

DESCRIBING COMMUNITY NEEDS: EXAMPLES FROM THE CIRCLES OF CARE INITIATIVE

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Abstract: The assessment of community needs was one of the key foundations of the Circles of Care planning effort. Grantees identified a range of needs at the child, adolescent, family, programmatic, and community levels. This information, along with an emphasis on the importance of each community's history and culture, served as an important guide for each program as they developed their model systems of care.

As indicated in the *Circles of Care* Guidance for Applicants (GFA), the Circles of Care (CoC) grantees were instructed to include “a process for assessing the needs of the population consistent with the outcome expectations” as part of their plan and design of the model for a System of Care. Thus, one of the initial tasks undertaken by the grantees was an assessment of their community's needs. The overall goals for this assessment were to:

1. Describe the key community-wide historical, socioeconomic, and health contexts for the CoC strategic planning efforts.
2. Determine how many children and adolescents suffer from serious emotional disturbances (SED) in the community.
3. Describe the specific difficulties that these children, youth, and their families struggle with as well as the individual, family, and community strengths that can be mobilized to address these difficulties.
4. Depict community members' perceptions regarding the availability, accessibility, and acceptability of existing services within the community

Data for the Needs Assessment

The CoC grantees were confronted with the daunting prospect of conducting a needs assessment with limited funds and time. Because of these factors, grantees were unable to conduct scientifically rigorous assessments, pinpointing the prevalence and characteristics of the children and adolescents with SED in their communities. Instead, the grantees employed an often-elegant combination of targeted primary data collection, analysis of secondary data, and careful review of the existing scientific literature to depict their communities' needs.

Primary Data

Focus groups and community surveys were the key primary data collection methodologies utilized by the grantees, and were used to identify community perceptions of the difficulties with which children, adolescents, and their families struggle as well as community perceptions regarding the availability, accessibility, and acceptability of existing services. Two grantees used a series of case studies to better understand the characteristics of children and adolescents with SED as well as their service system's responses to these difficulties.

Secondary Data

Secondary data collection was used by most of the grantees to supplement their primary data collection efforts. Secondary data included information from the U.S. Census, service utilization figures from statewide programs such as Medicaid, and information from service organizations such as behavioral health programs, schools, social services agencies, and law enforcement.

Review of Previous Needs Assessments and Research

Because of significant limitations in time and resources, the grantees also turned to the existing scientific literature to develop a variety of estimates for their needs assessments. Several grantees were able to identify important research studies that had been conducted in their communities, and were thus highly relevant for their assessments.

Key Findings

Community Characteristics

The grantees developed rich descriptions of their communities. A number of themes consistently appeared in these assessments, and can be broken into three areas: (a) historical and cultural contexts, (b) sociodemographics, and (c) community health.

Historical and Cultural Contexts

All of the grantees felt strongly that in order to understand the needs of the children and adolescents with SED and their families, it was critical to appreciate the history of their communities and their cultures. While each community's history is unique, all share a history of the denigration of rich cultures through centuries of genocide and cultural oppression. As noted in one grantee report, "in the 500 years since the arrival of White people, American Indians and Alaska Natives have experienced genocide, sweeping epidemics, forced assimilation, boarding schools, involuntary relocations, and displacement."¹ Many grantees noted that this history has compromised the abilities of American Indian and Alaska Native (AI/AN) communities to maintain their cultural practices. In addition, some grantees described how members of their communities struggle both accepting and finding acceptance in the majority culture. As one grantee noted in their review of the results of their community survey, "...[Community members] feel tenuously connected to the Native American community – especially if they are unable to document their tribal affiliations. They also are keenly aware of being outside the majority culture – yet unable to embrace their Native heritage due to lack of understanding of cultural practices and loss of their Native language."² This tenuous sense of connectedness was a particular challenge noted by the grantees located in urban communities, where members of an extraordinary number of tribes with diverse histories, cultures, and healing traditions are attempting to build a shared vision for children's mental health services.³

Indeed, many grantees believe that their communities suffer from a form of "Historical Trauma" that explains many of the socioeconomic, health, substance abuse, and mental health problems that they believe are all too common among community members. Grantees used a variety of terms in addition to Historical Trauma to describe this belief, including "Intergenerational Post Traumatic Stress Disorder," "Internalized Oppression," and "Post-Traumatic Demoralization Syndrome."

