



# **Adopting Special Needs Children From China**

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# Adoption: for the children

“All children in the world need forever homes. The focus in international adoption should not be to find the right child for a particular family, but **to find the right family for each child.**”



# Parental Expectations vs. Reality



# Adoption Mantra

- ◆ Give me a child with a normal brain.
- ◆ I can handle
  - ❖ Plumbing
  - ❖ Carpentry
  - ❖ Wiring
  - ❖ Genetics
- ◆ From the child, “Remember who I was, not who I am”.
  - ❖ Orphanage life or foster care, from here or anywhere.



# Nature Plus Nurture

Genetics/ Prenatal  
Exposure and Malnutrition  
(Nature)



Psychological, Physical,  
and Developmental  
Outcome

Family and Social  
History  
(Nuture)



# Risk Factors in International Adoption \*



- ◆ Prenatal Malnutrition- poverty
- ◆ Prenatal Alcohol Exposure- PAE/FASD
- ◆ Premature Birth- cause and complications
- ◆ Physically Neglected- e.g., Post-natal malnutrition
- ◆ Socially Neglected- Psycho-social dwarfism, Self-stimulation, Emotional incompetence
- ◆ Physically Abused- Injuries, sexual abuse
- ◆ Orphanage or Hospital

\*Adapted from University of Minnesota Adoption Clinic



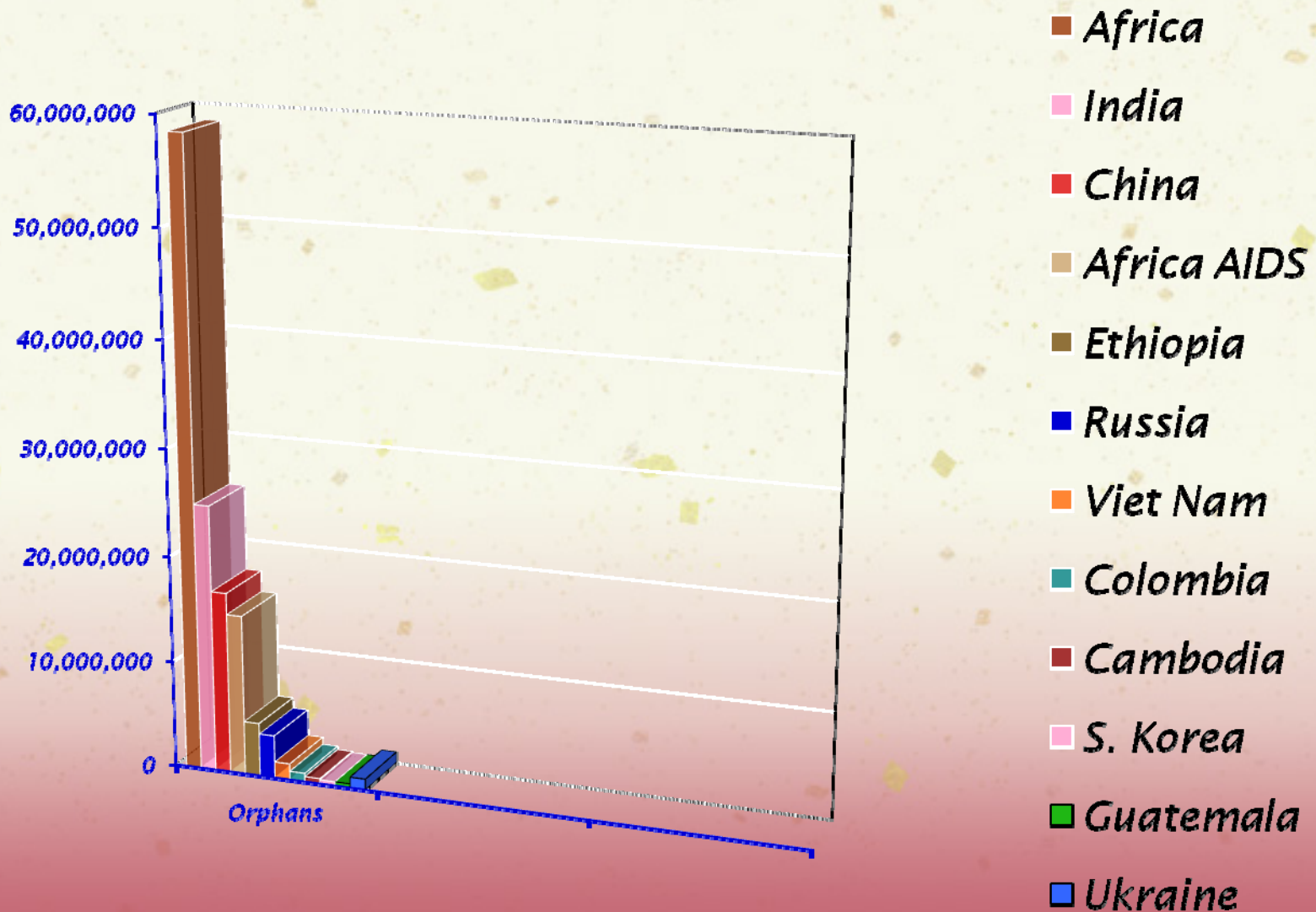
# Risk Factors & Results



- ◆ Higher risk correlates with poor psychological outcomes\*.
- ◆ Removal from biological parents means that the child suffered abuse or neglect.
- ◆ Abandonment means that medical and psychiatric history unknown.

