Asia-US Partnership
Early Child Development in Primary Care

Strengthening Nations Through Strong Families: An International Alliance in Early Childhood

May 20-22, 2009
Shanghai, China

Presented by:
Department of Pediatrics, John A. Burns School of Medicine
University of Hawai`i at Manoa

In Partnership with:
Shanghai Children's Medical Center

Letter from Conference Co-Chairs

Recognizing the importance of early child development is a growing global phenomenon. The health and well-being of our societies and cultures can be measured by the health and well-being of our children and the families who raise them.

Participating teams in Asia-US Partnership V met in Shanghai, China, in May 2009 to continue an international dialogue based on the science of early childhood while also working in practical ways to apply what the research has shown us. Our goal is to cultivate ongoing, international networks of inter-professional leaders and shape systems of care for young children and their families in participating countries.

AUSP V/Shanghai 2009- Strengthening Nations Through Strong Families: An International Alliance in Early Childhood would not have been possible without the work of many people both in Shanghai and Honolulu, and the assistance of US Planning Team members. We heartily thank all those who helped to plan this meeting, facilitate the conference sessions, and contributed to making this fifth AUSP meeting one of our most extraordinary gatherings to date.

Xie xie and Mahalo,

Xiaoming SHEN, MD, PhD, IFAAP
AUSP V Co-Chair, Shanghai

Calvin C. J. SIA, MD, FAAP
AUSP V Co-Chair, Hawai`i

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AUSP Priorities

The mission of the Asia-US Partnership (AUSP) is to improve child health in Asia and the United States through cross-cultural exchanges with leaders in pediatrics. AUSP gives priority to being a catalyst for change within participating countries by applying new scientific research on early childhood development to build integrated systems of health, education, and family support that meet the needs of all children. To do this, AUSP long term priorities are to:

1) Identify and prioritize scientific knowledge applicable to cross-cultural exchange;
2) Recognize the influence of culture on the principles of child development and delivery of care;
3) Deepen interactions within a network of country specific leaders in pediatrics and education for ongoing exchange and outreach; and,
4) Promote awareness of the importance of early child development.

One of the key outcomes of AUSP activities has been to develop and strengthen a close network of pediatric leaders and early child development professionals among seven country teams: China/Beijing, China/Shanghai, Hong Kong SAR, Philippines, Singapore, Thailand, and the United States.

Under the leadership of Calvin C. J. Sia, MD, FAAP, Department of Pediatrics, John A. Burns School of Medicine, University of Hawai`i at Manoa, the first Asia-US Think Tank meeting (2003) was convened in Honolulu Hawaii, to introduce cross cultural perspectives on "Early Child Development in Primary Care" with a relatively small group of pediatric leaders from each country focusing primarily on the new science of early brain development. The following three meetings (2004, 2006, 2007) enabled this group to focus on early child development and primary care and the importance of developing a system of care:

AUSP II- "Translating Theory of Early Childhood Development into Practice: Notion of Culture and Priorities"

AUSP III- "Emergent Issues in a Global Context"

AUSP IV- "Mobilizing Collaboration for Comprehensive Care"

Major partners supporting this initial phase of AUSP activities: Johnson & Johnson Pediatric Institute, LLC; World Bank; U.S. HRSA Maternal and Child Health Bureau; Consuelo Foundation of Hawaii and Philippines; and, the American Academy of Pediatrics.

Asia-US Partnership V

AUSP V (2009) took place in Shanghai and launched a new phase for AUSP aimed at developing greater shared leadership with more fully developing country teams:

- The meeting venue took place in an Asian country and was hosted by the China Shanghai team
- Conference facilitation and presentations expanded with an eye on cultivating leadership among various younger country team members
- Country teams contributed partial funding support for the meeting thus assuming a more proactive partnership in support of early childhood development and primary care

AUSP V focused specifically on family-centered care and the Medical Home through a number of presentations, panels, and discussions throughout the two-day meeting.

Conference Agenda

Day One: May 21, 2009
Welcome- Xiaoming SHEN, MD, PhD
AUSP Vision and 2009 Conference Theme- Calvin C. J. SIA, MD, FAAP
Shanghai Experience: Jinag FAN, MD, PhD, Xingming JIN, MD, Yanhong YE
Country Team Presentations: Fan JIANG, MD, PhD, Facilitator
Hong Kong- Aaron YU, MD; Patrick IP, MD; Tony Ka Fai LAU, MD
Philippines- Alexis REYES, MD; Andy MOLL, Consuelo Foundation
United States- Chet JOHNSON, MD, FAAP
Discussion: Inter-Professional Partnerships/Global Connections
Tom TONNIGES, MD, FAAP, Facilitator
US Centers for Disease Control Priority on Early Childhood Development
Edwin TREVATHAN, MD
Science Updates on Early Childhood
Jack SHONKOFF, MD

