a large number of individuals going without critical services such as housing and employment assistance.

Specific Mental Health Concerns

When asked about specific mental health concerns, participants noted that many mental illnesses common in non-disabled communities are common among individuals with DDIC. However, they noted that anxiety and social isolation are particularly important concerns for individuals with DDIC. For example, many individuals with DDIC may be aware of their cognitive limitations and their inability to function at the same level as some of their colleagues or friends may cause significant anxiety. One key informant noted,

“We see a lot of anxiety especially for people that have mild intellectual disability. They know they don’t fit in, there is social anxiety. It can be pretty debilitating.”

Key informants also mentioned that dementia is more common within this community.

Special Populations

Key informants identified special populations, specifically women and older adults, who face additional challenges in the community. These issues remain multifaceted and intertwined with other barriers among the population at large. For example, older adults face increasing issues because of declining physical health, a challenge intensified by a lack of employment, housing, and other financial constraints among the population of individuals with DDIC. Social isolation is also a major problem among older adults. This problem is exacerbated when persons with developmental disabilities are forced to move from high rent areas such as the Bay Area, losing their established base of support. According to one participant,

“[For] older adults across the board isolation is a huge thing. If you are a person who has a psych or cognitive disability, which often comes with age and you are isolated to boot, which comes with age, that’s a scary proposition.”

In addition to aging adults, contacts in the community highlighted specific barriers for women with developmental disabilities. Gender disparities in employment create multi-layered barriers for women who tend to make less money than their male counterparts. Given the fact that many individuals in the DDIC community experience significant barriers in housing and employment, this problem is exacerbated for women. Moreover, health care access, specifically with regard to women’s reproductive care, is also an issue when merged with the challenges of developmental disabilities. As one participant expressed,

“Many women with developmental disabilities have not had regular OBGYN care for example. They may be very frightened of having that kind of physical exam or having a mammogram. It takes longer to perform those examinations for someone with developmental disabilities.”

Finally, according to key informants, issues of sexual abuse among the individuals with DDIC also disproportionately affect women. This issue can be particularly difficult to recognize when a client’s developmental disability limits forms of expression. According to one interviewee,

“People with developmental disabilities are victimized much higher than any group and by far, as much as 10 times higher they are sexually assaulted. If they are nonverbal how do they respond? What we get is we learn about these abuses much later. It happens to men as well and is still much higher, but for the women it’s a disproportionate problem.”

Assets and Strengths:

The DDIC community of California has benefited from policy initiatives that allocate funding to services, specifically since the passing of the Lanterman Act in 1969. Participants emphasized that California is one of few areas where community-based services for individuals with DDIC have been mandated through statewide legislation. Over the past three decades, funding cuts and the recession have had a detrimental effect on many regional centers, but California is still home to 21 regional centers established under the Lanterman Act. As a result, services for individuals with DDIC have moved from instructional-based forms of treatment to home treatment and community-based services. This is especially true for children and as one interviewee noted, “we now see over 90 percent of children with DDIC residing in their homes.”

California’s system of support for the DDIC Community also continues to benefit from the involvement of the community itself. According to one key informant,

“[There’s] a huge strong parent network [in the community]. People with developmental disabilities are very well connected to one another. And they’re very involved in policy, more than most groups. They’re service providers are so linked into their policymakers.”

Additional assets include strong peer support models where consumers with disabilities are able to provide services and guidance to fellow members of the DDIC community. Key informants emphasized the rich level of personal encouragement available through peer services.

Recommendations

The most common recommendations centered on improving coordination of care and access to mental health services within the DDIC community. Key informants consistently emphasized a need for improved collaboration among Regional Centers for the developmentally disabled and mental health providers. As a potential avenue for improvement, informants suggested establishing joint training and collaboration programs between such agencies. According to one Regional Center provider,

“Crisis facilities are usually a need for us. That’s where we overlap with mental health. When someone is in crisis we don’t have that mental health expertise. When [a patient gets] hospitalized and discharged, [we have trouble] finding a place for them to step down, to stabilize and get them out of crisis.”

Interviewees also recommended prioritizing educational outreach and professional development to overcome the lack of appropriate services. Participants explained that only a small amount of mental health clinicians specialize in developmental disabilities while many providers are not prepared to deal with behavioral issues that can accompany developmental disabilities. According to one participant,

“[There is a need for] programs where professionals would be prepared to work with non-verbal, yet highly intelligent, individuals, many of which most likely would be part of the Autism Spectrum –growing to 1 in 8 of every child born in 2014.”

Moreover, an emphasis was also placed on increasing general visibility within the community. Informants noted the importance of hiring workers with both physical and psychological developmental disabilities as a strategy for mitigating this issue.

Limitations

This study was limited in scope, and thus the findings are not intended to be comprehensive and broadly generalizable. For example, the key informants for the RA communities generally work with communities in the northern region of California – Sacramento and the Bay Area. Many RA communities in southern regions such as Los Angeles and San Diego, come from different countries, speak different languages and have diverse histories of involvement in political conflict. Similarly, this report did not address issues of diversity of individuals with developmental disabilities and intellectual challenges. For example, LGBT individuals with DDIC may face a host of challenges related to their sexual identity and gender orientation. Ethnic minority individuals with DDIC may experience additional barriers to obtaining care and adequate screening and diagnosis due to cultural and language differences. Despite these limitations, the results yield insight into issues potentially faced by these communities. Further, the process provides a basis for future efforts aimed at identifying marginalized and vulnerable communities with emerging mental health needs and exploring their experiences and challenges.