\*University of Minnesota Adoption Project

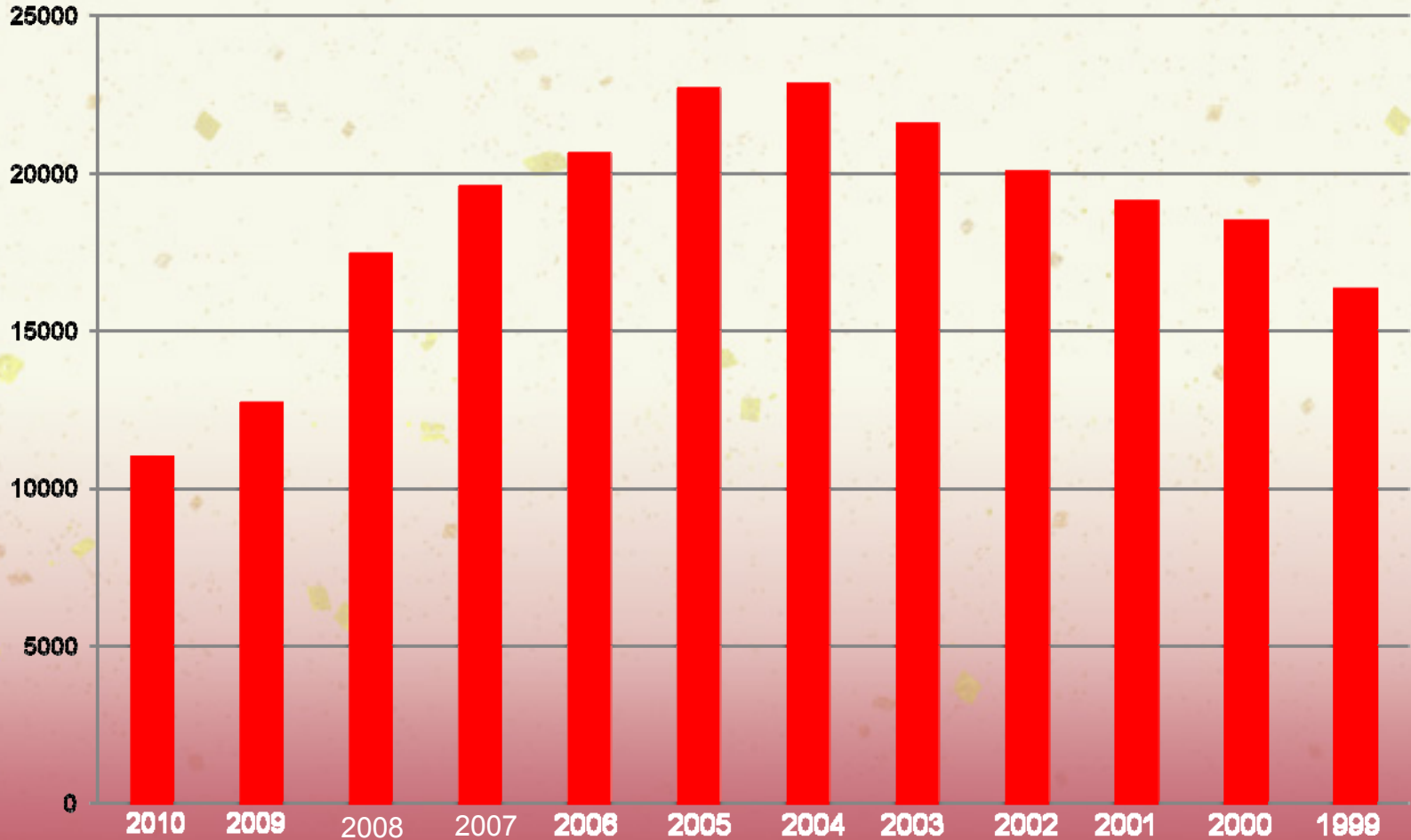
# 163,000,000 World Orphans\*



\*UNICEF-2009

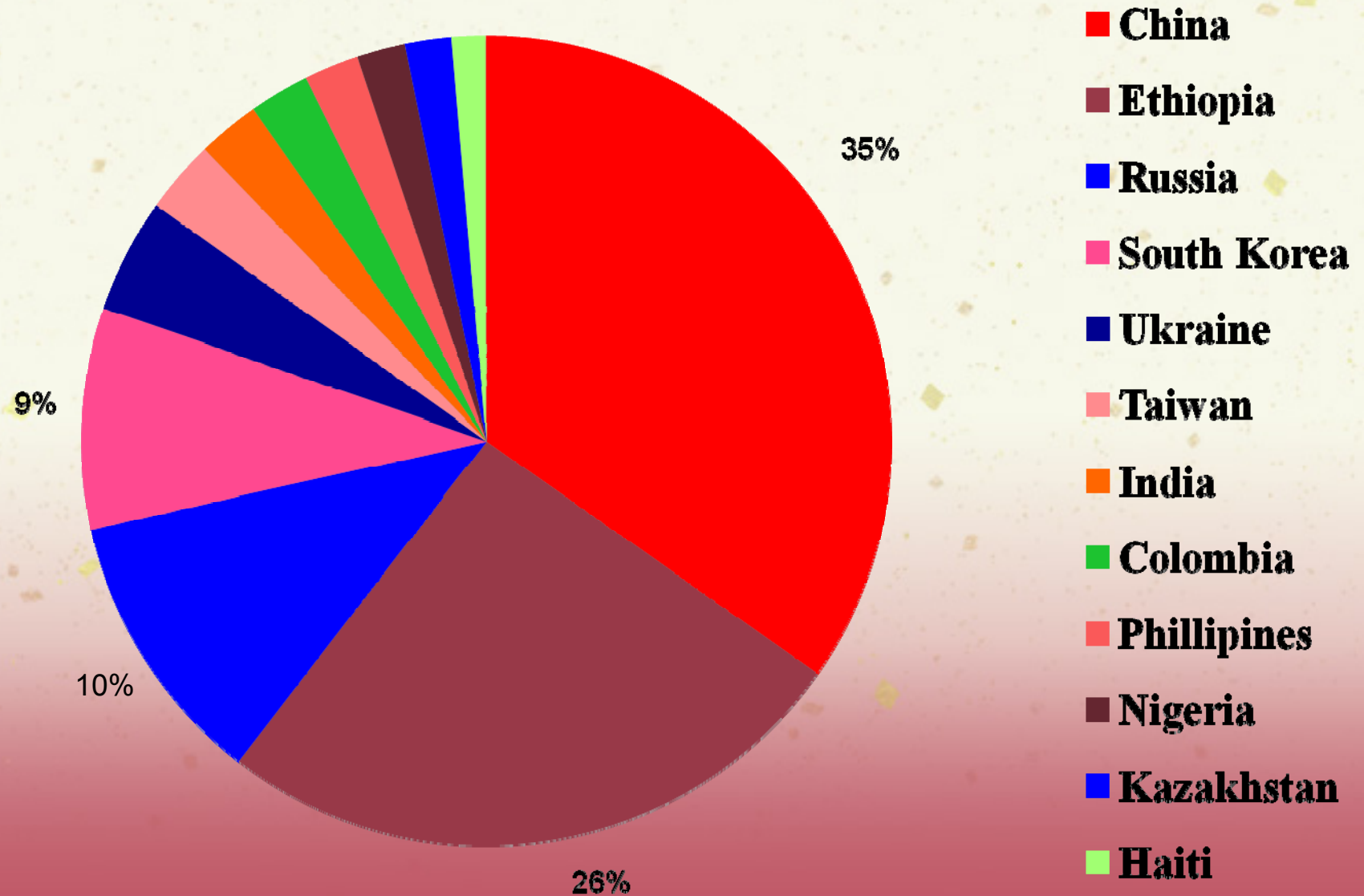


# US International Adoptions\*

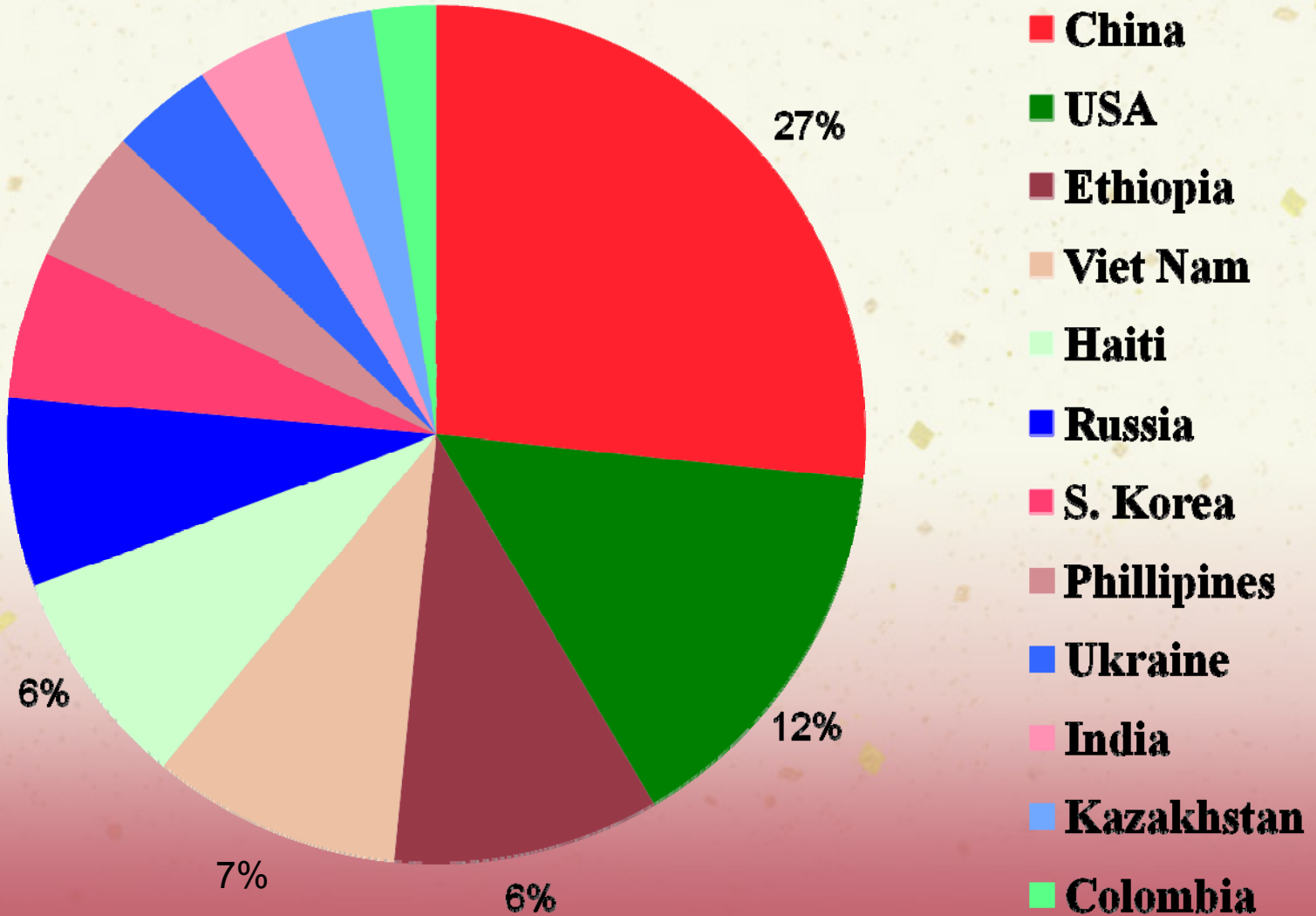


\*Data from Holt International

# US International Adoptions-2010



# Canadian International Adoptions- 2009



# Who Else Adopts from China?

## ◆ USA

❖ 3,081 (2009)

❖ 3,401 (2010)

## ◆ Canada- 2009

❖ 451

## ◆ Holland- 2009

❖ 283

## ◆ Sweden-2009

❖ 248

## ◆ Spain-2009

❖ 573

## ◆ Norway- 2009

❖ 106

## ◆ France-2009

❖ 102



# Why So Many Orphan Girls?

- ◆ Social system- Wife lives with husband's family, and takes care of his aging parents.
  - ❖ Economic realities for peasants
  - ❖ Girls not as socially or economically valuable
- ◆ One child rule
  - ❖ One boy, as first or second pregnancy, after paying large fine
  - ❖ Girls abandoned, to try for boy
  - ❖ Restrictive domestic adoption rules
- ◆ Poor access to health care
  - ❖ Children (boys and girls) with health problems abandoned
- ◆ Lack of comprehensive social welfare system for peasants

# Child-trafficking in China

- ◆ Reports in China Daily and New York Times, regarding infants taken away from their biological parents by provincial family planning authorities, then sold to orphanages for international adoption.
