Abstract

American Indian (AI) youth experience significant mental health disparities. The majority of AI youth live in urban areas, yet urban AI youth are underserved and unstudied. This manuscript describes a qualitative study of community mental health needs in an urban population of AI youth, conducted as part of the planning process for a system of care (SOC). Participants included 107 urban AI youth and families that participated in one of 16 focus groups assessing mental health needs and services. Forty-one percent of participants were youth or young adults. Data were coded and analyzed using qualitative software and then further analyzed and interpreted in partnership with a community research workgroup. Results indicated various community characteristics, mental health and wellness needs, and service system needs relevant to developing a system of care in this community. Key community, cultural, and social processes also emerged, reinforcing the importance of broader system changes to promote a sustainable SOC. These systems/policy changes are reviewed in the context of previous literature proposing necessary systems change to support behavioral health care in AI communities as well as to ensure that SOC implementation is consistent with core values and philosophy across all communities.

Key words: American Indian, urban, children and adolescents, mental health, system of care, qualitative

American Indian (AI)[1] youth are among the most vulnerable children and adolescents in the United States with rates of poverty, exposure to violence, mental health issues, and suicide/death rates that are staggering (Sarche & Spicer, 2008; U.S. DHHS, 2001). Extant research indicates that AIs are at higher risk than any other ethnic group for mental health problems (Costello, Messer, Bird, Cohen & Reinherz, 1998; Moncher, Holden & Trimble, 1997). AI youth experience exceedingly high rates of depression, anxiety, trauma, substance abuse, and suicide (Stiffman, Strilery, Brown, Limb & Ostmann, 2003) and are at high risk for a variety of poor outcomes, including teen pregnancy, school drop out, out of home placement, and accidental death (Witko, 2006).

Statistics illuminate tragic and disturbing behavioral and mental health disparities experienced by AIs, and especially AI youth. These disparities have emerged in the context of social, political, cultural, and historical dynamics since colonization. AI people were subject to one of the most significant and systematic genocides in world history (D'Andrea, 1994), and have endured prolonged exploitation, unimaginable loss, and profound suffering during the past 500 years. A legacy of trauma, poverty, disenfranchisement, discrimination, and failed U.S. policies aimed at annihilation and then assimilation is compounded by cultural differences compared to mainstream Western culture, a lack of adequate epidemiological and health-related data, and competition for scarce resources, which together contribute to the current physical, behavioral and mental health crisis for AIs. While the majority of AI youth now live in urban settings (Witko, 2006), urban AI youth represent an almost completely unstudied, and essentially invisible group of vulnerable children and adolescents with regard to mental health (or any other)

[1] American Indian, or AI, is used throughout this manuscript to refer to people of American Indian or Alaska Native descent.

issues. Substantial need exists for research examining the unique experience of urban AI youth in order to inform models of mental health promotion and intervention development.

The system of care (SOC) philosophy for mental health service delivery proposes a coordinated network of community-based services and supports that are organized to meet the challenges of youth with serious mental health needs and their families. In recognition of the unique and specific needs of AI communities in planning to implement SOCs, the Substance Abuse and Mental Health Services Administration (SAMHSA) launched the Circles of Care (COC) grant program in 1998. This program provides resources for community-based infrastructure development and planning for SOCs in AI communities. The community-based focus of COC is particularly important as previous research in AI communities has demonstrated that methodological approaches must be culturally-driven and leverage AI cultural strengths, belief systems, and competencies (Poupart, Baker & Red Horse, 2009). Such research is best pursued when communities and researchers form authentic partnerships, which are embodied in the principles and practice of community-based participatory research (CBPR) (Green & Mercer, 2001; Israel, Schulz, Parker, & Becker, 1998). Authentic partnerships are ones in which partners exhibit respect, collaboration, equal authority in decision-making, and open communication. Founded in CBPR principles, the purpose of a COC grant is to provide tribal and urban AI communities with resources to design holistic, community-based systems of care to support mental health and wellness for their youth and families.

The first step in developing a system of care is to assess the needs of the specific community that the SOC is expected to serve. This manuscript describes a qualitative study of community mental health and wellness needs in an urban population of AI youth that was conducted as part of a COC grant awarded to the American Indian Center of Chicago (AIC).

The AIC is the oldest urban Indian center in the country and the primary community agency serving the large Chicago AI community. The current study had the following primary objectives: (1) to actively involve the AI community in Chicago in a community-based participatory research project, and (2) to determine the mental health and service needs of AI youth and families in the Chicago community in order to develop culturally-appropriate services to meet these needs. The purpose of collecting these data was to inform the conceptualization, development, and implementation of an SOC for this community. Key study findings indicated a range of important community needs, but also highlighted various systemic challenges and broader social and conceptual shifts that may need to occur in SOC policy in order to develop a successful SOC in this community. Therefore, a third objective of this study became to (3) recognize community, cultural, and social processes (e.g. historical trauma, political divides, stigma and distrust, cultural relevance, and community readiness for change) that are critical in developing an effective system of care in this community, as well as indicate broader systemic changes needed to support diverse families and communities.