Summary and Conclusions:

This brief qualitative study exploring the needs and challenges faced by refugees and asylees (RA) as well as individuals with developmental disabilities and intellectual challenges (DDIC) found that overall, these communities experience disproportionate exposure to adverse life circumstances that place them at risk for the development of mental health problems. The exposure to extraordinary and extreme deprivation and trauma prevalent in RA communities, in combination with the intense burdens of resettlement that include finding rapid employment, learning English, and establishing new social networks place these individuals at risk for post-traumatic stress disorder, depression, anxiety, substance abuse, and poverty. For individuals

with DDIC, the recent cuts in funding to programs exacerbate the lack of resources available for individuals who require supported employment, housing assistance, and advocacy for mental health and health care.

Despite the numerous and significant challenges identified, key informants were also quick to mention existing effective programs and potential solutions to these problems. Key informants noted that prevention is key, as many of the more difficult mental health problems may be avoided with psycho education regarding mental health symptoms and treatment, social programs to reduce isolation, and services to address social and economic deprivation such as housing and supported employment. Utilizing existing community and faith based programs (for RA) and Regional Center and peer-run programs (for individuals with DDIC) to provide prevention services may greatly improve access to care and penetration into these communities. Thus, key informants noted that with targeted and tailored approaches, great strides may be made in improving the well-being of these communities. As the California Office of Health Equity launches efforts to reduce disparities in mental health, consideration should be given to the recommendations provided in this report, as relatively small investments in prevention are likely to produce great improvements for vulnerable communities.

DRAFT

References

- ARCA. History of Developmental Service Delivery System in California. <http://arcanet.org/pdfs/HistoryOfSystem.pdf> Retrieved on June 1, 2014.
- Asgary, R., & Segar, N. (2011). Barriers to health care access among refugee asylum seekers. *Journal of health care for the poor and underserved*, 22(2), 506-522.
- Bauminger, N. and Kasari, C. (2000), Loneliness and Friendship in High-Functioning Children with Autism. *Child Development*, 71: 447–456. doi: 10.1111/1467-8624.00156
- Bellini, Scott. "The development of social anxiety in adolescents with autism spectrum disorders." *Focus on Autism and Other Developmental Disabilities* 21.3 (2006): 138-145.
- Bethesda Institute, (2012). How Prevalent Are Developmental disabilities and intellectual challenges in the United States? <http://bethesda institute.org/document.doc?id=413> Retrieved on June 1, 2014.
- California Department of Social Services (2013). Fact Sheet: Refugee Resettlement Program. http://www.cdss.ca.gov/refugeeprogram/res/pdf/Factsheets/2014/RRP_Fact_Sheet_10.21.13.pdf Retrieved on June 1, 2014.
- California Department of Developmental Services, (2011). Fact Book: Eleventh Edition. http://www.dds.ca.gov/FactsStats/docs/factbook_11th.pdf Retrieved on June 1, 2014.
- Chishti, Muzaffar and Faye Hipsman. "Dramatic Surge in the Arrival of Unaccompanied Children Has Deep Roots and No Simple Solutions." *Migration Policy Institute* (2014).
- Constitutional Rights Foundation (2012). History Lesson 6: Refugees: International Law and US Policy. <http://www.crfimmigrationed.org/index.php/lessons-for-teachers/145-hl6> Retrieved on June 1, 2014.
- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 190(1), 27-35.
- Emerson, E. & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*, 191, 493-499.
- Eschbach, K., Hagan, J., Rodriguez, N., Hernandez-Leon, R., & Bailey, S. (1999). Death at the Border. *International Migration Review*, 430-454.
- Hsu, E., Davies, C. A., & Hansen, D. J. (2004). Understanding mental health needs of Southeast Asian refugees: Historical, cultural, and contextual challenges. *Clinical psychology review*, 24(2), 193-213.

Immigration Policy Center. (2010). Refugees: A Fact Sheet.
<http://www.immigrationpolicy.org/just-facts/refugees-fact-sheet> Retrieved on June 1, 2014.

Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental retardation and developmental disabilities research reviews*, 12(1), 70-82.

Lustig, S. L., Kia-Keating, M., Knight, W. G., Geltman, P., Ellis, H., Kinzie, J. D., ... & Saxe, G. N. (2004). Review of child and adolescent refugee mental health. *Journal of the American Academy of Child & Adolescent Psychiatry*, 43(1), 24-36.

Refugee Health Technical Assistance Center, (2011). Mental Health.
<http://refugeehealthta.org/physical-mental-health/mental-health/> Retrieved on June 1, 2014.

Shidlo, A., & Ahola, J. (2012). Mental Health Challenges of LGBT Forced Migrants.
www.uscis.gov/USCIS/Humanitarian/Refugees%20&%20Asylum/Asylum/Asylum%20Native%20Documents%20and%20Static%20Files/RAIO-Training-March-2012.pdf - See more at:
<http://www.fmreview.org/sogi/shidlo-ahola#sthash.kMtr15Aj.dpuf> Retrieved on June 1, 2014.

The Scan Foundation (2013). California's Developmental Disabilities Service System.
http://www.thescanfoundation.org/sites/thescanfoundation.org/files/ltc_fundamentals_brief_disability_system-6-26-13_0.pdf Retrieved on June 1, 2014.

Wassem, R E (2005). US policy on immigration and asylum seekers. CRS Report for Congress. CRS RL 32621. *Washington DC: Congressional Research Service.*