Day Two: May 22, 2009
Focus on Family Centered Care- Calvin C. J. SIA, MD, FAAP
Family Advocacy Keynote- Polly ARANGO, Co-Founder, US Family Voices
Discussion on Implementing Family-Centered Care
Sylvia YUEN, PhD, and Jean JOHNSON, DrPH, Facilitators
US Experience Involving Families: Alexis REYES, MD, Facilitator
Elizabeth McFARLANE, PhD, MPH, Jean JOHNSON, DrPH. Patricia HEU, MD
Elisabeth CHUN, MEd. Tom TONNIGES, MD, FAAP
AUSP Next Steps/Action Steps- Calvin C. J. SIA, MD, FAAP
Farewell Dinner

Conference Theme: Family-Centered Care and the Medical Home

Polly Arango, co-founder of the national Family Voices movement in the United States, began the AUSP V keynote address by acknowledging that families of children with special health care needs use the health/medical systems more frequently than most children. She compared the medical experiences of her family 30 years ago to that of today.

During her presentation, Ms. Arango detailed how her family had grown and evolved over the span of those three decades while at the same time medical science, medical practice, early childhood knowledge and practice, and government policymaking had also evolved in parallel ways.

Early childhood and pediatric providers agree that efforts to implement integrated systems of care need to be rigorously examined. Approval alone of policies to develop integrated

US Pediatric Care 30 Years Ago

- Child-Centered
- Family role determined by others- physicians, early educators, schools, community, 'the experts
- Family usually lacked information, viewed as bystanders, did not understand what is happening
- No policy definition of children with special health care needs
- Treatment decided by professionals
- Pediatric services not integrated
- Many children with special needs or disabilities placed in institutions

US Pediatric Care Today

- Family-Centered
- Care built on partnerships between family and professionals
- Family involved in every aspect as a team member- receiving information, making decisions
- Pediatric services and systems are more integrated
- Prevention a priority
- Intervention begins early for children with special needs
- Services are community-based, coordinated, culturally competent; children cared for at home
- Development of National Family Voices organization in 1990s, focusing on peer support, leadership training, information, partnerships, advocating for family centered care
- Brain research and early childhood development lead to better decisions and care

systems of care in the community may not necessarily result in the political will to actually develop such programs. Moreover, even if programs are implemented, they may not be implemented effectively, in which case integrated services may not make a positive difference in the lives of young children. This realization raises hard questions for early childhood and pediatric health professionals around the globe. Answers to this dilemma generally point to: 1) more accountability; and, 2) measuring outcomes.

Ms. Arango's main message was that accountability and measuring outcomes need to be directly related to family involvement in implementing programs and developing integrated systems of care in communities. She offered two questions as a litmus test for involving families: 1) "in what ways are the experience and expertise of families utilized?" and, 2) "what is needed to create or enhance family partnerships?" Families, whether as individual families or as representatives of family organizations, have to be involved in research, program development and implementation, and program evaluation.

Ms. Arango emphasized again and again that developing family-centered systems of care means that *"nothing about us happens without us!"*

Background to the Issues

Experiences during early childhood set a life-course trajectory for every young child that involves self-regulation, cognitive development, and social-emotional development, areas that contribute to shaping a child's later personal, health, educational, and professional outcomes. Because families are the "experts" on their children and their children's "first teachers," family involvement in addressing the needs of their young children in health, education, and social policies becomes key. Supporting and strengthening families with young children can lead directly to strengthening the communities and nations in which they live.

Families, health professionals and early educators generally understand "family-centered care" as a partnership experience characterized by mutual respect, listening, negotiation, and trust, a partnership where families are full participants in developing strategies to achieve optimal development for each of their children. However, advocating for family-centered care goes beyond families and professional partners working together to shape services required by a single child and a single family. This concept of "family-centered care" also engages families and professional partners working together to improve policies and practices within systems of care for young children, as advocates.

Why do families of young children support family-centered care?

