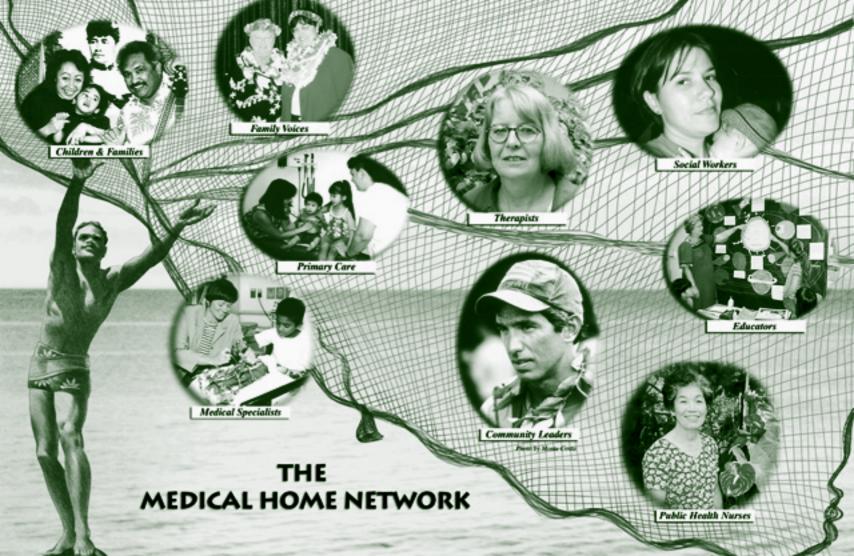
MEDICAL HOME: REACHING THE NEXT LEVEL

Culturally Effective Service and Training Partnerships to Benefit Children and Families



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Culturally Effective Care Continuum

This culturally effective continuum serves as a key for pediatricians to locate themselves. Earnest attempts were made to describe behavioral indicators familiar to pediatricians' experiences.

Cultural Behavior Indicators	Definition
Cultural Destructiveness	Antagonizing behavior that harms another group's identity and worth, e.g., racial profiling, discrimination policies in establishments, institutional racism, Ku Klux Klan (Cross, 1989).
Cultural Incapacity	"Inability to recognize differences from other cultures"; "cross-cultural ignorance, often characterized by support of the status quo"; e.g., prejudice, bigotry, ethnocentrism (Cross, 1989).
Cultural Blindness	"Minimization of the differences within and among cultures. Rather than minimizing cultural differences, one must acknowledge and respect the diversity and interactions among cultures within a community" (Lynch & Hanson, 1992). Policy level: "well-meaning but misguided" liberal policies and practices based on the belief that if only the dominant cultural practices were working properly, they would be universally applicable and effective for everyone (Cross, 1989).
Cultural Self- Awareness	Internalized process that helps one know consciously the origins of one's preferences, biases, and behaviors (Stone, Patton & Heen, 1999).
Cultural Awareness and Acceptance of Families	Individual inner process that helps determine an appreciation for the other's differences and demonstrates sensitivity and concern of the other's perspective (Goleman, 1998).
Cultural Competence	Demonstrated ability to convey respect of differences, continual reassessment of one's own cultural beliefs and assumptions. Ability to integrate cultural beliefs and values in the child and family encounter; seek opportunities for learning cultural knowledge and resources; and researching the range of adaptive strategies to meet the health needs of diverse ethnicities (Cross, 1989).
Culturally Effective Care	Demonstrated care that is characterized by the physicians' knowledge, understanding and appreciation of cultural diversity. Physicians demonstrate strong interpersonal communication skills necessary to incorporate a set of beliefs and values. Complements treatment with traditional healing methods in the child and family encounter, which strengthens the therapeutic relationship and optimizes child health (AAP, 1999).
Culturally Effective Advocacy	Ability to influence changes in service, training, research and policies to support the child's and family's culture at all levels—individual, community, state, federal. Ability to persuade key stakeholders in new or changes in policy, legislation and regulations affecting CSHCN and their families (Aronson, 1999; Goleman, 1998).

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Calvin C.J. Sia, MD Principal Investigator Mālama Pono Project



Preface

As I sit working on this monograph at 5:30 in the morning, I'm remembering my 12 years with Calvin C.J. Sia, MD, an exemplary practicing pediatrician for over 40 years. Dr. Sia is the visionary of the *medical home* concept and is working with many of you to achieve the ultimate outcome for children across the country: "Every child deserves a medical home."

My memories of Dr. Sia draw for me a picture of a gentle teacher and guide. His wisdom is demonstrated through his stories about his patients, their families, pediatricians, nurses, and teachers. His stories about being at the right place at the right time in his encounters with a legislator, a department head, interested philanthropist, or a nationally respected expert all point to his commitment to the thousands of children he served and millions of children he will have served using his natural talents as a visionary.

Dr. Sia's life and practice embodies the seven elements of the medical home. He shows his warmth, always caring for his patients with a genuine smile; he personifies the first element of the medical home, "compassion." He guides parents with reverence and honors their place as their child's first teacher, which exemplifies "family-centered care and culturally effective care," the second and third elements of the medical home. His relationships with the nurse, social worker, early childhood educator and fellow pediatrician are respectful. He acknowledges their expertise. In return they become "grateful and dear friends." In this way he embodies "comprehensive care," the fourth element of the medical home. He lives each day with a commitment to "continuous and coordinated care," the fifth and sixth elements of the medical home. He listens to a parent with as much respect as he listens to a congressman. He advocates unrelentlessly for the medical home (like his nationally known Healthy Start program) within which he envisions an integrated early childhood system that creates successful paths to "access" effective health care, especially for the vulnerable, the seventh element of the medical home.

Dr. Sia has taken us from rather bleak beginnings to vigorous collective efforts in reaching for the dream that all children will have a medical home. He has worked hard to drive the concept to full implementation and yet he is aware of the "questioning" parent or a doubting pediatrician or a busy politician. Dr. Sia saw the strengths of others and encouraged them to use their "sensitivities" to advocate for the children.

"Thank you" only begins to express the appreciation we feel. The spirit of aloha and the gift of heart is truly exemplified in Dr. Sia as an authentic, culturally effective champion not only for the children of Hawai'i but also for the children of the nation and the world.

Sharon Taba, MEd Project Director Mālama Pono Project



WHERE ARE THE PARENTS?

by Sue Stuyvesant

All too often an official, who should know better, asks why parents of special needs children aren't appearing at important meetings to discuss issues, or lobbying for new services, or providing written submissions to task forces. Spectrum is happy to present to you an answer to that official, who seems to have relatives in every county, province, or state in the land.

WHERE ARE THE PARENTS?

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed.

They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

WHERE ARE THE PARENTS?

They are at home, diapering their 15 year old son, or trying to lift their 100 lb. daughter onto the toilet. They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube.

They are administering medications, changing catheters and switching oxygen tanks.

WHERE ARE THE PARENTS?

They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for tests results to come back and wondering: is this the time when my child doesn't pull through?

They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ.

They are waiting in long lines in county clinics because no insurance company will touch their child.

WHERE ARE THE PARENTS?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another member of the family, harm. They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cut backs of their own.

WHERE ARE THE PARENTS?

They are trying to spend time with their non-disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive.

They are struggling to keep a marriage together, because adversity does not always bring you closer.

They are working 2 and sometime 3 jobs in order to keep up with the extra expenses. And sometimes they are a single parent struggling to do it all by themselves.

WHERE ARE THE PARENTS?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything.

They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families. They are busy, trying to survive.

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