The Need for Systems of Care in Urban AI Communities

According to the U.S. Census Bureau (2008), there are 4.5 million people who identify themselves as AI in the United States, of which approximately 30% are under the age of 18. There are over 500 federally recognized tribes and over 100 state recognized tribes, each of which has unique social and cultural systems. In addition, approximately 67% of the AI population in the United States lives in urban areas rather than on reservations (U.S. Census Bureau, 2000). Chicago has one of the largest urban AI populations: 20,898 in Cook County and up to 50,000 in the larger metropolitan area (U.S. Census Bureau, 2000).

Mental Health Disparities in American Indian Youth

AIs are at higher risk than any other cultural group for mental illness and AI youth may be at high risk for various psychiatric disorders, including substance abuse, depression, anxiety, attention deficit hyperactivity disorder (ADHD), conduct disorder, and suicide (Beals, Piasecki, Nelson, et al., 1997; Beals, Novins, Whitesell, et al., 2005; Costello, Farmer, Angold, Burns & Erklani,1998; Moncher et al.,1997; Whitbeck, Yu, Johnson, Hoyt & Walls, 2008; Zvolensky, McNeil, Porter & Stewart, 2001). Evidence suggests a rapid increase in the prevalence of psychiatric disorders over the course of adolescence in AI youth. Whitbeck and colleagues (2008) reported an increase in the prevalence of a single lifetime disorder from 25.6% at ages 10-12 to 44.8% at ages 13-15 in their longitudinal study of AI youth on four reservations. In addition, AI people have the highest suicide rates of any ethnic group in the United States; data from the Indian Health Service (2003) indicate that suicide is the 2nd leading cause of death for AI youth aged 15-24 and is 3.5 times higher than the national average. As a whole, AI youth are more likely to: die before they reach adulthood, die an accidental death, die as the result of homicide, commit suicide, be in court-ordered foster care, be in federal custody, experience violent victimization, and drop out of school when compared to youth in any other ethnic group (Sarche& Spicer, 2008; Witko, 2006).

American Indian Youth in Urban Communities

Consistent with efforts to assimilate AIs into mainstream society, federal legislation was enacted in the 1950s and 60s to relocate AIs to urban settings, where inter-tribal diversity and integration would dilute AI culture and force assimilation to the mainstream. AIs were promised economic opportunity and job training, which stimulated a migration of AIs to cities. However, once these AIs arrived they were met with little governmental support, leading to unemployment, poverty, and social and cultural isolation (Witko, 2006). Separated from their tribal homeland,

urban AI families found themselves facing these problems, including oppression and racism, with limited coping skills, no economic security, and the absence of the tight-knit social support of their tribal communities (Clark & Witko, 2006). These factors contributed to feelings of alienation, disempowerment, and hopelessness (Clark & Witko, 2006).

We know very little regarding the current psychosocial contexts of urban AI communities. The few studies specifically focused on urban AIs have found high rates of substance abuse, depression, anxiety, suicidality, and trauma, compounded by poverty, unemployment, family and community violence, and low rates of service utilization (Evaneshko, 1999). Indeed, a recent report on urban AI health documented that urban AIs experience extreme poverty, demonstrate significant health and mental health disparities, face numerous challenges trying to access quality health care services, and are largely ignored by the American health care system (Urban Indian Health Commission (UIHC), 2007). AI youth in urban settings, who are likely the children or grandchildren of those relocated, may be affected by historical trauma and accumulated stress, and they may experience loss of traditional cultural heritage, stress over negotiating their ethnic and cultural identity, racism, and oppression. They must also deal with the multiple stresses of urban living, including their disadvantaged economic status. Data from the Youth Risk Behavior Survey (CDC, 1996) indicate that urban AI youth are more likely to engage in a variety of high risk behaviors than their European American counterparts, including illegal drug use, early initiation of sexual intercourse, use of tobacco, alcohol, and marijuana, carrying weapons, physical fights at school, and school avoidance (Rutman, Park, Castor, Taualii, & Forquers, 2008).

The Chicago American Indian Community

Although there is limited epidemiological data specific to Chicago, previous efforts suggest that this AI community suffers from the same problems (disadvantaged socioeconomic status, high-risk status of youth, and behavioral and mental health disparities) that have been documented in other urban AI communities (UIHI, 2009; U.S. Census Bureau, 2008). A general health needs assessment conducted in Chicago by the Urban Indian Health Institute/Seattle Indian Health Board (2009) indicated that substance abuse, anxiety/stress, depression, suicide, financial problems, unemployment, accidents, teen pregnancy, community violence, domestic violence, housing issues, legal problems, and insurance and health care access issues were significant problems, and concluded that the Chicago community had substantial health needs as well as social and economic factors that put community members at risk for not receiving needed services. The study described in this manuscript comprised a qualitative needs assessment study to further assess the specific needs of youth in the Chicago AI community in order to plan for an SOC. In addition, our CBPR and qualitative methods facilitated the examination of important community, cultural, and social processes that may affect the development and implementation of an SOC in urban AI communities and have implications for broader system changes needed to sustain an effective SOC in other communities.