Cultural oppression, cumulative and unresolved trauma, [are] most frequently referred to [as] historical trauma and internalized oppression. 'The act of turning our rage upon ourselves, upon our families and our people through distress patterns and hurt that result from the racism and oppression of the majority society, with symptoms of Post-Traumatic Stress Disorder...'⁴

Despite this history, ongoing oppression, and its impacts, all of the grantees emphasized the many cultural strengths that exist within their communities. Grantees saw evidence of this resiliency in a number of areas including population growth, efforts to increase the number of speakers of their AI/AN languages, and the richness of their cultures and networks of traditional healers. As one community member reported: "We keep coming back as a people, although we were conquered, through our spirituality and ceremonies. The buffalo and animals are also returning."⁵ Others identified community strengths from which children, adolescents, and their families can draw support. These included rich traditional resources, extended kinship networks, and vibrant community organizations such as churches, recreational and educational programs. Several grantees noted substantial improvement in high school graduation rates as a sign of the strengthening of their communities: "Educationally, the numbers of Native children in the highest quartile for reading, math, and language arts in rural districts are approaching the statewide average. Educational supports such as the Alaska Native Knowledge Network and the Alaska Rural Systemic Initiative are working to more closely align indigenous knowledge and existing educational programs."⁶

Sociodemographics

A variety of sociodemographic characteristics were cited by the grantees as important for appreciating the contexts of their strategic planning efforts. High unemployment and poverty were the most frequently cited statistics by the grantees (see Table 1 for several examples). Grantees in rural areas also emphasized the geographic isolation of many of the families that they hoped to serve, and that limited transportation options and poor telephone services were significant obstacles to provision of services in their communities.⁷ Others noted their rapidly growing populations and the relatively high percentage of their population 22 years of age and younger (see Table 2) as indicators of both the need for improved children's mental health services and significant potential for positive change in their communities.

As observed in the previous section, several grantees noted the educational gains that are occurring in their communities (although this was tempered by concerns regarding the high prevalence of youth dropping out of school in several grantee communities). Finally, two grantees identified the growth of gaming in their communities as an extraordinary economic

boon that is reshaping their communities and creating new opportunities for their children and adolescents. These opportunities include both direct effects such as employment as well as indirect effects such as improved housing, schools, and scholarships to pursue college and graduate education.⁸

Table 1
Employment, Income, and Poverty in Four Circles of Care Communities

Grantee	Employment Statistics	Income and Poverty Statistics
Cheyenne River Sioux Tribe	78% of workforce unemployed.	Income of 95% of employed fall below federal poverty guidelines.
Choctaw Nation of Oklahoma	7.8% unemployment rate for Oklahoma in 1997 (compared to a US unemployment rate of 4.0%.	35.3% of children living below federal poverty guidelines.
Feather River Tribal Health		29.6% of households in community survey reported an income of less than \$10,000.
Urban Indian Health Board	9% unemployment rate for American Indians living in the San Francisco Bay Area.	15% of American Indians living in the San Francisco Bay area are living in poverty.

Community Health

As in the case of the sociodemographic characteristics reported above, many grantees identified a number of indicators of the health of their communities, and in particular the health of their children and adolescents. Grantees cited many troubling statistics that argue for a significant need for improving family-focused children’s mental health services. These included high arrest, accident, and substance abuse rates for both adults and adolescents. Some grantees pointed to high rates of domestic violence and child abuse and neglect, as well as consequent foster care placements as another important indicator of community health. Several grantees raised concerns about high rates of teenage pregnancy in their communities. Examples of these statistics are displayed in Table 2.