- ◆ 17,000,000 orphans in China, 2009 (UNICEF)
  - ❖ Not enough orphans?
  - ❖ Limited numbers of orphanages with international adoption programs
- ◆ Waiting children not as desirable
  - ❖ Biological parents unable to pay for correction of even minor problems

# Why Such Long Waiting Times?

- ◆ China does not want to be first in international adoptions
  - ❖ China grows more important on international economic and political stage
- ◆ Limited number of orphanages involved in international adoptions (about 250)
- ◆ Foreigners taking Chinese children away
  - ❖ Raises questions about China's ability to care for its own children
  - ❖ Exposure of social fabric, de-valuing girls
  - ❖ National pride vs. economic reality
- ◆ Male: female ratios in some provinces 1.7:1
- ◆ U.S. dollar no longer as desirable
  - ❖ Orphanage donation increases as dollar drops

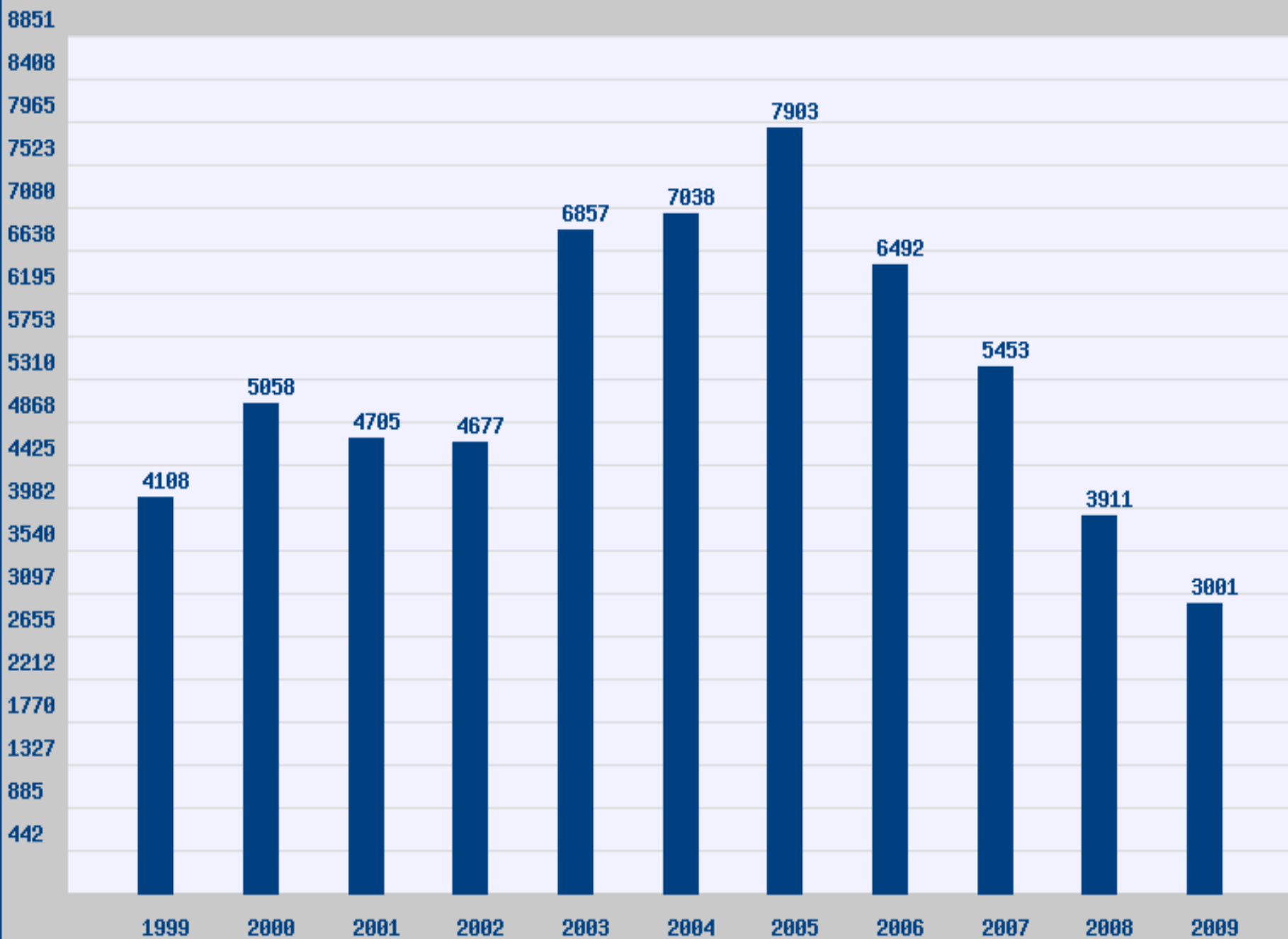
# UNICEF

- ◆ International adoption is a last resort, after:
  - ❖ Domestic adoption
  - ❖ Family care
  - ❖ Foster care
- ◆ Concerns about child- trafficking
  - ❖ Exploitation (slavery, sex industry) linked with International Adoption (2003 White Paper)
- ◆ What will happen to the orphans, left in institutions, or the street children?
- ◆ Who will pay to develop the necessary economic and social- service infrastructure?
  - ❖ Nurturance, Nutrition, Health care, Education.