Methods

This study was conducted using a CBPR approach and utilized a culturally-informed methodology. To develop our focus group guide, we adapted the *Community Story Framework*, a culturally-informed qualitative methodology developed for use with AI communities (Four Worlds Centre for Development Learning, 2000). The *Community Story Framework* was developed as a tool for participatory analysis in AI communities and brings people together in small groups to discuss important issues in community life, such as the well-being of youth and

families, in the context of such domains as family life, social life, emotional life, and cultural/spiritual life. Our structured focus group guide included additional questions assessing three main domains: (1) the mental health/positive development needs of urban AI youth in Chicago, (2) the available support systems, mental health services, and service utilization, and (3) potential cultural and historical parameters that might drive the development of innovative service approaches to meet community needs. Sample questions from the focus group guide include: “What are some of the problems that youth in our community face today?”, “What do you hear about mental health services in our community?”, and “What would life be like for youth in a healthy family and community?” A community workgroup actively participated in the development of the focus group guide.

Participants for this study were recruited through community announcements, networking at events and pow-wows, posted flyers, and word-of-mouth. Sixteen focus groups were completed with a total of 107 youth and families participating. Informed consent, parental permission for youth under 18, and youth assent was obtained prior to participation. One hundred percent of participants identified as AI. Forty-one percent of participants were under the age of 25, and 14% were under age 18. Eighteen percent of participants were community elders (a community elder is generally defined as a senior community member with cultural wisdom and a commitment to sharing and teaching). Sixty-six percent of participants were female. Each group had 6-12 participants and lasted two hours. Groups were organized by age group (e.g., teens, young adults, adults, elders) and generally included a mix of genders. Groups were facilitated by two of the authors of this manuscript (AW and KS), who are in leadership roles on the COC grant and have working relationships with the AIC (one is an AIC staff member, the other is on the AIC Board) and experience working in this community. The structure of the groups was

standardized; facilitators asked questions in the same manner and sequence across all 16 groups. The research protocol was approved by the University of Illinois at Chicago IRB.

Each focus group was audio recorded and professionally transcribed. A coding structure was developed based on eight core domains of interest that represented areas of interest for analysis. The eight codes were: (1) community characteristics; (2) community demographics; (3) indicators of health and mental health; (4) risk and protective factors; (5) definitions of mental illness; (6) service system needs; (7) barriers to accessing services; and (8) acceptability of existing services. Two authors (EW and ES), who also have relationships with AIC and are from the Chicago AI community, served as coders on the project. They established reliability by double coding three transcripts, and completed the analysis of the transcripts using AtlasTi software. Data analysis involved coding text, producing text reports by code, and identifying and counting themes from text through an iterative process of reviewing code reports. After initial coding by the research team, code reports were reviewed by our community research workgroup, a committee of community members who volunteered to assist with study design and data analyses. Community workgroup members reviewed the code reports and discussed findings with project staff in bi-weekly committee meetings. This process served to validate coding completed by initial coders as well as facilitating discussion to ensure that codes were adequately discussed in depth and considered in context when interpreting themes.

Results

Data were coded to determine the primary themes emerging for each of the codes. The themes for each code are listed in Table 1. While all identified themes are listed in the table, results discussed below were limited to those that may be most pertinent to developing SOC

components. These themes were identified by the research team and agreed upon by the community research committee during analysis and consensus meetings.

Community Characteristics

The first two codes were developed to assess community demographics as well as specific community, cultural, or social factors that characterize the Chicago AI community. Specifically, the **community characteristics** code was used to capture characteristics such as historical influences, identity issues, politics, relocation effects, dynamics in community, aspects of urban AI culture, and traditions/practices in community. Participants reported (1) increased *dispersion* of the AI population across the Chicago metropolitan area over the past 20-30 years. Gentrification has forced the AI community out of its original geographical location and families are now located across the expansive city and suburbs. Participants associated this phenomenon with a perceived invisibility of AI people in the larger Chicago community as well as with other aspects of cultural dispersion, such as mixed heritage due to inter-race coupling, decreased knowledge of language and participation in cultural traditions, and the stresses of trying to "live between two worlds." For example, one participant noted the effect of dispersion and integration within the urban community as contributing to a potential loss of cultural knowledge:

> I believe there needs to be some working on that particular issue in that living on the reservation and then leaving as a product of Indian relocation- the only way I would get a lot of the cultural things was to go back to my reservation and spend summers there. A lot of things became a void and I had to relearn those as an adult because I found importance in those things. And so living in an urban environment you lose those things, unless there is a concerted effort to take that cultural information and impart that to the youth because they are living in their own world. They go play basketball after school and they get integrated with other races and stuff, there is a pan racial, ethnic thing in an urban area.

Second, participants highlighted (2) a sense of *division* in the AI community. They noted physical dispersion, intertribal diversity, tensions between community leaders and organizations,

and the diminished interdependence that once existed, as contributing to feelings of disconnection and division between community members. One participant stated:

> Well, one thing I see about a lot of Natives is that they are separate. My tribe is this and your tribe is this. And we talk about each other. And we don't really come together as Native people. If you are a Native, you are a Native. I don't care whether you are from north, south, east or west, because we should love each other being Native, Native people.

