WORDS HAVE POWER: (RE)-DEFINING SERIOUS EMOTIONAL DISTURBANCE FOR AMERICAN INDIAN AND ALASKA NATIVE CHILDREN AND THEIR FAMILIES

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Abstract: Circles of Care grantees were provided the opportunity to develop a locally relevant definition of serious emotional disturbance (SED) that would be used to define what type of emotional, behavioral, and mental disability would be required to receive services. After conducting detailed assessments of the definition in the guidance for applicants and the definitions used by others in their respective states, seven of the nine grantees developed their own local, project-specific definitions through the participation of community focus groups and Advisory Councils. The definitions for SED developed by rural grantees all included American Indian and Alaska Native concepts specific to each tribal community's culture; the urban grantee's definition was purposely focused for reaching out to non-professional members of the community. This opportunity for the communities to redefine SED not only provided each community with a definition which would be more culturally specific, but also proved to be an extraordinary exercise in empowerment and self-determination.

The second component of the Circles of Care (CoC) evaluation process was to develop a locally relevant definition of serious emotional disturbance (SED). The CoC guidance for applicants (GFA) allowed grantees to define what kind and level of emotional, behavioral, or mental disability would be required for eligibility for services under their strategic plans. This allowance was important for several reasons. First, the GFA anticipated that the term SED might be perceived as stigmatizing, and that some communities might be concerned that such labels could impact the future opportunities for children and families who would be served in these new systems of care. Second, some communities might prefer strength-based conceptualizations of need in place of the deficit-based concepts used in standard definitions of

SED. Third, it was anticipated that DSM-IV conceptualizations of dysfunction might map poorly onto local conceptualizations of health and illness. Fourth, it was also clear that the definition of the target population would have significant implications for the design of a model system of care. For example, a broadly defined target population would likely require greater capacity within the model systems of care and might require a broader array of services.

Because of the critical importance of characterizing each community's concept of SED, as well as that of defining the target population for the model system of care, each grantee developed a process for examining the standard definition of SED as described in the GFA and accepting, modifying, expanding, or replacing this definition as appropriate for the community to be served. Therefore, the grantees pursued a dual approach to defining SED for their programs. First, most grantees conducted detailed assessments of the CoC GFA definition as well as the definitions used within their communities by other health, education, and human service organizations. Evaluation staff researched and compiled these various definitions, and these assessments were conducted by CoC project staff, often in conjunction with each grantee's project Advisory Board (which for most grantees included representation by parents, youths, elders, treatment providers, and upon occasion, elected officials). Some grantees brought these definitions to focus groups or culturally appropriate alternatives such as Gatherings of Native Americans (GONA's) for further review. Second, seven of the grantees developed their own local, project-specific definitions of SED. These definitions were developed through the participation of community focus groups with substantial involvement from project staff and their Advisory Boards.

Assessment of Existing Definitions

Grantees gained a number of important insights through their detailed analyses of existing definitions of SED. For example, one grantee identified seven different SED definitions that were used by various service organizations within their community. These included two federal definitions (the Substance Abuse and Mental Health Services Administration as well as the Bureau of Indian Affairs), two state definitions (from mental health and education departments), as well as several definitions that were developed locally. Such a wide range of definitions would clearly raise challenges for developing a wrap-around approach to service delivery. Other challenges included the reliance on only a subset of DSM-IV diagnoses, or specific diagnostic categories. For example, the Fairbanks Native Association/Tanana Chiefs Conference group found that "the [state Department of Education definition] does not include children with Conduct Disorders, Substance Abuse, Fetal Alcohol Syndrome or Fetal Alcohol Effects, or Attention Deficit/Hyperactivity Disorder." Some grantees were also troubled by the impairment component of the standard definition of SED, finding it overly restrictive and precluding services

for youth at high risk for developing more severe emotional and behavioral problems. For instance, the Urban Indian Health Board community in Oakland felt strongly about avoiding the use of labels, including SED. Rather than focusing on treatment, this group preferred directing their efforts toward preventing at-risk youth from developing problems, and felt that the use of the term SED deterred them from this focus. As one Oakland community member said: "Let's just call them 'urban kids.'" As a result, the discussion surrounding the redefinition of SED was uneasy and focus group participants would either draw a blank or express their dislike for labels and redirect the discussion to another topic.