Table 2
Selected Indicators of Community Health from the *Circles of Care*
Communities

Grantee	Health Indicators
Cheyenne River Sioux Tribe	2,311 juvenile arrests in a population of 3,025 children and adolescents (1999-2000). 154 cases of child abuse, neglect, sexual abuse, and endangerment (1999-2000).
Choctaw Nation of Oklahoma	Teen birth rate of 75 per 1,000 (ages 15-19, 1999) compared to a state average of 63.3. 1,244 confirmed reports of child abuse and neglect (1997).
Fairbanks Native Association/ Tanana Chiefs Conference	Chart diagnosis of 3.6% for Fetal Alcohol Syndrome and Fetal Alcohol Effects but providers estimate the rate is closer to 34%. 1,213 substantiated reports of harm to children (1999).
Feather River Tribal Health	A community survey of Native American adults found that 33.2% of respondents had been in jail, prison, or juvenile hall at one time in their life.
First Nations Community HealthSource	Parent's focus group identified substance abuse by family members as a major community risk factor for the development of SED among their children and adolescents.
In-Care Network	2,600 Indian children were served by the State of Montana in 1999, representing 12% of all American Indians residing in this State. Of these 67% were in foster care and 25% are diagnosed with a SED.
Inter-Tribal Council of Michigan	Infant mortality rate of 11.81 per 1,000 (1996-1998) compared to a state average of 8.11. 76.2% of pregnant women received prenatal care (1996-1998) compared to a state average of 81.6%.
Oglala Lakota Nation	The planning committee noted a high prevalence of diabetes and a poor health care system as important indicators of community health.
Urban Indian Health Board	The planning committee noted the high prevalence of alcohol abuse, depression, and domestic violence in the San Francisco Bay Area Native American community.

Table 3
Estimates of American Indian/Alaska Native Population and Prevalence of SED

Grantee	Population Estimates		Children & Adolescents with or at highest risk for SED	
	AI/AN Population	AI/AN Children & Adolescents	Number	Percentage of AI/AN Adolescents in Community
Cheyenne River Sioux Tribe	10,589	3,038	517	17.0%
Choctaw Nation of Oklahoma	31,249	12,553	-	-
Fairbanks Native Association/ Tanana Chiefs Conference	9,748	3,823	500	13.1%
Feather River Tribal Health	8,000	2,080	520	25.0%
First Nations Community HealthSource	11,457	3,437	-	-
In-Care Network	56,068	22,083	-	-
Inter-Tribal Council of Michigan	12,354	6,913	2,007	29.0%
Oglala Lakota Nation	14,562	5,000	1,250	20.0%
Urban Indian Health Board	79,897	10,000	2,250	22.5%

Notes: Some grantees found the information available to them to be too conflicting to produce an estimate of the prevalence of SED among the children and adolescents in their communities. All those that did produce estimates saw them as only a rough guide to the level of need in their communities.

Prevalence of SED

The *Circles of Care* grantees took a variety of approaches in developing their estimates of the prevalence of SED among the children and adolescents residing in their communities, which are displayed in the right-hand columns of Table 3. Most started with federally generated estimates of SED, such as the *Surgeon General's Report on Mental Health* (U.S. Department of Health and Human Services, 1999), which estimated that 5 to 9% of children ages 9 to 17 could be classified as having a SED. Grantees also reviewed the existing research literature, but the studies cited focused on the prevalence of psychiatric diagnoses which would be expected to include some youths who did not meet the severe impairment criteria required for most definitions of SED (Beals et al., 1997; Costello, Farmer, Angold, Burns, & Erkanli, 1997). Grantees also conducted detailed analyses of data from local service agencies such as behavioral health programs, social welfare,

schools, and law enforcement. Several grantees used interviews with service providers to further inform their estimates.

