**Systems of Care in Tribal Communities Case Study**[[1]](#footnote-1)

By

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**Abstract:** *This case explores the complexity of serving Native American children with severe emotional disturbances (SED). Part I examines the prevalence of mental health problems in Native American children and adolescents and the availability of appropriate mental health services in American Indian communities. The movement toward a system of care model for treatment of SED, where fractured services are weaved together to more effectively serve children with serious mental health needs in resource-challenged environments, is also described. Part I tells the story of the development and implementation of the Circles of Care program, which allowed tribes and tribal organizations to create plans for culturally appropriate systems of care. In Part II, the case concludes with two fictional examples of what life is like for a family with a child experiencing a SED.*

Part I: Services for Native American children with Severe Emotional Disturbances

Mental Health in Native American Communities[[3]](#footnote-3)

There is a scarcity of studies on the mental health of Native American children and adolescents, which makes comparing the mental health of American Indian/Alaska Native youth with that of other ethnic and cultural groups in the United States difficult. In part, this is due to a previous generation of social scientists overemphasizing negative beliefs about American Indians, promoting stereotypes of Native Americans as “sick” or “suicidal” (Trimble, 2000). This characterization led to reluctance by tribal groups to support more research in their communities.

Despite the lack of hard research, existing evidence suggests a high rate of mental health problems among Native American children and adolescents. Citing the *American Indian Children’s Mental Health Services: An Assessment of Tribal Access to Children’s Mental Health Funding and a Review of Tribal Mental Health Programs* (SAMHSA, 1998), McNevins and Shepard-Erickson (2001) estimated that one in 11 Indian children suffers from a serious emotional disturbance (SED), a rate considerably higher than the national average. Indian Health Service (IHS) estimates suggest that suicide rates for American Indians/Alaska Natives 10–24 years of age are approximately 2.5 times higher than national averages (May, 1990). According to the IHS, homicide has been the second leading cause of death among American Indians aged 1–14 and the third leading cause of death among those aged 1–24. In addition, Beiser et al. (1998) found that at approximately nine years of age, many American Indian children experience marked declines in academic performance and increases in depression and acting out.

As indicated by McNevins and Shepard-Erickson (2001), the ratio of mental health service providers to Indian children has been a dismal 1:25,000. Congressional appropriations for the IHS, the key federal agency responsible for the provision of mental health service to Native American people, enable IHS to address only 43% of the known need for mental health services in Native American populations (Dixon, Mather, Shelton, and Roubideaux, 2001).

In addition, few professionals are trained in child and adolescent mental health work with Native American children. A Congressional report reviewing the mental health needs of American Indian/Alaska Native adolescents and the services available to them revealed that the IHS had funded only 17 mental health providers who were trained to treat adolescents and children (U.S. Congress, 1990). Also in question is the cultural competence of the clinicians and programs that do provide mental health services, as well as the cultural appropriateness of services (Novins, Fleming, Beals, and Manson, 2000).

The mental health issues of Native American children are best understood in the context of historical trauma. Historical trauma or wounding refers to the effect of historical events and social reality on the psychology and behavior of generations of individuals over time. Moane (1994) notes that psychological patterns inherited from colonization may be passed on through family dynamics. Although controlled research on historical wounding is lacking (Lee, 1994), Moane (1994) states that colonialism used mechanisms of control including physical coercion, sexual abuse, economic exploitation, political exclusion, and control of ideas and culture. These mechanisms have led to dependency, fear, ambivalence toward the colonizer, suppression of anger and rage, a sense of inferiority, self-hatred, loss of identity, violence among Native American people, and vulnerability to psychological distress. Although the specific effects are largely unknown, historical trauma is understood to be a root cause of the suffering of Indian families today (Moane, 1994).

However, along with the high number and rate of mental health problems among Native American children and adolescents there exists a great resilience, strength, and vitality of Native American groups. This resilience is not typically measured. Also not measured are the effects of traditional spirituality, language, and participation in ceremonies (Beiser et al., 1998; Garrett, 1999).

Systems of Care for Children with Severe Emotional Disturbances

SED is aterm describing serious mental illness in children that may include depression, behavioral issues, and impaired functioning in a number of areas of life. The Individuals with Disabilities Education Act (IDEA) defines SED as “a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance:

* An inability to learn which cannot be explained by intellectual, sensory, or health factors.
* An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
* Inappropriate types of behavior or feelings under normal circumstances.
* A general pervasive mood of unhappiness or depression” (U.S. Department of Education, 2011).

Historically, there has been a paucity of services for children with SED. A 1969 report from the Joint Commission on the Mental Health of Children indicated that children with SED were being treated inappropriately, placed in excessively restrictive settings, and denied access to multiple services. More than a decade later, a Children’s Defense Fund study conducted by Knitzer and Olsen (1982) confirmed these reports. Knitzer and Olsen documented that two-thirds of the nation’s children with SED were not receiving needed services.