The **community demographics** code was used to capture sociodemographic characteristics such as housing, employment rate, poverty, neighborhood issues, school drop-out, and family structure. One prominent theme was (1) *violence* in community, most notably violence associated with aspects of inner city living such as gangs, drugs, and dangerous neighborhoods. One participant illustrated this theme, stating:

> And my big concern is, the kids in this neighborhood-you know, we saw three shootings out here about six months ago. One young man died on that doorstep over there. That makes an impact on you, you know. So it is like gangs and drugs are eating our children up and spitting them out and putting them into incarceration. They do not belong there. What I see is, it takes a whole village to raise a child. And I think we try to do that.

In addition, participants noted (2) *financial instability*, including lack of employment, relying on public assistance, housing problems, and youth having to contribute to family finances. Finally, participants discussed the (3) challenges related to *parenting*, including the prevalence of single parents, extended family raising children, and teen parenting.

<u>Mental Health and Wellness</u>

The next set of codes was designed to capture themes associated with conceptualizations and experience of mental health and wellness in the AI community in Chicago. First, the **mental health indicators** code was used to capture indicators of community health or mental health such as arrest rates, substance abuse, gang violence, foster care placements, HIV, and chronic illnesses. We chose to focus on both indicators of positive mental health in addition to negative mental health. Indicators of positive mental health and wellness included (1) *healthy lifestyle*

behaviors, such as healthy eating and youth/family participation in sports activities and athletics; (2) *spiritual strength*, which participants described as having the spiritual grounding to weather life's challenges; (3) *regular spiritual practice*, which included prayer, participation in ceremony, and teaching youth spiritual traditions; and (4) positive and healthy *coping skills*. Indicators of negative mental health noted by participants included (1) *alcohol and drug usage*; (2) *violence*; (3) *gangs*; (4) *unhealthy lifestyle behaviors*, such as poor diet, lack of exercise, and mismanagement of chronic illnesses; (5) *stress and anxiety*; and (6) the negative impact of *poverty*. In general, participants noted the high prevalence of indicators of negative mental health, such as violence (both community violence as well as violence occurring within families), poverty, substance abuse, and high stress levels, and the need for more focus on promoting indicators of positive mental health and wellness, such as using spirituality to promote a sense of purpose and balance, the development of good coping skills, and fostering healthy relationships.

The **risk and protection** codes were used to capture community strengths (e.g. use of Native language, traditional practices, close-knit families, programs for youth, academic achievement, positive role models) and risks (e.g. spiritual problems, stressful life events, poverty, trauma and historical trauma, racism). Themes emerging related to community protective factors included: (1) the importance of a *sense of belonging* – to family, to community, and to society; (2) having a strong connection to *extended family* members who provide nurturing relationships for youth; and (3) having a *supportive, involved community* that prioritizes the healthy development of youth and maintenance of healthy families. Themes related to community risk included (1) *negative coping skills*, such as alcohol and anger/violence; (2) a *lack of structure and guidance* for youth; (3) *chronic stress*; (4) *community*

division; (5) a *lack of connection to community*; and (5) *poor communication*. Although some of these themes (e.g. negative coping skills, stress) may appear to be individual-level risk factors, the focus of this discussion was on how these factors were pervasive enough throughout community that they represented community-level risk factors influencing overall youth and family wellness. In general, participants noted that many of the core aspects of protection from risk, such as a strong sense of family and the importance of community life, exist but are diminished by exposure to risk factors such as chronic stressors, lack of good communication, and a sense of loss. In particular, participants noted that compounded risk factors contribute to a lack of sense of purpose and direction for many community youth. One young adult stated:

> I think lack of direction is always just at the root of so many struggles with youth, period. Especially in this community, I've been in this community my entire life. And I just think maybe, for many different reasons, family or just lack of resources, lack of a place to even just go…But there's no sense of direction of what a person wants to do, or where to go, or what to do with their time constructively. I think there's maybe not enough encouragement. I think there are in certain arenas. Everyone says "go to school, go to school." But then for a lot of people, you don't have the money to go to school… So then what do you do then? So I think that causes a lot of despair and then you kind of give up.

The **definition of mental illness** code was used to capture any discussion relevant to local definitions of wellness, mental health, or emotional health. There was not much explicit discussion of mental illness by participants in this study. When asked to describe the meaning of mental or emotional health, the predominant response was (1) achieving *balance*, with the predominant description of a lack of mental health as being *out of balance*. Other discussion coded in this domain indicated (2) *stigma* and distrust related to mainstream mental illness diagnoses. Participants also emphasized a preference for (3) more *culturally-relevant definitions*, such as balance and holistic wellness. One participant illustrated this theme by stating:

> People have a tendency these days to identify you by your sicknesses, so you become a collection of sicknesses that people are managing…I think the idea should be that good wellness should look at sickness as disease, but not disease as in a thing, but disease as in dis-

> ease. The dis-ease is you have gotten out of balance. There is something that is not making your life work the way it should be and we are going to move you from that uneasy place again to a healthy place.

In addition, participants tended to focus on root causes of behavioral or emotional difficulties, such as (4) feelings of *alienation and disconnection from family and community*. Finally, (5) the experience of *trauma*, both individually and collectively as a community, emerged as a major theme related to emotional and behavioral difficulties experienced by youth. The discussion of trauma ranged from community violence, such as gangs and drug violence, to sexual abuse within families, to the collective historical trauma experienced by the urban AI community in Chicago and AI peoples as a whole.