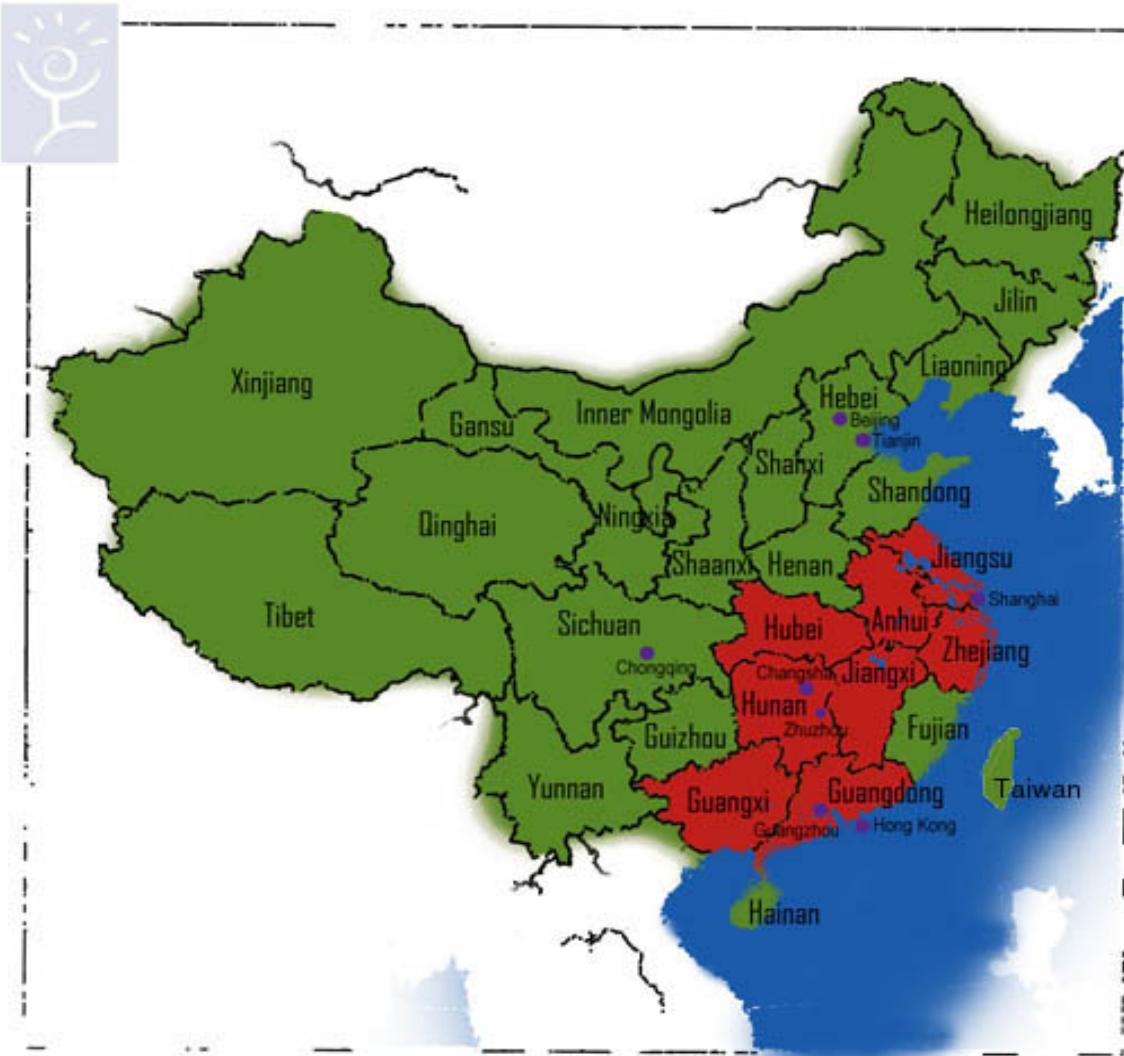




# Adoptions From China To The United States



# From Which Provinces Are Chinese Adoptees?



Majority of Chinese adoptions from Red Provinces.

# Which Country Has the Healthiest Orphans?

- ◆ No one country is lower in risks.
- ◆ Depends upon the risks of the child, circumstances of birth and life prior to adoption.



Country	2009	Foster Care	Placed at birth?	Fetal Alcohol	Lead >10
China	3001	Rare	Yes	No	Yes
Ethiopia	2277	No	No	No	No
Russia	2328	No	Mostly	Yes	Rare
S. Korea	1080	Yes	Yes	Rare	No
Guatemala*	756	Yes	Mostly	No	No
Ukraine	610	No	Mostly	Yes	Rare
Vietnam*	481	Rare	Mostly	No	No
Haiti	330	No	Mostly	No	No
U.S.	200+	Yes	Mostly	Yes	Rare

# Are All Orphanage Children Really Special Needs?



## Poverty and Orphanage Life



- ◆ Malnutrition
- ◆ First, a child loses weight, then, height, and last, brain growth ( and head circumference).
- ◆ Drugs- alcohol, smoking, drugs of abuse
- ◆ Direct and indirect damage to brain in-utero.
- ◆ Post-natal neglect and abuse
- ◆ Prevents development of “emotional” brain centers.

Children’s brains can recover, but are irrevocably changed.  
Despite this, the vast majority of adoptees do very well.

# Health Problems in Orphanage Children

## Diseases of poverty

### ◆ Environmental



- ◆ Lead poisoning
- ◆ Pollution of air and water
- ◆ Maternal drug use (FAS)
- ◆ Malnutrition causing:
  - ❖ Hypothyroidism
  - ❖ Rickets
  - ❖ Growth Delay/ Failure
  - ❖ Immune Deficiency

# Health Problems in Adoptees

## Diseases of poverty

### ◆ Infectious



### ◆ HIV

### ◆ Hepatitis B & C

### ◆ Syphilis

### ◆ Tuberculosis

### ◆ Intestinal parasites

### ◆ H.Pylori

### ◆ Opportunistic Infections

❖ Weakened immunity

❖ Skin, respiratory, etc.

# Effects of institutionalization: Malnutrition



- ◆ Children lose one month of growth for every 3-4 months in an orphanage.
- ◆ Standard growth charts can be used to document growth rate (WHO, CDC).
- ◆ Even apparently well-nourished children may have nutritional deficiencies.
- ◆ Nearly all children show rapid catch-up within 6 months. If delays persist, consider growth delay evaluation.