As a result of findings such as these, Congress appropriated funds for programs administered through the Center for Mental Health Services (CMHS). CMHS leads federal efforts to treat mental illnesses by promoting mental health and by preventing the development or worsening of mental illness when possible. Through the CMHS, federal funding has been invested in building and operating children’s mental health services that use the “system of care” values and principles.[[4]](#footnote-4)

Systems of care initiatives are meant to create interagency systems allowing easy movement from one service to another. The goals of these systems are to: ensure children are served in the least restrictive setting; ensure the needs of cultural and ethnic groups are addressed; include multiple agencies in the development of systems (such as schools, substance abuse treatment providers, and mental health providers); make families an integral part of the planning process; and give numerous mental health agencies an equal chance in the process.

Research on the effectiveness of systems of care as an intervention has been scarce, and the results are inconsistent at the child and family outcomes level. System of care studies have shown that system coordination alone improves access to services for children and families and satisfaction with services, as well as results in reduced hospitalization and other restrictive forms of care. However, these studies have also shown that clinical outcomes for children—for example, alleviation of symptoms, functioning, or reduction of impairments—were the same for children receiving coordinated services through systems of care and receiving usual services (Hoagwood, Burns, Kiser, Ringeisen & Schoenwald, 2001). However, the process of defining and measuring the success and effectiveness of systems of care as an intervention is still in its infancy. For example, current research on the effectiveness of systems of care as an intervention has only followed youth for a short time period (6 months to two years) and this may be too short a time frame to document any significant changes. According to Farmer (2000), the field has not clearly specified when desired outcomes should be documented and what conditions are necessary to build on changes after treatment has ended.

**Circles of Care**

Although service demonstration grants issued under systems of care initiatives funded a few American Indian tribal organizations, by the late 1990s, the number of projects funded were greatly outnumbered by those Native American organizations whose applications were turned down (Federal Center for Mental Health Services, 1998). Despite high levels of need in Indian Country for improved mental health service systems for children, very few tribes and tribal organizations seemed poised to procure funds to this end.

In 1994, the Substance Abuse and Mental Health Services Administration (SAMHSA) and the IHS convened a workgroup to review Native American mental health issues. The workgroup met over four years to develop the Circles of Care initiative, a grant program targeted specifically to tribal programs to facilitate the development of systems of care models in tribal communities. The grant awards did not fund actual services but instead funded strategic planning and evaluation tasks. The purpose of the grant program was to “position tribes and urban Indian organizations advantageously for future service system implementation and development” (U.S. Department of Health and Human Services, 1998).

Support for the Circles of Care program was due partly to the recognition that organizations providing services to American Indian/Alaska Native children and adolescents and their families faced unique challenges in developing new, coordinated programs. Creating such programs in Indian Country is complicated by a long history of programs planned for tribal communities by outsiders, primarily the U.S. government. In the past, most tribal communities acquired whatever program was thrust upon them. This resulted in a kind of forced passivity among Native people that diminished their ability to provide necessities to their people, much less to plan for the future (Fox, Clifford-Stoltenberg, and Simmons, 2005). Furthermore, mainstream mental health care has developed independently of, and with a different frame of reference than, mental health care in Native communities. Mainstream, non-tribal people for whom mental health services have been targeted have primarily guided the planning and provision of services (Fox, Clifford-Stoltenberg, and Simmons, 2005).

In 1998, under the Circles of Care grant program, nine three-year tribal grants were awarded to plan, design, and assess the feasibility of a culturally appropriate mental health service model for Native children with SED based on systems of care principles. The grants were meant to build within tribal governments and urban Indian communities the infrastructure, knowledge, and skills needed to create sustainable programs for Native children with mental health needs and their families. The intent of asking the Circles of Care sites to develop a children’s mental health system was both to design a mental health program that would address the different cultural and philosophical needs of Indian Country, and to allow tribal programs the self-determination and tools to deal with unique historical challenges in planning and coordinating services.

The Circles of Care project was designed to develop plans that would meet the special needs (such as for traditional healing) of Native Americans while involving all interested people and agencies, including families and communities, as major participants in the planning. Using this approach, each Circles of Care grantee was supposed to produce:

* A description of existing services,
* An assessment of community needs for mental health and related services (this included a community-specific definition of SED),
* A plan for measuring outcomes in its systems of care model,
* An assessment of the feasibility of the proposed service system model, and
* Three annual assessments of the planning effort.

Notably, tribal grantees often emphasized that the difficulties these children faced could be understood only by appreciating the history of their communities in terms of both historical trauma and great resiliency. Grantee outcome measurement plans often included outcomes such as integrating traditional values with systems of care requirements, building a bridge between the Indian and mainstream worlds of mental health, developing leadership skills and expertise among Native families and groups, and determining the characteristics of a healthy Native child or family. Their feasibility assessments also put culture in the forefront, involving collection not only of information about the financial viability of the proposed program but also the cultural relevance of a proposed service[[5]](#footnote-5) (Fox, Clifford-Stoltenberg, and Simmons, n.d.).