Service Needs

The final group of codes was designed to assess perspectives about the current service system and what community members perceive to be the gaps and unmet service needs. The first code, **service system needs**, was used to capture what kinds of services are (or are not) available in the community and to assess gaps in services, unavailability of services or programs, and problems with available services. Participants noted a significant need for (1) *funding* for programs and (2) improvements in *infrastructure*. Participants described lack of funding and infrastructure challenges such as lack of staffing and/or expertise needed as contributing to a sparse and constantly changing menu of available health and mental health services within community. Participants also discussed (3) the need for *specific services* aimed at mental and behavioral wellness for youth; (4) the need for services that are *culturally-relevant* (e.g. that incorporate traditional medicine or spiritual practices) and based within their community; and (5) the need for more services and programs that facilitate healthy social interaction and *promote*

general wellness. Speaking specifically about what is needed in terms of services, one participant stated:

> Creating more opportunities for the healing process and exposure to all of those things [traditional practices]. Spirituality, there's a lot of connections with medicine men and women in the community now. There are more opportunities for other clinical work. And finding a balance that works for families that is culturally appropriate helps a lot.

The **barriers to accessing services** code was used to assess any difficulties accessing current services. The themes emerging under this code included (1) *poor communication and lack of knowledge* about accessing mental and behavioral health services; (2) *practical barriers* such as insurance, financial issues, and transportation; (3) *stigma* related to accessing services; and (4) impact of barriers such as *lack of trust*. In particular, participants reported not accessing services for fear of being called crazy or being the subject of gossip, as well as having concerns about confidentiality, especially when utilizing local community agencies where others might see them arriving for appointments or where other community members might be employed. Participants also discussed not trusting non-AI practitioners or providers not familiar with AI culture to understand their unique needs and value systems. Finally, participants discussed (5) a preference for *utilizing community supports* and family members or peers when in distress, rather than accessing mainstream mental health services. One participant described this phenomenon by saying:

> I think that the mental health services that we used to have came from everybody else's community. And if you wanted something the chances are there was someone else in the community you were going to run into when you were waiting…that was going through the same thing or had the same thing and they helped you out with it…family meant a lot more. And you had family wherever you looked. And that was your mental health services. It was either your peers or your age group or someone else that was walking around the streets, just the way you were.

The final code in this group, **acceptability of existing services** assessed the acceptability of existing services, including the cultural appropriateness and quality of available services.

Participants highlighted the importance of having providers that are (1) *perceptive* to their unique needs; and (2) with whom they can build *a trusting relationship*. Participants agreed on (3) the general *absence of quality services* available for youth and also discussed (4) the *community politics* (e.g. relationship dynamics and history between community leaders and agencies) driving the utilization of different programs and services within community.

Youth-specific Findings

As 41% of the sample was under the age of 25, the findings discussed above generally characterize the findings of youth and young adults that were sampled in this study. However, when youth data were analyzed separately, a few additional youth-specific themes emerged. Youth-specific themes included (1) developing *skills to cope* with stress and negative situations; and (2) the need for *positive role models* within family and community. Within the **community characteristics codes**, youth identified (1) *tribal identity* as important because it provides a sense of community and belonging and enhances knowledge of language and traditions. Youth also discussed (2) the interplay between *community cohesion* and maintaining cultural ties, while also maintaining *individual identities* and being free to have their own ideas and perspectives as an important characteristic of community life. Finally, youth identified (3) *peer pressure* as underlying many of the other community characteristics identified, such as substance use, gangs, violence, and teen pregnancy. Peer pressure was also a prominent theme within the **mental health and wellness codes**, where it was identified to impede wellness and healthy coping through serving as a mechanism through which youth become involved in abusing substances, violent behavior, and joining gangs. In addition, youth participants discussed the need for (1) *role models* to demonstrate healthy coping and healthy lifestyle behaviors, and who were interested in being involved in youth's lives and teaching culture. Many youth identified the

importance of (2) *cultural and spiritual health* and their desire to connect or re-connect with cultural and spiritual traditions. For example, one youth stated:

> Having a culture, having traditions kind of gives you, maybe, a purpose or something, to take care of or something to hold. And, having something like that, you know, a form of responsibility, kind of makes you stronger. You know, having responsibility to carry traditions and to uphold the culture, you know, it gives you something to do, to care about, you know what I mean, an outlet in itself.

Finally, youth stressed the need for (3) *positive reinforcement* from adults and teachers; (4) *accountability* from adults and organizations; and (5) the need for individuals and institutions in their lives to promote a sense of *cultural pride*. All these things were identified as coping mechanisms or buffers that would help them manage the intense risk factors and stressors in their daily lives. Within the **service needs** codes, one interesting additional theme that emerged specific to youth responses was the barrier presented by (1) the message that youth need to be strong and proud (particularly males), which causes *shame and embarrassment* and prevents youth from seeking help when they need it.