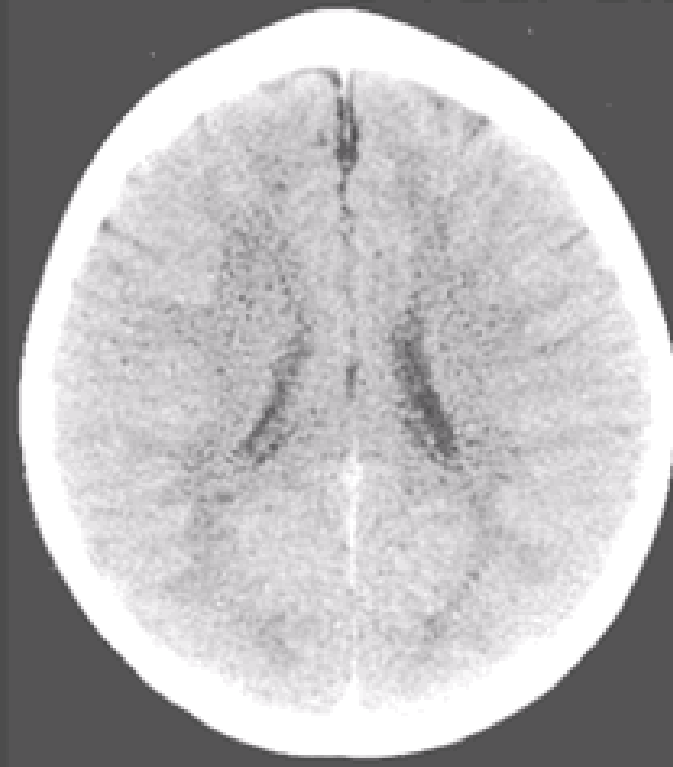




# Neglect in Infancy

- ◆ Small Brain
- ◆ Neglect, maternal malnutrition
- ◆ Pre-frontal cortex
- ◆ Global developmental delays
- ◆ Constant stress
- ◆ Executive function over emotion
- ◆ Quasi-autistic behaviors
- ◆ Hyper-alertness, abnormal responses
- ◆ Rocking, sensory processing

## 3-Year-Old Children



Normal

Child Trauma Academy



Extreme Neglect

1997 Bruce D. Perry, M.D., Ph.D.

In instances of neglect, sensory deprivation results in a smaller head size, as reflected by CT scan.

# Mental Health Problems in Adoptees\*

- ◆ Reactive Attachment Disorder
- ◆ Ongoing abuse or neglect (before you met)
- ◆ Autistic Spectrum Disorder
- ◆ Profound neglect in first year
- ◆ Inherited disorders
- ◆ Schizophrenia, Bipolar Disorder, mental retardation, ADD/ADHD
- ◆ Post-traumatic Stress
- ◆ Abuse and/or ongoing neglect, adoption, disruption
- ◆ Fetal Alcohol Syndrome or future toxin-mediated neurological/psychological effects, yet unseen
- ◆ Drug use during pregnancy, not **yet** a problem in China.

\*Parental psychiatric history rarely known

# Prenatal Substance Abuse Will Be a Problem in China



- ◆ Rising middle class in China increases risk of maternal alcohol use, increased incidence of STD's, and more HIV and hepatitis, in the future (e.g., South Korea).
- ◆ Difficult to isolate effects of single drug exposure.
- ◆ Alcohol and nicotine often adjunct drugs.
- ◆ Impossible to determine timing and frequency of substance abuse (history often unreliable).
- ◆ Withdrawal symptoms do not predict future impairments.

# ADHD and Environmental Exposures\*



- ◆ Lead
  - ◆ Correlates with increased incidence of ADHD (10-20 mg/dl increased risk 2.5 times, and over 20 mg/dl increased risk 4.5 times).
- ◆ Tobacco smoke
  - ◆ Prenatal smoking is associated with higher incidence of ADHD (girls risk increased 4.6 times, and boys 2 times)

\*Brown, Kahn, et.al., “Exposures to Environmental Toxicants and Attention Deficit Hyperactivity Disorder in US Children Environmental Health Perspectives, September, 2006

# Effects of institutionalization: Developmental delays



- ◆ Seen in up to 50 – 75% of adoptees.
- ◆ Children from any country (and even from foster care) may be affected.
- ◆ Often due to infant care practices in the birth country: limited floor time, isolated cribs.
- ◆ Language may take longer to catch-up.
  - ◆ May be related to limited language exposure, learning a second language. Consider sign language.
  - ◆ Previously undiagnosed ear infections may compound the problem.

# Overcoming Orphanage Delays

- ◆ Living in an orphanage will cause a 20-33% loss in developmental milestones, that is, one month lost for every three to five months in the orphanage.
- ◆ Recovery of lost milestones depends upon the child's emotional resiliency and intellectual capacity. Parental intellectual capacity and past problems rarely known.
- ◆ The quality of care in the orphanage is a crucial factor (Caregiver: child ratio, resources, hygiene, light, joy).
- ◆ Post-adoption, the vast majority of international adoptees blossom, developmentally, but, delays, emotional and physical problems should be quickly identified and addressed.



Wuhan Child Welfare Institute





# What Does Adopting an Older Orphanage Child Mean to ME?



- ◆ Most families can handle the “routine” crises raising a child.
- ◆ Older children, who have lived in institutions for prolonged periods, will likely have intellectual deficits and psychological problems that will NOT go away, just with your love.
- ◆ Issues, such as profound neglect, or physical and sexual abuse, at the hands of staff and older children, must be addressed.
- ◆ Adoptive parents must be ready to become a “therapeutic home” if necessary, and have time and energy to devote to that task.



# Chinese Waiting Children

- ◆ Minor or major health problems.
- ◆ May be correctible or permanent problems.
- ◆ Faster adoption time-line.
- ◆ Necessary resources must be available, for you to care for child's special need(s).
- ◆ Unknowns



# New Waiting Child List

- ◆ In the past, individual adoptive parents would decide to pursue a waiting child. Whatever agency had the child on its Waiting Child list, would work with the family.
- ◆ Requested response times were variable, but less than Hague guidelines of two weeks.
- ◆ More information variably available.
- ◆ Now, all agencies view a single list, and are responsible for placing a “hold” on a child for whom they have a family, who should be interested. The agency, which already works with the family, continues to.
- ◆ Requested response times are as little as 24 hours.
- ◆ More information, usually after acceptance.
- ◆ Exception for severely disabled and older children.

# Making Sense out of the Waiting Child Lists

◆ Plumbing

◆ Heart

◆ Circulatory system

◆ Genito-urinary system

◆ Gastro-intestinal system

◆ Wiring

◆ Brain and Nervous system

◆ Carpentry

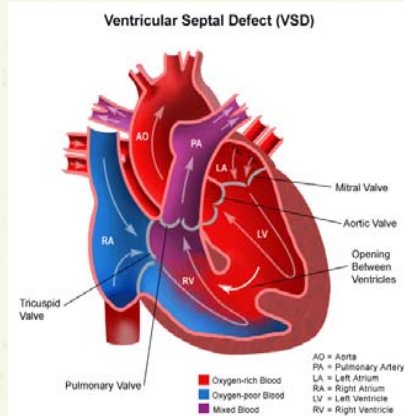
◆ Bones, structural support, skin

◆ Genetics, syndromes

◆ Inherited diseases and combinations of above

# Plumbing

## ◆ Heart



## ◆ Congenital heart problems

- ❖ Correctable, if so, fixed?
- ❖ Increased pressure stress or increased volume stress
- ❖ Decreased oxygen (blue baby)
- ❖ Rate or rhythm problems