The grantees struggled to develop a best estimate from these different sources. This was largely the result of the difficulty in successfully triangulating the conflicting estimates that emerged from different sources, particularly as the grantees questioned the reliability of the information they had gathered. For example, many grantees were concerned that the federal estimates would not be applicable to their communities and that many children and adolescents with SED were not receiving services in their community.

Providers felt that the ... [project's calculated] estimate of 450 to 500 is too low to serve as an estimate of the number of Native children experiencing SED... Factors contributing to this underestimation... include: (a) the invisibility of many children in need, who do not show up for treatment; (b) provider discomfort with giving children severe diagnoses, on account of the resulting stigmatization...; and (c) the fact that the most severely disturbed children... are referred elsewhere for treatment and are thus not reflected in the... study.⁹

In the end, most grantees viewed their estimates as only a rough guide to the levels of need in their communities. Some grantees concluded that the information they gathered was so conflicting that any estimate would likely be too unreliable to be useful for their strategic planning. These grantees chose not to produce a final estimate, as reflected in Table 3.

In reviewing these estimates, it is particularly notable that all of the grantees settled on figures that were higher than that estimated by the Surgeon General. Whereas the Surgeon General arrived at an estimate of 5 to 9%, the CoC grantees arrived at estimates between 12.5 and 29%. There are several reasons that account for the differences in these estimates and their wide range. First, the Surgeon General's Report focused on children ages 9 to 17, whereas the CoC grantees included a wider age range: 0-22. Second, many of the grantees were uncomfortable focusing on children and adolescents whose difficulties met strict criteria for SED, and chose to include youth at "high risk" for SED. Third, many grantees concluded that the prevalence of children and adolescents suffering from SED in their communities was indeed higher than the available national estimates.

Children, Adolescents, and Families in Need

The CoC grantees developed detailed descriptions of children and adolescents in need. Grantees gathered information from community members and treatment providers as well as administrative and clinical

records. Some grantees also drew information from policy and research publications. Key findings are summarized below and in Table 4.

The grantee communities identified a number of common characteristics among the children and adolescents with SED in their communities. Suicide and related-behaviors as well as juvenile delinquency were identified by most of the grantees as symptoms and behaviors of particular concern. Posttraumatic Stress Disorder, Attention Deficit/Hyperactivity Disorder, Major Depression, and Conduct Disorder were the most common diagnoses from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV); (American Psychiatric Association, 1994) identified by providers as being typical among children and adolescents with SED. Grantees also identified comorbid substance use as an important manifestation of SED among the children and adolescents in their communities.

In terms of families, many grantees indicated that children with SED come from single-parent families. They also identified substance abuse and mental health problems among parents of children and adolescents with SED as an all too common situation in their communities. A few grantees felt that families with children and adolescents with SED were often poorly connected with their communities and cultures.

While the above methods provided the grantees with information about the children and adolescents with SED and families as a group, the uniqueness of each child and family was lost in these groupings. To address this weakness, some grantees also conducted case studies to explore needs on a more individual basis. While the case study findings were consistent with the group data described above, the grantees gained a number of additional insights from this exercise. For example, one grantee's case studies documented poignantly the multiple layers of difficulties – health, mental health, substance abuse, domestic violence, and learning problems – that were characteristic of these children and adolescents. These findings reinforced the planning committee's commitment to creating coordinated, multi-sector, and multi-modal wrap-around services.¹⁰ Another grantee community documented similar findings in its case studies, but also noted that serious emotional problems can emerge at very young ages and can persist and sometimes worsen through childhood and adolescence.¹¹

Availability, Accessibility, and Acceptability of Services

In this component of the needs assessment, grantees developed a more complete understanding of the way services are perceived by people in the community. The grantees addressed three specific questions: (a) What services are available in the community?; (b) How accessible are they to children, adolescents, and families in the community?; and (c) How acceptable are they?¹² Key findings from this exercise are outlined in Table 5.