Community, Cultural, and Social Processes

There were several subtle yet powerful themes that emerged in our analyses that did not fit neatly into our coding domains, or were so consistent throughout many coding domains that they were deemed to represent pervasive and significant processes within community experience that may relate to youth and family mental health and community needs. These themes were either discussed explicitly during focus groups or emerged through the integration of data and discussion with community research workgroup members. They included (1) the impact of *historical trauma* (i.e. the collective emotional and psychological injury, both over the life course and across generations, resulting from catastrophic history of genocide); (2) *political divisiveness* within community and community organizations; (3) the need for *a sense of belonging*; (4)

challenges in the *cultural connection* between youth and adults/elders; (5) *stigma* about mental and behavioral health, (6) *internalized oppression* (i.e. accepting the oppressor's perception of you), (7) *strained interactions with outside systems* (e.g. public schools, health care); and (8) fear of *loss of culture and tradition*. The examination of these community, cultural, and social processes was identified to be critical in developing meaningful, sustainable, and effective interventions or systems of services to promote mental health and well-being for urban AI youth and families in Chicago. Of these, the most significant and overarching theme discussed by participants and by research team and workgroup members analyzing data was the impact of trauma on community life in the Chicago AI community. It was proposed that historical trauma is a powerful psychological, social, and structural phenomenon that contributes to community dynamics, including: divisiveness and disconnection within community; self-focused and parallel oppression (i.e. oppressing one's own people); the loss of culture through dispersion, forgetting or assimilation; a sense of inferiority and different-ness that separates youth from their non-AI peers and society; tension between AI communities and outside systems; and a pervasive sense of alienation, anxiety, and depression that characterizes a typical trauma response. One participant stated:

> There is so much grief and it is not expressed. It is acted out. And grief sometimes turns into anger. And then you've got anger, and these kids growing up [thinking] 'I don't want to be around here. These people are mad at me.' And they [youth] don't know that they are not causing it.

It was also noteworthy that, although discussion often centered on challenges, needs, and barriers, as this was an important objective of this study, participants and workgroup members also emphasized the capacity for resiliency, adaptation, and cultural renewal evidenced by AI peoples. There was a sense conveyed by participants that AI cultural strengths and resources could heal the community, shape positive youth development, and enhance relationships between

the Chicago AI community and the broader system if properly understood and leveraged. One participant illustrated the importance of leveraging community strengths, beliefs, and values to heal by saying: "And it's the people that will heal each other from the inside…it's the people who will heal other people from the inside".

Discussion

Our discussion is organized around four prominent themes emerging from this study that we believe are relevant to systems change for this and other AI communities: (1) the need to address the role of historical trauma and internalized oppression in shaping divisions within community and affecting a community's readiness for change, (2) the importance of extensive community mobilization efforts to address community politics, factions of the community, and organizational alliances, (3) the need to honor locally-meaningful conceptualizations of mental health and wellness, and (4) the need for community-based and culturally-relevant clinical services and programs. We address the broader implications of these findings in our conclusions.

Addressing Historical Trauma and Internalized Oppression

Throughout the implementation of this study, participants acknowledged that the collective trauma experienced by AI people over the life course and across generations related to genocide has contributed to the social, political, cultural, and historical dynamics within Indian country (and between Indian country and mainstream society) since colonization. In addition, internalized oppression was recognized to contribute to the politics, divisions, disconnection, perceived loss of culture, invisibility and strained interactions with outside systems. Participants in this study perceived that historical trauma may directly relate to community risk factors, mental health issues, environmental stressors, and stigma about mental health. In addition,

participants perceived that a legacy of trauma and oppression may contribute to the tendency for community members to sometimes divide and work against rather than with each other, even when shared commitment and passion is evident, or to become disconnected and burned out.

To address the impact of historical trauma, an SOC could include education, training, and opportunities for open dialogue. This could take the form of outreach, trainings for community leaders, program directors and community members on historical trauma, its impact on AI communities and organizations, and methods for addressing and healing from its effects. There are national models for community building and healing from historical trauma (for examples, see http://historicaltrauma.com/interventions.html) that could be incorporated into the planning and program development phases of an SOC. An SOC could also incorporate culturally-based training in methods of effective communication and relationship-building to help address the divisiveness and burn-out associated with effects of historical trauma. Such programs exist; for example, the Healthy Native Communities Fellowship (http://www.hncpartners.org) brings teams of AI community members from around the country together for intensive training to become change agents creating wellness strategies for their communities grounded in AI cultural and spiritual teachings. Finally, an SOC may include regular community talking circles or group sessions conducted by trained community facilitators to bring community members together to discuss sensitive topics, such as trauma, racism, and oppression, as well as empower them to problem-solve and plan for the future in a safe and structured setting. The incorporation of these SOC components would constitute a focus on community development and empowerment, prevention, and a reliance on indigenous ways of knowing and supports in order to heal.

Mobilizing Community to Heal Relationships and Division

There was a sense from study participants that the trauma of relocation, combined with the stresses of urban living, the dispersion of the community throughout the metropolitan area, and divisions between AI-serving organizations competing for constituents and resources has led some community members to feel disconnected, uncertain of their place within community, or simply too overwhelmed and stressed to participant in community life in the way they would like. The data also indicated that promoting a sense of belonging to community was a key component in achieving family mental health and wellness.