The goal of Circles of Care was to develop culturally appropriate mental health service models for Native youth who were experiencing SED as well as for their families. To accomplish this, significant obstacles to the development of culturally appropriate plans had to be overcome, including barriers such as staffing problems, geographic distances, and tough political climates. This planning effort also meant involving vulnerable youth, their families and community members in planning for systems that may not ever be implemented. Circles of Care grants offered no guarantee of stability across programs once grant funding ended to carry forward the plans and dreams that community members identified in creating their mental health system plans. The number of systems of care grants available to tribal grantees was far fewer than the number of Circles of Care grants awarded.

**Part II: Families Experiencing a SED**

**Anna and Brandon**

Anna is the mother of a sixteen-year old boy named Brandon. Brandon has been having significant problems at school. He has been skipping, with absences from some classes every single day. Sometimes he misses whole days, and Anna doesn’t know what he does during those times. Recently Anna caught Brandon smoking marijuana in his room at home and grounded him. His response to being “grounded” was simply not to come home in the evenings. Last night, Anna found him at a local park with his friends. She knows they were drinking alcohol and suspects they were using drugs, too. Although he agreed to come home with her when she showed up at the park, Anna doesn’t know whether he would be willing to get in the car with her if it happens again. Anna was scared going to the park; she is afraid of his anger.

Anna feels she has tried everything to get him to go to school. Anna believes she is fighting a losing battle with Brandon and with his school. Her attempts to get modifications to his Individualized Education Plan (IEP) were successful at first, but since then, Brandon has not responded to the changes and he continued skipping over the year. The school is beginning to “blow her off.”

Anna takes Brandon to see a counselor, but does not think it is helping him much. Brandon tells Anna that the counselor “doesn’t get him.” She is feeling more and more afraid of Brandon during his angry tirades. She thinks that she may have to give up custody to the state so Brandon can be placed in some kind of residential facility, but the closest one is several hours drive from her home on the reservation. Anna wants Brandon to get the help he needs and feels that she has tried everything she can. She just doesn’t know what to do. She does not want to relinquish custody and does not want to send him away, but feels desperate.

**Rob, Diane, and Amy**

Rob and Diane are very worried about their daughter Amy. About midway through the school year last year, Amy started acting differently. She began hanging out in her room and stopped going out with friends. Rob and Diane do not know exactly what happened, but Amy’s sister told them she thought something bad took place with some girls at school. Rob and Diane thought that whatever it was would “blow over,” but then Amy started skipping school, something she had never done before. Not only that, but at home she either refused to talk to anyone or she yelled at everyone.

When summer rolled around, Rob and Diane decided to send Amy to stay with some relatives, thinking that a change of scenery might help the situation. But if things were bad before Amy left, they were worse when she came home. Amy seemed even more moody than before--just as withdrawn, but jumpy and anxious too. As the months passed, Rob and Diane had to face that things were not getting better. Amy’s school called them to say they were concerned about Amy’s academic performance. By mid-year, she was barely passing most of her classes, even though she had always been a decent student. Rob and Diane were not sure what was going on and did not know what to do. They decided to turn to the school for help.

Amy’s school offered her tutoring to help her catch up academically. Rob and Diane asked if the school could help with some counseling, and school administrators told them to check with their health insurance or the IHS clinic about counseling options. Since Rob and Diane did not have health insurance, and the IHS clinic said they did not have a counselor who could see her right now, that recommendation went nowhere.

Rob and Diane still held out hope that Amy might “come around.” But when Diane noticed some cuts along Amy’s arms and legs, Rob and Diane realized just how bad things had gotten and were forced to admit that something was really wrong. When they pressured her, Amy confessed that during her stay over the summer, she had been molested and nearly sexually assaulted by her cousin’s friend. Rob and Diane thought about finding a counselor for Amy, but did not think they would be able to find one near where they live. They did not know who to turn to for help or whom to trust. Rob and Diane were concerned about Amy and wanted to help her, but they were also afraid they would be blamed for Amy’s problems.

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**Appendix A**

The values and principles of systems of care (as presented by Stroul and Friedman (1986)) are as follows:

*Core Values*

1. The system of care should be child-centered and family-focused, with the needs of the child and family dictating the types and mix of services provided.
2. The system of care should be community-based, with the locus of services as well as management and decision-making responsibility resting at the community level.
3. The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

*Guiding Principles*

1. Children with emotional disturbances should have access to a comprehensive array of services that address the child’s physical, emotional, social, and educational needs.
2. Children with emotional disturbances should receive individualized services guided by an individualized service plan in accordance with the unique needs and potential of each child.
3. Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
4. The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
5. Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating services.
6. Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.
7. Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.
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2. Amanda Cross-Hemmer is a consultant to the National Indian Child Welfare Association. [↑](#footnote-ref-2)
3. The following section is a synopsis of material presented by Fox, Clifford-Stoltenberg, and Simmons (2005) in *The Circles of Care Evaluation Report: Planning Services for Tribal Communities.* [↑](#footnote-ref-3)
4. For a detailed description of systems of care values and principles, see Appendix A. [↑](#footnote-ref-4)
5. To read about specific American Indian/Alaska Native Circles of Care programs, see Clay, R.A. (November/December 2010). [↑](#footnote-ref-5)