Table 4
Key Characteristics of Children and Adolescents with SED and their Families

Grantee	Key Findings
Cheyenne River Sioux Tribe	<u>From Mental health programs:</u> suicide ideation, attempts and gestures; attention deficit disorder, depressive disorders, family relational problems. <u>From youth interviews:</u> substance abuse, gangs/violence, behavioral incidents, no family guidance. <u>From parent interviews:</u> substance abuse, gangs, behavioral acting out, no role models, no cultural awareness.
Choctaw Nation of Oklahoma	<u>From focus groups:</u> A child may suffer from SED if they – attempt suicide; constantly lie or steal or get into troubles; are quiet, too clingy, and starved for love; are restless, can't concentrate, and don't pay attention; constantly cry, are nervous or uneasy, and unusually upset; are destructive towards others or objects; are unable to study.
Fairbanks Native Assoc./ Tanana Chiefs Conference	<u>From provider surveys:</u> <i>Most common DSM-IV disorders:</i> adjustment disorder, attention deficit/hyperactivity disorder, major depressive episode, alcohol dependence. <u>From community surveys:</u> <i>Problems in rural and urban households</i> – depression, stress, chronic fatigue/tiredness, anxiety/nervousness.
Feather River Tribal Health	<u>From provider surveys:</u> <i>Common reasons for entry into services</i> – substance use problems, social problems, family/support group problems, conduct problems. <u>From community surveys:</u> <i>Problems in families</i> – alcohol-related problems, domestic violence, post traumatic stress disorder and intergenerational stress, unemployment.
First Nations Community HealthSource	<u>Common themes across surveys and focus groups:</u> <i>Presenting problems of children and adolescents</i> – aggression, depression, substance abuse problems, anger management problems, acting out behaviors, suicidal tendencies, negative attitude. <i>Risk factors for development of SED</i> – substance abuse by family member, domestic violence, child abuse/neglect, disintegration of family unit, acculturation issues, peer pressure, lack of parental guidance/parents unable to parent their children, breakdown of family system, poverty, lack of finances.
In-Care Network	<u>From State of Montana administrative records:</u> <i>Most common DSM-IV diagnoses/diagnostic groupings</i> – Attention Deficit/Hyperactivity Disorder, Disruptive Behavior Disorders, Mood Disorders, Adjustment Disorders, Anxiety Disorders, Substance Abuse.
Inter-Tribal Council of Michigan	<u>From community mental health service provider report:</u> <i>Diagnostic categories of children and adolescents with SED who received services</i> – attention deficit/hyperactivity disorder; adjustment disorder, learning disorder, oppositional defiant disorder, conduct disorder, autistic disorder, depressive disorders, substance use disorder, psychotic disorders
Oglala Lakota Nation	<u>From parent surveys:</u> <i>The most pressing needs of their children</i> – problems with paying attention, flunking school, dropping out of school, not believing much in Creator or God, not interested in helping the community, family conflict, attachment (emotional bonding) problems, feeling nervous a lot. <u>From teacher surveys:</u> <i>Prevalent problems among the youth at their school</i> – behavioral and emotional problems (e.g., hitting, yelling, skipping class) and trouble with learning and connecting (e.g., disrespectful, not motivated)
Urban Indian Health Board	<u>Chart review:</u> <i>Most common problems among children and adolescents in treatment</i> – substance use disorders, anxiety disorders, mood disorders.

Table 5
Circles of Care Community Perspectives of the Availability, Accessibility, and Acceptability of Services