Therefore, an SOC would need to include innovative methods to mobilize community and address barriers such as geographical dispersion, divisions among community members and agencies, and the invisibility of the AI population within the larger urban service system. To address geographic dispersion and disconnection, community members indicated that recreational activities planned and sponsored by multiple organizations would help to bring people together, build community, create a sense of belonging and empowerment, and enable the sharing of information. To address divisions between community agencies, an SOC might include the creation of a cross-agency collaborative working committee to develop a plan for outreach, education, and coordinated efforts to deliver services. To address the issue of AI invisibility within the larger political and social service system landscape, an SOC would include structures (e.g., the creation of a stakeholder network) to facilitate community mobilization and organizing in order to more effectively advocate about the needs of the community to policy makers at the city and state level. Consistent with Cook & Kilmer's (2010a) work emphasizing the importance of an ecological approach to SOC delivery, such community building and coordination efforts would require that an SOC take an ecological perspective on mental health,

one that honored the holistic impact of family and community factors, and allowed for the promotion of healthy systems in addition to healthy individuals.

Honoring Local Definitions of Mental Health and Wellness

Participants noted that a sense of belonging to community, a strong and stable connection to family and extended family, and youth's belief that community members were supportive and involved in their lives did or could lead to helping youth and families achieve a sense of balance, healthy lifestyle practices, spiritual health, positive coping skills, and feelings of purpose and happiness. Participants discussed the need to promote wellness and prevention, to address the powerful stigma associated with mental illness, and to embrace culturally-relevant conceptualizations of mental health and wellness from a holistic worldview.

To address these needs, an SOC may need to be framed more from a wellness promotion/prevention perspective, rather than as a method to address youth with severe disorders or difficulties. SOCs are traditionally focused on coordinating services for youth with severe emotional and behavioral disorders ("SEBD"). This deficit-based approach may need to be eliminated and replaced with one that promotes a strength-based approach, prevention, and a holistic wellness perspective. A focus on promoting wellness, balance, support and strengthening of the entire family system within the community context is far more consistent with AI values of interdependence, spiritual strength, and holistic well-being than a traditional mental health model focused on identifying a "patient" and creating a plan for clinical services to address deficits and illness in that individual. For example, an SOC that was consistent with AI values might identify a child/family in need of services based on a constellation of risk factors and engage the family in wrap-around services and supports embedded within community and mainstream systems (e.g. school, community agencies). Children/families who already

demonstrate emotional or behavioral difficulties could have additional clinical services added to their wrap-around plan. This shift would be consistent with what has been proposed by Kilmer et al. (2010) in order to address the disconnect between principles and practice and bring SOCs more in line with their family-centered philosophy. In addition, this approach would decrease stigma by promoting the notion that all children and families need supports and services for healthy development and by embedding most services in systems that were mainstream and familiar to families. On the whole, our data suggest that in order for an SOC to be embraced by AI youth and families, it may require a shift from the more traditional systems of deficit-based clinical care and case management services to encompass a broader range of community-based programs and practices that are empowering, health promoting, and holistic.

Implementing Community-Based and Culturally-Relevant Clinical Services

The most common service need discussed was funding for programs and services. The perception was that programs and services within community are fleeting, coming and going with different grants or individuals, but not sustainable due to precarious funding streams and lack of consistent infrastructure. Participants noted barriers such as poor communication between service providers, fragmented services that do not address multiple important contributors to mental health problems (e.g., family stress, community violence, poverty, and unemployment), stigma about mental health services, a lack of trust in providers, and the absence of quality, culturally-informed mental health services for youth. Notably, despite identifying service needs and barriers regarding clinical services, the prevailing notion among participants was that people in community, including youth, prefer to draw on community supports and indigenous relationships (peers, family, and community members) in times of need rather than seeking out mainstream clinical services. This finding is consistent with previous literature summarizing the

lack of informal and everyday supports reported by a range of families participating in SOCs despite the importance attributed to these factors by families (Cook & Kilmer, 2010b).

Findings from this study indicate that a successful SOC for urban AIs would have secure funding, sufficient infrastructure, coordinated and collaborative high-quality services with providers and agencies that work together, well-disseminated information about available programs and services, clinicians who were sensitive to the unique needs of this community and knowledgeable about AI culture (if not AI themselves), and components to address barriers such as lack of insurance and transportation. However, the tendency to rely on indigenous community supports versus the health care system to address mental health issues suggests that programs that build capacity within community, address the various stressors that challenge family wellness (e.g. economic distress, unemployment) and empower community members to take leadership roles in promoting health and wellness through informal support systems would be effective. Services typically incorporated into SOC wrap-around models (but not usually considered traditional mental health services), might emphasize prevention and wellness promotion components such as job preparation and financial literacy programs, violence prevention, youth mentorship programs, education/school support, parent training, and culture-based interventions (e.g. drumming, arts, Native games, storytelling, ceremony) that promote cultural identity and pride. Such an approach would require that SOCs take a family-centered preventative approach to mental health, allowing for services to be provided to entire families and to youth at-risk (vs. only to an "identified patient") and to provide funding to strengthen indigenous resources and supports.