Perhaps most important was the common sentiment that the available definitions of SED did not incorporate traditional American Indian and Alaska Native (AI/AN) perspectives. For example, the existing SED definitions are deficit- rather than strength-based, fail to emphasize the important family and community contexts of emotional and behavioral difficulties, and fail to note that some of these difficulties may be part of an individual's and family's life path. For example, the In-Care Network in Billings, Montana stated, "There is a strong value in Native tribal cultures of the Northern Plains region that says every person, no matter what age – from infants to elders – has the right to follow their own path and that we all bring a gift to the whole community. That value does not allow room to dwell on deficits."

Decision to Pursue a Program-Specific Definition

Following their analyses of existing definitions of SED, the grantees were confronted with the decision of whether or not to develop their own, program-specific definition of SED. For seven of the grantees, the many concerns regarding existing definitions led them to pursue new, community and culturally appropriate definitions. For the other two grantees, including the need for a new definition was less clear. For example, the In-Care Network was concerned that the whole concept of SED was incompatible with the cultures of the tribes they served in predominately rural Montana settings.

An important urban-rural distinction emerged through this decision process regarding the development of a local, more culturally grounded SED definition. First Nations Community HealthSource, serving the urban AI/AN community in Albuquerque, did not think an additional definition would aid their efforts to serve children and adolescents with emotional problems and their families. This was particularly true of their setting because they had to communicate and interface with the existing and extensive urban system of care and its many non-Native organizations that were already using a confusing range of SED definitions. The Urban Indian Health Board, serving the urban AI/AN community in the San Francisco Bay area, came to a similar conclusion regarding a clinical definition, as they felt such a definition would interfere with their plan to serve all AI/AN children and adolescents through

a variety of funding streams, many of which would mandate their own definitions. As they noted,

> The Circles of Care has struggled with the definition and the usage of the term "severely emotionally disturbed" (SED). We prefer not to use this term when we don't have to. The Circles of Care is designed to serve all children, regardless of whether they are labeled SED according to appropriate state and federal definitions. Our system of care has many different funding streams. Service provided through funding that depends upon DSM-IV classifications will comply with legal definitions of SED.

Instead, the Urban Indian Health Board, in response to the serious community concerns regarding the labeling of their children noted earlier, replaced the term SED entirely in their community-focused work by instead saying the project would serve "our most needy and vulnerable children." At the same time, the Urban Indian Health Board worked within the existing clinical definitions of SED as they formed partnerships with other human services agencies and developed grant applications to expand their own services

Program-Specific Definitions of SED

The definitions of SED developed by the seven CoC grantees that chose to purse this effort are reproduced in Table 1. While each grantee took a different approach and arrived at unique definitions of SED, a number of characteristics are common to many of these definitions.

First, three of the grantees used words or phrases from their own languages, thus emphasizing the placement of their definition within the context of their community's culture. Second, most definitions emphasized the community context – that SED not only affects the individual but also affects the family and community. This emphasis was quite different from standard definitions of SED, which instead emphasize that SED is the illness of an individual that manifests itself through functional impairment within the family, at school, or in the greater community. Thus, consistent with the notion of the relational worldview (Cross, Earle, Echo-Hawke Solie, & Mannes, 2000), CoC grantee definitions served to emphasize the powerful interconnectedness of their community members.