Grantee	Key Findings
Cheyenne River Sioux Tribe	<p><u>Availability:</u> Youth recommended sports activities, counseling, substance abuse prevention and treatment services, and tutors be made more available. Parents recommended the development of youth/recreation center, more counseling services, and more programs to increase awareness regarding the negative consequences of substance abuse. Elders recommended that cultural practices should be added to the current system of services.</p> <p><u>Accessibility:</u> Community focus groups identified transportation to the Agency town as a major barrier to accessing services for families in the outlying communities. Cancelled appointments and long waits for services were also cited as a barrier as was the lack of providers who speak and understand Lakota.</p> <p><u>Acceptability:</u> <i>"While the Project did not specifically ask if... residents were completely satisfied with current services, the variety of problems or areas needing improvement by those surveyed... indicates there is a need to improve existing services."</i></p>
Choctaw Nation of Oklahoma	<p><u>Availability:</u> <i>"The need for communities and individuals to have access to information on available services was the primary concern for many of the communities. Individuals did not always know where to start when seeking help."</i></p> <p><u>Accessibility:</u> Barriers most often listed – poverty, lack of knowledge of services, lack of transportation.</p> <p><u>Acceptability:</u> <i>"Many of the participants... [felt that] unless a... family member had special needs not much thought was given to services."</i></p>
Fairbanks Native Assoc./ Tanana Chiefs Conference	<p><u>Availability:</u> <i>"There is not a mechanism in place to gather information or to find out what would work best..."</i></p> <p><u>Accessibility:</u> <i>"The system is extremely hard to access and obtain services... There is a reluctance to label the children in need within the school system."</i></p> <p><u>Acceptability:</u> Stigma, concerns about lack of confidentiality, and inconsistencies within systems and across providers all raised questions regarding the acceptability of existing services.</p>
Feather River Tribal Health	<p><u>Availability and Accessibility:</u> <i>"On the whole it appears that services are available, though they are difficult at times to access due to filled appointments and issues of transportation."</i></p> <p><u>Acceptability:</u> <i>"There is also the issue of cultural competency on the part of agency staffs concerning their knowledge about the Native American community."</i></p>
First Nations Community HealthSource	<p><u>Availability:</u> Need for more counseling, cultural and recreational activities, educational support programs, and parent education and parenting classes. Also noted that many families are unaware of the services available to them.</p> <p><u>Accessibility and Acceptability:</u> Lack of transportation, inability to pay for services, managed care rules and regulations, scheduling difficulties, language and lack of cultural sensitivity were all identified as barriers to accessing care.</p>

Table Continues

Table 5 Continued
Circles of Care Community Perspectives of the Availability, Accessibility, and Acceptability of Services

Grantee	Key Findings
Inter-Tribal Council of Michigan	<p>Availability: <i>"Community members reported that in many instances, they do not know what kinds of services their tribes are providing, let alone what state agency services are available."</i></p> <p>Accessibility and Acceptability: Barriers to accessing services included inability to pay for services, lack of transportation, lack of confidentiality, fear of stigma, racism, and lack of trust.</p>
Oglala Lakota Nation	<p>Availability: <i>Parent-identified service system gaps – family counseling, mentoring, individual counseling, drug and alcohol education. Youth-identified service system gaps: individual counseling, violence/gang prevention, family counseling, drug and alcohol education.</i></p> <p>Accessibility: Long travel distances and lack of transportation was noted as the primary barrier to accessing services.</p> <p>Acceptability: <i>"Regarding the relationship between service providers and families, on a 1 to 5 scale with 1 representing 'highly included as empowered and full partner' and 5 representing disempowered and not given any chances to partner,' parents responses had a mean... of 2.74."</i></p>
Urban Indian Health Board	<p>Availability, Accessibility, and Acceptability: <i>"There are extensive mental health and substance abuse service systems in San Francisco and Alameda County. These services are available through a managed care system that is not well utilized by Native people. During the past year the California Legislature Joint Committee on Mental Health Reform held hearings on barriers that minority groups experienced in accessing services. They concluded that cultural competency is an unrealized goal and recommended that strategies be developed to achieve a cultural competent system of care' linking school, health, and social service agencies."</i></p>

A common theme was that community members were largely unaware of what services are available in their community. The most common themes regarding the accessibility of services for grantees serving rural areas was the geographic isolation of many families and difficulties in securing transportation to access services. In urban areas, income, managed care, and administrative barriers such as difficulty scheduling appointments were most common. In terms of acceptability, the lack of cultural competency of service providers was the major concern with regard to the services available to community members in almost every grantee community.