Systems and Policy Changes

These findings also highlight several system/policy changes specific (or at least particularly warranted) in AI communities. First, the expansion of mechanisms of reimbursement to include traditional healers would allow SOCs serving AI communities to formally incorporate traditional ceremony and spiritual practices into their array of behavioral health services, a need consistently identified by AI communities (Gone, 2007). Second, the training and reimbursement of paraprofessionals to deliver services would enable capacity-building within communities so that community members knowledgeable about community and cultural issues were able to serve their own communities. The approach of using paraprofessionals has proven a successful method of service delivery in AI communities (Walkup et al., 2009) and also helps address the issue of a lack of trained providers in rural or remote AI communities. Third, policies could be enacted that facilitate the incorporation of mental health services within existing structures and build on informal supports already available in the community, such as primary care facilities, schools, cultural/community centers, and families. This will foster a more integrated approach and help address barriers related to the serious stigma associated with seeking traditional Western mental health services in many AI communities. Fourth, the alteration of policy to further support prevention services as a primary focus of SOCs will support the incorporation of mechanisms to address historical trauma, institutionalized racism, and the current realities of many AI communities, including poverty and unemployment, so that these issues can be addressed before they manifest in emotional or behavioral difficulties, or diagnosable mental health problems. Finally, policies could be established that require those funded to plan and implement SOCs to include formal, articulated methods of ensuring that their work is consistent with an authentic community-based participatory process, empowering families and communities to support and promote their own

indigenous practices, and helping communities to develop an evidence base to support their culturally-based methods of healing and wellness promotion (i.e. a practice-based evidence vs. evidence-based practice approach). These recommended system/policy changes are supported by our data, but also consistent with previous recommendations for systemic policy changes to behavioral health systems based on a comprehensive review of behavioral health and healthcare in AI communities nationwide (Goodkind, et al., 2010).

Strengths of this study include its focus on a unique and underserved population and use of an innovative qualitative methodology to assess community needs. However, there are limitations in that study design and data analysis that are worthy of note. First, this study relied on participants to self-select their participation and the sample represents only a fraction of the total community. Thus, the study sample may not be representative of the entire urban AI population in Chicago. In addition, though the use of focus groups stimulated discussion, relationship-building, and consensus, some participants may have been uncomfortable discussing more sensitive topics in a group format and thus, may have limited what they shared. Finally, as with all qualitative analysis, though we used a structured coding system and data analytic software to enhance the rigor of the study, coding was completed by two community research assistants and is therefore subjective based on their perceptions of how the text fit with different codes. This bias was alleviated somewhat by the use of a community research workgroup who also reviewed transcripts and completed their own process of identifying themes, which was then compared to what the original coders had identified.

Conclusions

Taken together, findings from this study indicate that an effective SOC for the AI community in Chicago would incorporate methods to strengthen community and family ties, heal

relationships within community, re-connect families to traditional ways, focus on prevention, empower community members to drive program development, and enhance community-based supports. These findings are consistent with community psychology theory, which emphasizes the importance of ecology, community development, diversity, context, collaboration, empowerment, prevention, and participatory action (Rappaport & Seidman, 2000) in affecting individual and social change. Also evident in these findings is as the importance of promoting a psychological sense of community (Sarason, 1974). These findings are consistent with SOC values that emphasize diverse and coordinated community-based services and supports, families as important decision-makers, and the conceptualization of the child from within an ecological perspective (Cook & Kilmer, 2010a; Kilmer, Cook, & Munsell, 2010). However, it has been consistently demonstrated that there is a substantial gap between SOC philosophy and values and actual practice and that this gap may at least partially explain the mixed outcomes in SOC research (Kilmer, et al., 2010). In particular, it has been noted that the family-centered care philosophy of SOC is not supported by current policy (Kilmer, et al., 2010); SOC implementation does not always take into account the ecological perspective, especially as related to the incorporation of prevention and informal supports for families (Cook & Kilmer, 2010a, 2010b); that most current behavioral health systems and policies do not support the implementation of a comprehensive wrap-around model (Bruns, et al., 2010); and that SOCs are not always developed and implemented using an authentic community-based participatory process (Pullman, 2009).

In the context of this previous research, the current study adds support to the notion that systems/policy changes need to occur in order to support the implementation of SOCs that meet the needs of diverse communities and reflect core values of SOC philosophy. Specifically,

consistent with previous literature that has proposed specific system/policy changes in SOC delivery (Cook & Kilmer, 2010a; Kilmer et al., 2010), the findings of this study suggest: (1) support for an ecological focus -- a shift away from a sole or primary focus on clinical services for an identified patient, to address a broader range of programs and services for at-risk youth and families, (e.g., community stressors, poverty, unemployment) with funding to support prevention and the strengthening of informal supports for families; and (2) support for a community-based, family-centered care approach -- an emphasis on family-centered care and family-based decision-making supported by funding for services to parents, siblings and other family care-takers, an authentic involvement of family members in care-planning, and funding to support community development practices that support a sense of community belonging and well-being. The translation of these values, which already define SOC philosophy, into actual policy changes would support the sustainability of SOCs such as the one desired by AI community members – one that is holistic, focused on wellness and prevention, provides services to address broader community stressors, such as poverty and unemployment, and supports the entire family system.

Given the resonance of these findings with both community psychology theory and work on the implementation of SOC in diverse communities, it is likely that these system and policy recommendations have considerable relevance beyond AI communities. Indeed, they may represent critical next steps for transforming behavioral health systems of care so that they meet the needs of diverse communities, fully reflect the philosophies and values by which SOCs were originally conceptualized, and promote effective and sustainable SOCs that produce consistent positive outcomes for youth and families.

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