- Family-centered care acknowledges the family as their child's most important caregiver
- Family-centered care respects the knowledge and expertise that families and pediatric professionals together bring to the care of a child
- Family-centered care reinforces the importance of care that is community-based and culturally effective
- Family-centered care means that families, like their professional partners, require objective, honest and ongoing information, in their own language and preferred style
- Family-centered care helps families be better families
- Family-centered care supports professional partners as they learn to more effectively provide care to children in medical school and residency training, grand rounds, and involving families as faculty and in curriculum development

Ms. Arango advocated for family involvement in every aspect of systems-building:

- Professional development for early childhood providers
- The development of materials pediatricians provide to families
- Parent training- resource workshops, involvement in identifying and organizing community services
- Education and training of health and early childhood professionals
- Program development- family as advisors, family as staff, families as the voice in communicating mission
- Involving families in all phases of research, including development of research tools, collecting data, assessing the quality and impact of new or existing programs and policies, and analysis
- Including families in policy development as members on advisory committees
- Family involvement means- stipends for participation, compensation for travel and child care expenses, salary for parent position

This keynote presentation offered a compelling example based in the history and culture of the United States and also sparked discussion about the concept of "family" and what family-centered care would look like in other communities and cultures represented by AUSP country teams.

Families in any country are diverse—differently prepared for partnering with pediatric professionals within existing systems of care due to poverty, education, cultures, laws, and institutions. Similarly, pediatric professionals and systems of care are diverse based on differences in training, laws, institutions, and culture.

For example, China has a one-child policy that means a "family" remains very small while the sheer numbers of people living in China overwhelm health facilities with vast numbers of patients. In Hong Kong and China, this results in acute, episodic pediatric visits taking place in a very short time frame, rarely providing continuous and comprehensive care. In the Philippines, "families" generally include many children, multiple generations, aunts, uncles, and cousins that "may be hard to fit in a single photo" yet substantial numbers of adults are absent for years at a time to find work in cities or outside the country. In the United States, Head Start is a federal early education program for low-income children that can develop very strong supports for families in accessing appropriate pediatric health care, yet only 3% of eligible children are enrolled in the program.

Philippines Example: Dr. Jose ACUIN

"We gathered together a group of families—all had children with autism. There were no existing services for our children, and we knew we couldn't depend on the government because the economy was so bad. So, rather than concentrating on changing policies, we created our own program—a school for children with autism spectrum disorders. The school has grown, and we have just begun a bakery where the children learn new skills. Here, families run the school and are fully engaged in developing curriculum that introduces our children to the community while also introducing the community to our children."

How does the concept of family centered care change across cultures, shifting from concerns in individual practice to issues related to policy and systems development? AUSP participants identified the following:

- Include community partners in addressing children's needs
- Work in interdisciplinary groups
- Empower families to increase leadership experience
- Expand development of the discipline of community pediatrics
- Build community pediatric networks
- Keep identifying new areas of high-risk families
- Examine impact of poverty in developing integrated systems of family centered care
- Promote family centered care as topic for policy and training
- Assure quality in everything we do: research based, beneficial, cost effective
- Develop systems for *all* children

HAWAI`I Example: Building Partnerships with Families to Create Systems of Care

The Hawaii team presented an integrated model of family-centered care with base assumptions: early childhood sets the life course trajectory for children; and, prevention and intervention programs working with parents may be effective in altering life course trajectories. The following highlights Hawaii examples of an integrated system:

- Good Beginnings Alliance is a statewide organization with a strong commitment to young children that they are safe, healthy, and ready to succeed. Collaborations and partnerships focus on: 1) professional development for early childhood providers; 2) materials for pediatricians to distribute to families; 3) parenting workshops.

- Family-Professional Partnerships include: 1) policy development; 2) program development; 3) education and training. Families serve on advisory committees in efforts including: Hawaii Early Intervention Coordinating Council, Autism Spectrum Disorders Benefits and Coverage Task Force, Early Hearing Detection and Intervention Advisory Committee, Newborn Metabolic Screening Advisory Committee, Special Education Advisory Council. Families contribute to designing written material for early childhood services, present at conferences and workshops; support families in building skills and knowledge.

- Family Voices of Hawai‘i, part of the national Family Voices organization, helps families and professionals work together to improve health care for children and youth with special health care needs. This is done in a number of ways, including individual peer support, training, research through focus groups and surveys, access to shared national information and ideas, conferences, and resource guides.

- The Center of Disability Studies (CDS), based in the College of Education, University of Hawaii at Manoa, has a rich diversity in understanding families and their needs, focusing on teaching, research, and service. CDS sponsors annual Pacific Rim Conferences and publishes the Review of Disability Studies: An International Journal. Program activities ensure people with disabilities take leadership roles on community advocacy.

• The Center on the Family, based at the University of Hawaii at Manoa, enhances the well-being of families throuh interdisciplinary research, education, and community outreach. The Center conducts applied and basic research and generates and disseminates science-based information that aims to improve the quality of life for Hawaii's families, including children and elders, by targeting those who work with them.

• The Hawaii State Department of Health/Family Health Services Division offers services for young children as part of the statewide maternal and child health system of care promoting, and coordinated with, the medical home. These services include newborn metabolic screening, newborn hearing screening, genetic/metabolic services, early intervention services for children age 0-3 years with or at risk for developmental delays, and child/family services for children with special health care needs.