Impact on the Planning Process

The results of the community needs assessment had a direct impact on the planning process, as grantees incorporated into their final models for a System of Care those elements that were identified by the community and

providers as lacking or desired services for their children as well as modifications in services currently available. In particular, they were able to address the availability, accessibility, and acceptability concerns that were identified through the community needs assessment, including such things as developing satellite clinics to address the lack of transportation and phones, special training programs to get more AI/AN providers trained and credentialed, and traditional support systems to focus on the strengths that the community has to offer the system. The process emphasized the very real differences between what the community saw as its needs and what providers felt were important components for a System of Care as well as the grantees' own ideas of what would best serve their community.

The Community Readiness Model, developed by a team of researchers at the Tri-Ethnic Center for Prevention Research (Donnermeyer, Plested, Edwards, Oetting, & Littlethunder, 1997; Jumper-Thurman, Plested, Edwards, Helm, & Oetting, 2001; Kumpfer, Whiteside, Wandersman, & Cardenas, 1997; Oetting, et al., 1995; Plested, Smitham, Jumper-Thurman, Oetting, & Edwards, 1999), was used by two of the grantee sites in their planning process. Specifically, it was used to assess the level of community readiness to accept and address the development of a service system plan as well as to assess the readiness for implementing pilot projects. Key informant surveys were used to assess readiness with community members (i.e., providers of services or users of the services available) responsible for the planning, funding and implementation of service systems and knowledgeable about their communities. The information gathered through this method was used to assist in providing knowledge about service gaps, service needs, the community's willingness to use the services, and established the priorities of the community. The model also assisted in generating community/tribal collaboration and investment so that the model for a System of Care was community specific and culturally appropriate.

The community needs assessment resulted in a number of challenges and opportunities that also had an impact on the planning process. One of the challenges the grantees faced was the timing of this task to be completed during the first year of the initiative. Grantees were asking for community input on often-sensitive information when trust had not yet been established. Trust, not only between community members but also providers and other agency personnel, was an essential element in this process, in order to obtain cooperation and be more assured that honest feelings were being shared about community needs. Trust also ensured the provision of accurate information. The issue of trust was also a factor with regard to the competitiveness for funding that grantees observed between programs. Once trust had been established, the programs were more willing to work together and share resources. For these reasons, some grantees suggested that this task be initiated during the second year of the initiative, after rapport had been established.

Another challenge included an ethical dilemma: how does one garner community input and support for, and design a comprehensive System of Care to address their identified needs, when funding to implement such a system was not guaranteed? The need for immediate services was very great in many of the grantee communities, and it was difficult for some community members to understand that this initiative was only a planning effort. However, many did come to comprehend the importance of such an effort and became strong supporters. This initiative was developed, in part, to strategically place AI/AN communities in a position to apply for the SAMHSA-funded *Comprehensive Community Mental Health Services Program for Children and Their Families* initiative to implement their System of Care. Thus, many of the grantees focused on this necessary funding goal. In contrast, some communities did submit applications to fund various components of their System of Care as immediate needs and opportunities for funding were identified during the initiative. However, for the majority of grantees, the concerns regarding funding to implement and sustain such a system continued throughout the initiative.

Although some grantees found it a challenge to gather information from programs that might not be forthcoming with information, possibly due to the competition for funds and other resources, an opportunity was provided when the grantees were able to share information that was collected through their needs assessment. These programs and agencies then used the needs assessment information in submitting grant applications that in many cases were successfully funded, thereby bringing needed and desired services into the community. Thus, as a result of the efforts on this initiative, many agencies and programs came to realize the need to work together for the success of the new system. The community itself became more involved in the process, with members often volunteering to assist in the planning effort. In addition, the information gathered through the needs assessment was used to educate community members and providers about the prevalence of SED and other related mental health concerns in their community.