A number of other characteristics of these definitions are particularly notable. All used AI/AN concepts such as disharmony, inability to maintain "balance," vulnerability, and the spiritual nature of these difficulties. The two grantees serving Lakota communities included in their definition that impacts of the outside world, both in historic and contemporary terms, are a major cause of SED among the children and adolescents in their communities. In

Table 1
Definitions of Serious Emotional Disturbance from Seven *Circles of Care* Communities

Grantee	Definition
Cheyenne River Sioux Tribe	*"The project has redefined SED as 'Unci Maka Ta Cinca' (Grandmother Earth's Children):* *1. Children who do not function well with family and community members. These children have strong mixed emotions.* *2. Children experience multiple emotional disturbances such as lack of capability to cope with love and hate caused by historical trauma, alcohol, abandonment, lack of spirituality, identity loss, physical abuse, spousal abuse, elderly abuse, child abuse, death, denial, teen pregnancy, parent/child conflict, parental neglect, dependence, low esteem, poor school performance/attendance, absent parent, poor romantic relationships, mental illness, dishonesty, depression, anxiety, stress, anger, fear, guilt, sorrow, greed, jealousy, ignorance, idleness, doubt, shame, and poverty. Also, SED comes from outside the realm of Lakota Culture."*
Choctaw Nation of Oklahoma	*Emotional disturbance is a temporary disharmony often involving the family, school, and community, which may affect the mental, physical, spiritual, and/or emotional well being of its members."*
Fairbanks Native Assoc./ Tanana Chiefs Conference	*"SED is a temporary disharmony involving the community, school, and family that affects the physical, emotional, spiritual, and intellectual well being of its members. The healing of our children, families, and communities is a flexible, evolving process that returns us to our most basic belief that children are precious (ch'eghutsen')."*
Feather River Tribal Health	*Severe emotional disturbance in Native American children can be an emotional, behavioral, or spiritual disorder. If a child is ignored, put-down, or does not otherwise feel valued, he or she may become depressed, have thought disorders, or engage in deleterious conduct or other harmful activities that adversely impact his or her health and well-being, that of the family and that of the Native American Community."*
Inter-Tribal Council of Michigan	*"Unable to maintain balance that enables a person to function within community context, mind, body, and spirit. Without intervention, this state of imbalance will continue for more than one (1) year."*
Oglala Lakota Nation	*"Children with SEDs are (Sacred) Children from families who have experienced trauma. Many of these children are victims of sexual abuse who feel unloved and disconnected from the community. They and their families suffer from the symptoms of historical wounding, such as shame and anger, and are in need of healing of the spirit. The shame and anger are acted out in behaviors such as chemical addiction, sexually acting out, disrespect toward elders and parents, deep sadness, suicide attempts and fighting, stealing, violent acts, nervousness, gang participation, and problems succeeding in school."*
Urban Indian Health Board	*"The most vulnerable and needy children in our community."*

addition, several grantees developed a list of specific difficulties that children with SED are likely to suffer. For example, the Fairbanks Native Association/ Tanana Chiefs Conference identified the following as indicators of SED: suicide attempt, substance abuse, violence, fetal alcohol syndrome/fetal alcohol effects, and individual/collective generational trauma.

Conclusions

The analysis of existing definitions of SED and the new definitions that six of the grantees developed are among the most important products of the CoC initiative. What may be less clear, but is perhaps of more lasting importance, is the transforming nature that these exercises had on the grantee staff, their community partners, and the planning effort as a whole. The opportunity to discuss, analyze, and reconstruct the concept of SED was, for many grantee communities, an extraordinary exercise in empowerment and self-determination. In the end, rather than being governed by externally imposed, existing definitions, the grantees gained control of these definitions themselves. This was even true of those grantees that did not elect to develop definitions of their own, as they came away from these exercises with a greater understanding and appreciation of the nature of these definitions, their utilities and strengths, as well as their substantial weaknesses.

Examining the definition of SED energized communities to think in novel and creative ways. This exercise suggested alternative possibilities to existing services and Western understandings regarding children's problems. For many grantees, these new local definitions provided important guidance to their planning efforts, always grounding services within cultural understanding. Through this process, CoC communities became further empowered to envision how culturally appropriate services for AI/AN children and their families in their local communities might look, and further determined to make them a reality.

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