• The Johns Hopkins School of Medicine, Hawaii Department of Health, Community Healthy Start Provider Network, and the Hawaii Medical School Department of Pediatrics developed a research to practice partnership to improve home visiting service quality and family/child outcomes. This partnership began in 1993 with a randomized control trial and continues today using a variety of research methodologies. The collaboration has informed home visiting programs locally and nationally in their efforts to improve family functioning, prevent child maltreatment and promote child health and development.

What We've Learned in Hawaii about Family Partnerships:

- Families are the constant in a child's life
- Families teach as much as learn
- Families are powerful and effective advocates of system improvement
- Families thrive on partnerships and often become great assets and resources to service providers
- Families learn from each other through family-to-family support
- Families are the strength of a nation

Benefits of Family Partnerships:

- Services matched to child and family
- More information and data for providers in creating service plans
- More effective services
- Better child outcomes
- Happier, healthier families, communities, and nations

AUSP V Delegates & Guests

China/Shanghai Team
Xiaoming SHEN, MD, PhD, IFAAP, Team Leader
Fan JIANG, MD, PhD
Xingming JIN , MD
Hanhong YE

China/Hong Kong SAR Team
Arron Chak Man YU, MD, Team Leader
Patrick IP, MD
Tony Ka Fai LAU, MD

Philippines Team
Alexis REYES, MD, Team Leader
Cecilia S. ACUIN, PhD
Jose M. ACUIN, MD
Marilyn MANUEL
Andy MOLL

USA/Hawaii Team
Elisabeth CHUN, MEd
Patricia HEU, MD MPH
Jean JOHNSON, Dr.PH

Chet JOHNSON, MD, FAAP, Team Leader
Elizabeth McFARLANE, PhD MPH
Calvin C. J. SIA, MD, FAAP
Thomas F. TONNIGES, MD, FAAP
Sylvia YUEN, PhD

Conference Resources
Polly ARANGO, Family Voices, USA
Jack P. SHONKOFF, MD, Center for the Developing Child, USA
Edwin TREVATHAN, MD, MPH, Centers for Disease Control, USA

Other Guest Participants
Meng MAO, MD, Chengdu, China
Gillian NAJARIAN, Massachusetts, USA
Xiaobing ZOU, MD, Guangzhou, China
Xiu XU, MD, Shanghai, China

We regret that the following people were not able to join us due to last minute cancelations related to the outbreak of the H1N1 virus and other acute illness. We look forward to seeing them at future AUSP events:

China/Beijing Team—Jin JIANG, MA; Xi Ru WU, MD; Weilan LIANG, MD
China/Hong Kong SAR—Wai Fun Anna CHENG, MD; Chun Bong CHOW, MD; Nai Kong LEUNG, MD, Hon FAAP
Singapore Team—Lai Yun HO, FRCPCH, FAAP
Thailand Team—Nittaya KOTCHAHBAKDI, MD
United States—Merle McPHERSON, MD, FAAP

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Conference Planning Teams:

Hawaii/United States
Calvin SIA, MD, FAAP, Co-Chair
Elisabeth CHUN, MEd
Patricia HEU, MD, MPH
Jean JOHNSON, DrPH
Marlene KEAWE, MBA
Louise IWAISHI, MD, FAAP
Elizabeth McFARLANE, PhD
Merle McPHERSON, MD, FAAP
Leolinda PARLIN, BA
Kathryn STHAY, BBA
Bonnie STRICKLAND, PhD
Sharon TABA, MEd
Fan TAIT, MD, FAAP
Tom TONNIGES, MD, FAAP
Lynn B. WILSON, PhD
Mary E. YOUNG, MD
Sylvia YUEN, PhD

Shanghai
Xiaoming SHEN, MD, PhD, Co-Chair
Fan JIANG, MD
Feng LI, MD
Liming AO, MD
Fang FANG, MD

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Katherine SIA
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Robert JOHNSON
Eric KEAWE

Photos:
Amy JOHNSON
Robert JOHNSON
Sharon TABA

Graphics and Layout:
Lynn B. WILSON, PhD

Report Writing:
Lynn B. WILSON, PhD
in consultation with
Calvin C. J. SIA, MD, FAAP
and Sharon TABA, MEd

Contact:
Sharon TABA, MEd, Medical Home Works! Community Pediatrics Institute, Department of Pediatrics
John A. Burns School of Medicine, University of Hawai`i at Manoa
1319 Punahou Street, Seventh Floor, Honolulu, HI 96826 USA
Email <sharon@medicalhomeworks.net>
Telephone +1.808.9838196
Fax +1.808.9451570