Conclusions and Implications

Overall, grantees found that there are many children and adolescents suffering from SED and subsequent difficulties often manifest themselves in complex ways. Grantees emphasized that these difficulties can only be understood by appreciating the history of their communities, both in terms of the historical trauma experienced by their peoples as well as their impressive resiliency. Grantees noted that community members feel that a variety of services are lacking in their communities, that they are difficult to access, and that many services fail to provide culturally competent services. For the communities, participation in the community needs assessment was an opportunity for their voice to be heard and to identify the needs that they felt were important to address as part of a comprehensive System of Care. The

initiative also reinforced the need for community support in undertaking such a planning effort and its eventual success within the community. For evaluators, this effort emphasized not only the need to listen to what the communities had to say but to involve them in the process as much as possible. The effort also demonstrated the utility of incorporating a variety of methods, such as those identified previously, to gather information on community needs from a variety of sources. For policymakers, it emphasized the need to address other complex economic and social issues (e.g., unemployment, poverty, historical trauma) as a mechanism for impacting the lives of youth and their families who experience a SED. The initiative also served as a basis for further planning and external funding. In conclusion, the CoC grantees conducted needs assessments that were impressively thorough given the limited time and resources available for this task. These needs assessments formed an important foundation for the grantees' strategic planning effort and provided the basic background information critical to securing community support, as well as external funding. Subsequent to the needs assessments, community support and external funding are essential elements in further planning, system development, and service delivery.

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References

- American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth edition (DSM-IV)*. Washington, DC: American Psychiatric Association.
- Beals, J., Piasecki, J., Nelson, S., Jones, M., Keane, E., Dauphinais, P., Red Shirt, R., Sack, W., & Manson, S. M. (1997). Psychiatric disorder among American Indian adolescents: Prevalence in Northern Plains youth. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36, 1252-1259.
- Costello, E. J., Farmer, E. M., Angold, A., Burns, B. J., & Erkanli, A. (1997). Psychiatric disorders among American Indian and White youth in Appalachia: The Great Smoky Mountains Study. *American Journal of Public Health*, 87, 827-832.

- Donnermeyer, J. F., Plested, B. A., Edwards, R. W., Oetting, G., & Littlethunder, L. (1997). Community readiness and prevention programs. *Journal of the Community Development Society, 28*, 65-83.
- Jumper-Thurman, P., Plested, B. A., Edwards, R. W., Helm, H. M., & Oetting, E. R. (2001). Using the Community Readiness Model in Native communities. *Health Promotion and Substance Abuse Prevention Among American Indian and Alaska Native Communities: Issues in Cultural Competence, CSAP 9*, 129-158.
- Kumpfer, K., Whiteside, H. O., Wandersman, A., & Cardenas, E. (1997). *Community readiness for drug abuse prevention: Issues, tips and tools*. Rockville, MD: National Institute on Drug Abuse.
- Oetting, E. R., Donnermeyer, J. F., Plested, B. A., Edwards, R. W., Kelly, K., & Beauvais, F. (1995). Assessing community readiness for prevention. *International Journal of the Addictions, 30*, 659-683.
- Plested, B., Smitham, D. M., Jumper-Thurman, P., Oetting, E. R., & Edwards, R. W. (1999). Readiness for drug use prevention in rural minority communities. *Substance Use & Misuse, 34*, 521-544.
- U.S. Department of Health and Human Services. (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services.

Footnotes

¹Urban Indian Health Board

²Feather River Tribal Health

³First Nations Community HealthSource

⁴Inter-Tribal Council of Michigan

⁵Cheyenne River Sioux Tribe

⁶Fairbanks Native Association/Tanana Chiefs Conference

⁷Cheyenne River Sioux Tribe

⁸Inter-Tribal Council of Michigan, Feather River Tribal Health

⁹Fairbanks Native Association/Tanana Chiefs Conference

¹⁰Inter-Tribal Council of Michigan

¹¹Fairbanks Native Association/Tanana Chiefs Conference

¹²The grantees also conducted a detailed description of the services present in their communities. This is presented in a separate section of this Special Issue.

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