## ◆ Lung problem

## ◆ Blood vessels

## ◆ Genito-urinary

## ◆ Gastro-intestinal

## ◆ Oxygen/ Carbon dioxide

## ◆ Tumor, anemia

## ◆ Kidneys, bladder, urethra, internal and external genitalia

## ◆ Mouth to anus structural, digestive, endocrine

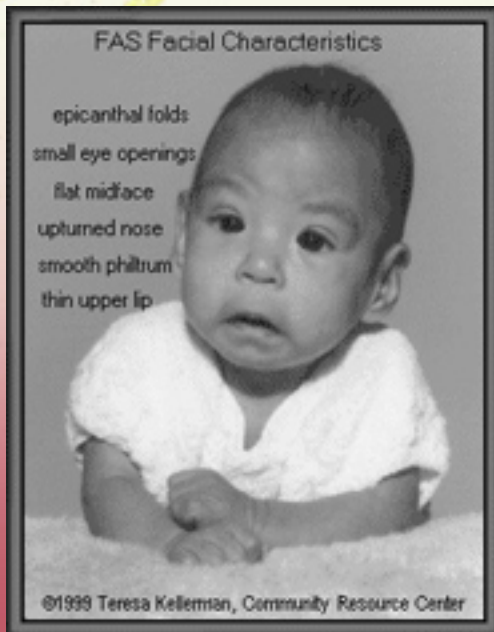
# Wiring

## ◆ Brain

- ◆ Structural abnormality
- ◆ Functional abnormality
- ◆ Fixable/ permanent

## ◆ Nervous system

- ◆ Spinal cord
- ◆ Peripheral nerves
- ◆ Fixable/ permanent



# Carpentry

◆ Bones

◆ Structural

◆ Skin, soft tissue

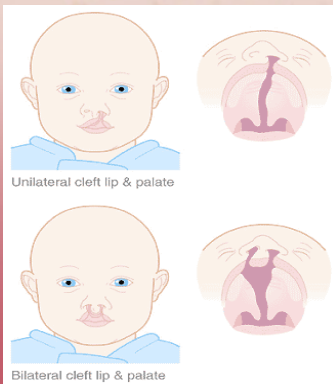
◆ Intact/ missing

❖ Correctable/ permanent

❖ Congenital/ acquired

◆ Connective tissues, muscles

◆ Defect, tumor, color, texture



# Genetics



◆ Inherited

◆ Physical (structure and function), psychiatric (structure and function)

◆ Syndromes

◆ Identifiable combinations of structural and functional abnormalities



Skin folds at the corner of the eye  
Low nasal bridge  
Short nose  
Indistinct philtrum (groove between nose and upper lip)



Small head circumference  
Small eye opening  
Small midface  
Thin upper lip



# Key Issues



- ◆ Fixable, wholly or in part?
- ◆ Where are we, now?
- ◆ Therapy or other interventions?
- ◆ Family dynamics
- ◆ Covered by insurance?
- ◆ Long term prognosis?
- ◆ What can or needs to be done?
- ◆ Tests, x-rays, records?
- ◆ What will be needed after or instead of fixing?
- ◆ Can our family afford it?
- ◆ Can we afford it, financially?
- ◆ What is the best and worst we can expect?



# Examples of Physical Special Needs

- ◆ Congenital heart disease
- ◆ Cleft lip and Palate
- ◆ Spina Bifida
- ◆ Club foot
- ◆ Hepatitis B
- ◆ Hemangioma
- ◆ Prematurity
- ◆ HIV



# Example- Congenital Heart Disease

**1/200-1/500 births\***

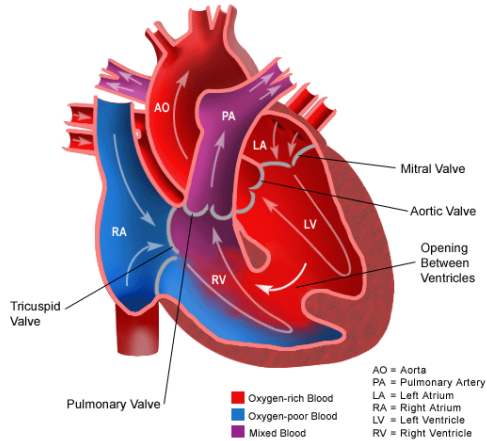
- ◆ Past history
- ◆ Present condition
  - ❖ Stable? For how long?
- ◆ Necessary intervention
  - ❖ Surgery or surgeries
  - ❖ How soon needed?
  - ❖ Palliation vs. cure
  - ❖ Medications? For what?
- ◆ Associated problems
  - ❖ Developmental?
- ◆ Diagnosis, tests, hospitalizations?
- ◆ How serious is the problem?
  - ❖ How sick, now?
- ◆ What needs to be done, and how soon?
  - ❖ Echocardiogram, Cardiac catheterization, Surgery
  - ❖ Hospitalizations, orphanage vs. foster care
- ◆ Syndromes
- ◆ Other undiagnosed problems

\*Nelson's Textbook of Pediatrics, 16th ed. 2000, p. 1362

# Types of Congenital Heart Disease

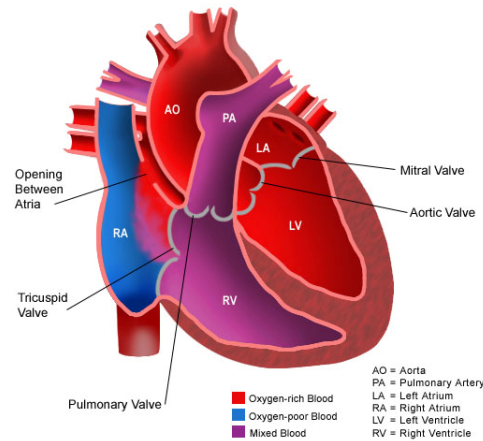
25-30%

Ventricular Septal Defect (VSD)



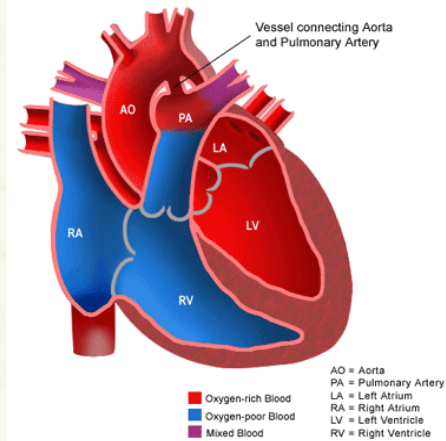
6-8%

Atrial Septal Defect (ASD)



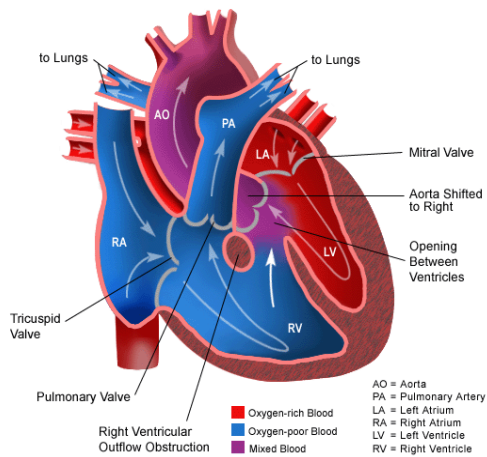
6-8%

Patent Ductus Arteriosus (PDA)



5-7%

Tetralogy of Fallot (TOF or "Tet")



Aortic Valvular Stenosis 5-7%

Pulmonic Valvular Stenosis 5-7%

Transposition of Great Vessels 3-5%

Hypoplastic Left Ventricle 1-3%

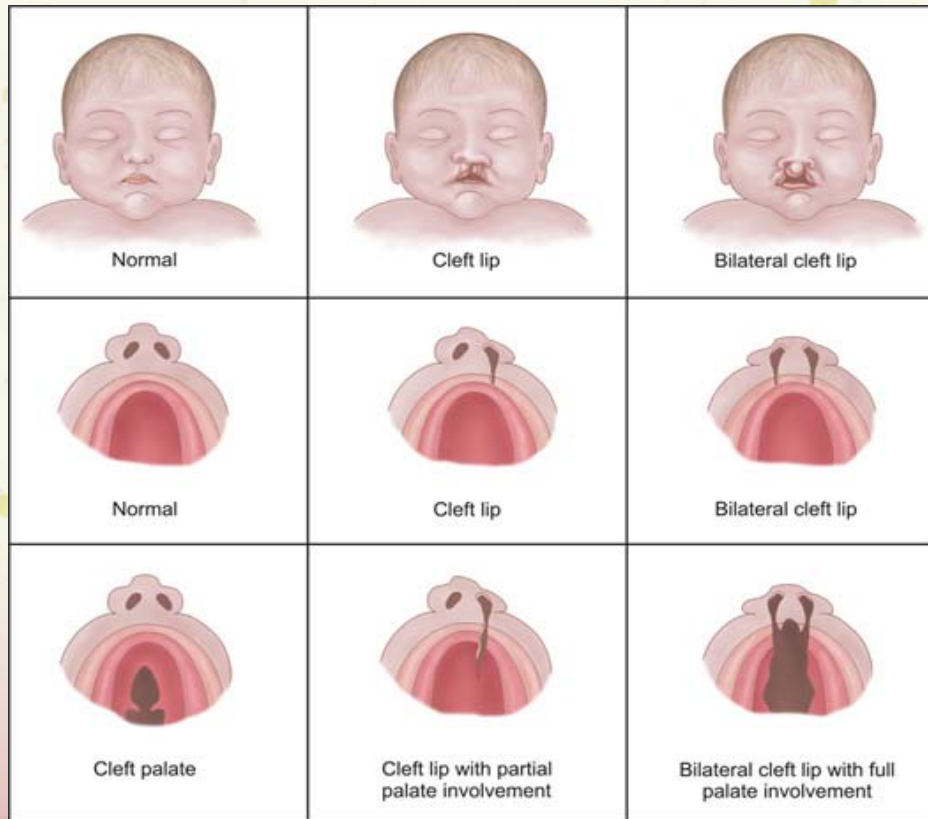
Hypoplastic Right Ventricle 1-3%

Tricuspid Atresia 1-3%

Data from Nelson's Textbook of Pediatrics, p. 1362

# Cleft Lip and Cleft Palate 1/750 Births\*

- ◆ Cleft lip only- 20%
  - ❖ Unilateral
  - ❖ Bilateral
- ◆ Cleft palate only- 30%
  - ❖ Severity
- ◆ Cleft lip and palate- 50%
  - ❖ Unilateral or Bilateral
  - ❖ Complete or Partial
- ◆ Associated with
  - ❖ Cardiac abnormalities
  - ❖ Hearing problems
  - ❖ Feeding problems
  - ❖ Speech delays



\*eMedicine, Pravin Patel, MD,  
Associate Professor in Plastic Surgery,  
Children's Memorial Hospital

# Cleft Lip and Cleft Palate

## ◆ Repair

- ❖ Cleft lip at 2-3 months of age
- ❖ Cleft palate at 6-24 months



## ◆ Revisions

- ❖ Vermillion border
- ❖ Upper lip scar and nostril
- ❖ Palatal function- speech and feeding

## ◆ Ear ventilation tubes



# Spina Bifida- 1/1,300 births (US)

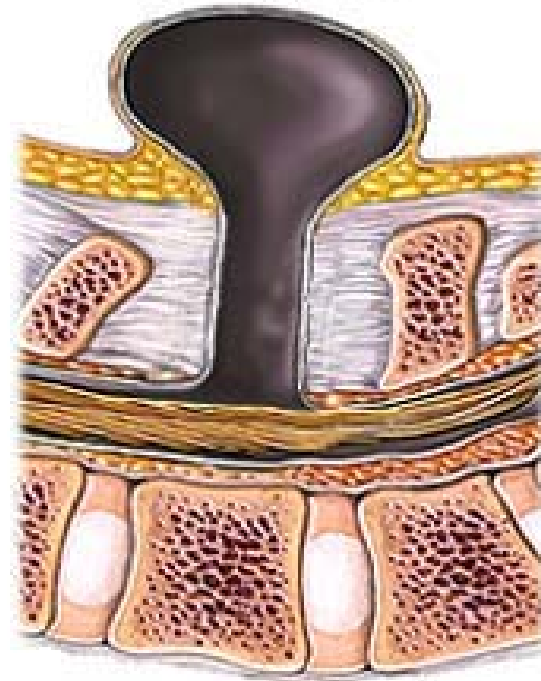
- ◆ Spina Bifida Occulta in 23-40% of population
  - ❖ Pilonidal dimple or hair tuft
  - ❖ Bony vertebral defect
- ◆ Meningocele
  - ❖ Only lining of spinal cord in sac
- ◆ Myelomeningocele
  - ❖ Sac contains nerves, nerve roots and can contain the spinal cord
  - ❖ Nerve deficit depends upon level of defect
  - ❖ 70-90% develop hydrocephalus

# Myelomeningocele and Meningocele



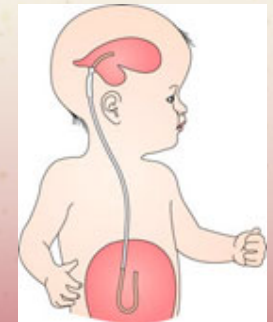
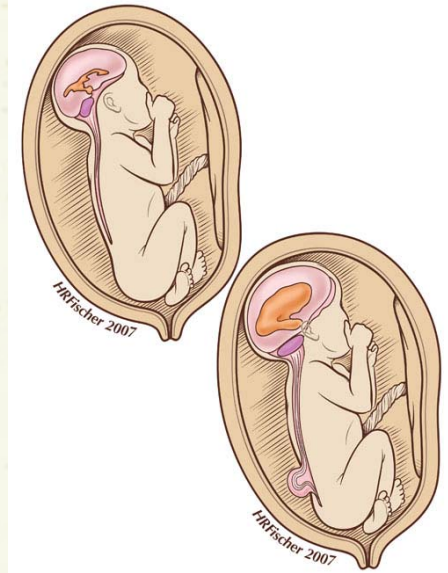
Meningomyelocele

Meningocele



# Associated Problems

- ◆ Hydrocephalus- Arnold Chiari Type II
  - ❖ Plain CT scan of the brain will show trapping of fluid
  - ❖ Ventriculo-peritoneal shunt (drainage tube from brain to abdominal cavity)
- ◆ Limited mobility
  - ❖ Lumbar and sacral nerve roots supply bladder, rectum, sex organs, legs, and feet
  - ❖ Wheel chair, braces
- ◆ Tethered spinal cord
  - ❖ Spinal cord stuck in scar or surrounding tissue
  - ❖ Uncommon in meningocele or occulta
  - ❖ Treatment is surgical release





# More Associated Problems

## ◆ Urinary tract

- ❖ Injury to the internal pudendal nerve
- ❖ Incomplete bladder emptying -> infections, kidney damage
- ❖ Intermittent urinary catheterization
- ❖ Sexual dysfunction

## ◆ Psychological

- ❖ Social Isolation -> Immaturity, depression
- ❖ 80% have normal intelligence

## ◆ Latex allergy

- ❖ 73% of children with meningocele

## ◆ Prevention

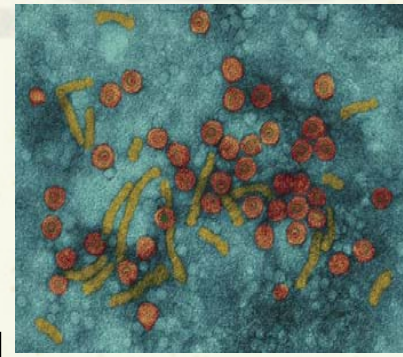
- ❖ Folic acid (B- vitamin) supplementation in pregnancy
- ❖ Incidence higher in third world

# Club Foot- Talipes Equinovarus- 1/1,000 Births

- ◆ Bilateral in 30-50%
- ◆ Serial casting begun in first few days of life
  - ❖ 50-89% successful
- ◆ Surgical correction
  - ❖ Earlier -> better result
  - ❖ 81% satisfactory results
  - ❖ Recurrence rate 10-50%
- ◆ Associated problems
  - ❖ Spina Bifida, Arthrogryposis, Congenital hip dislocation, Myotonic Dystrophy



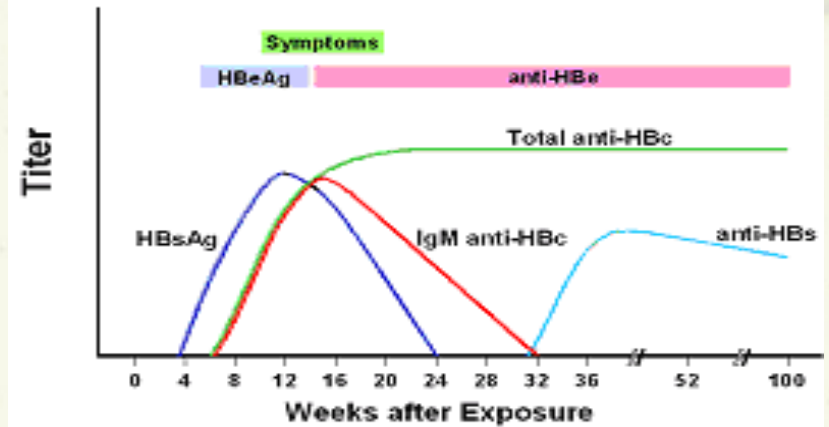
# Hepatitis B\*



- ◆ One-third of the world's population infected
  - ❖ 350,000,000 people are life-long carriers
  - ❖ 250,000 people die, annually from chronic infection
- ◆ Chronic infection occurs in:
  - ❖ 90 % of infants infected at birth
  - ❖ 30% of children infected at 1-5 years of age
  - ❖ 6% of people infected after 5 years of age
- ◆ Death from chronic liver disease occurs in:
  - ❖ 15-25% of chronically infected people
- ◆ Incubation period is one to six months

# Testing for Hepatitis B

Acute Hepatitis B Virus Infection with Recovery  
Typical Serologic Course



- ◆ HBsAg
- ◆ HBsAb
- ◆ HBcAb
- ◆ HBcAb- IgM
- ◆ HBeAg
- ◆ HBeAb
- ◆ PCR
- ◆ Surface antigen of virus
- ◆ **If only Antibody to surface antigen, only from vaccine**
- ◆ Resolving infection
- ◆ Resolving acute infection
- ◆ Infectious
- ◆ Resolving infection
- ◆ Viral genetic footprint

# Prematurity

## U.S. vs. Chinese Health Care

- ◆ 36-38 weeks
  - ❖ Mild vs. Degree 1
- ◆ 33-36 weeks
  - ❖ Moderate vs. Degree 2
- ◆ Less than 32 weeks
  - ❖ Severe vs. Degree 3
- ◆ Perinatal asphyxia vs. Perinatal encephalopathy
  - ❖ Different concepts of fetal well-being, especially during delivery.



# Causes of Prematurity

- ◆ Poverty and Minority
- ◆ Lack of prenatal care
- ◆ Poor prenatal nutrition
- ◆ Adolescent mother
- ◆ Substance abuse
- ◆ Medical conditions
  - ❖ Diabetes
  - ❖ Heart disease
  - ❖ Infections
- ◆ Previous history of premature birth

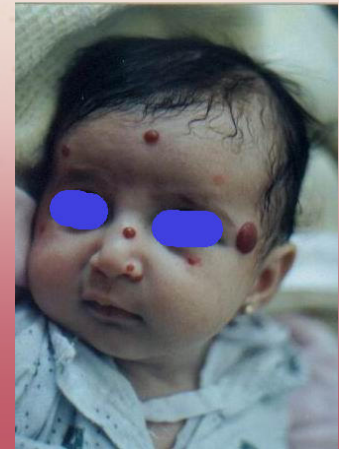


# Problems of Premature Infants

- ◆ Under-developed lungs
  - ❖ Respiratory distress syndrome
  - ❖ Apnea (forgetting to breathe)
- ◆ Under-developed organs
  - ❖ Kidneys, liver, skin, intestines.
- ◆ Brain and eyes susceptible to bleeding
  - ❖ Intracranial hemorrhage
  - ❖ Retinopathy of prematurity
- ◆ Implications for the future
  - ❖ Developmental
  - ❖ Cerebral Palsy
  - ❖ Chronic medical problems

# Hemangiomas 1/50 newborns

- ◆ Hemangiomas are benign blood vessel tumors.
- ◆ Vary from Nevus Flammeus (Stork Bite and Angel Kiss), to Congenital Hemangiomas (skin and internal organ hemangiomas).
- ◆ May involve small vessels or larger ones.
- ◆ Female to male- 4:1.
- ◆ 25% of premature babies, born at less than 1 kg.
- ◆ 80% single lesion, and 20% multiple lesions.





# HIV in China



- ◆ 2007- 700,000- 1 million HIV positive people (estimated, due to rural under-reporting).
- ◆ Henan, Sichuan, Xinjiang Uygur Autonomous Region, and Yunnan
  - ❖ Henan- Plasma donations
  - ❖ Yunnan- IV drug use
- ◆ Yunnan and Xinjiang
  - ❖ 0.6- 0.8% of pregnant women HIV positive

# HIV Testing



◆ ELISA

◆ Western Blot

◆ PCR



◆ Screening- **mother's and child's antibodies**

◆ More specific for HIV

◆ Very specific for viral presence. Lab quality essential to avoid false negatives.

# Human Immunodeficiency Virus

- ◆ Risk dependent upon maternal sexual habits, drug abuse.
- ◆ Testing in many prenatal clinics is *optional*
- ◆ Screening does not distinguish between maternal and child antibodies.
- ◆ Maternal antibody may be present until 18 months old.
- ◆ Children often fail to grow on track with other children.
- ◆ Developmental delays more than expected.
- ◆ Early and continuing treatment is key to long term survival

# HIV in the World (UNAIDS)

- ◆ 15,000,000 AIDS orphans in Sub-Saharan Africa
  - ❖ 1.2 million AIDS orphans
- ◆ Ethiopia- 2.6% of women 15-49
  - ❖ 898,350 AIDS orphans
- ◆ Viet Nam- 0.37% of pregnant women
  - ❖ 122-263,000 people living with AIDS
- ◆ South Africa- 5.5 million people living with HIV
- ◆ Haiti- 3.1% of pregnant women
  - ❖ 3% of women 15-44 years-old
- ◆ India- 2-3.1 million people living with AIDS
  - ❖ 0.36% of 1 billion people



# So, What If the Brain Isn't Normal?

- ◆ Intellectual Impairment
- ◆ Fetal Alcohol Spectrum Disorder
- ◆ Cerebral Palsy
- ◆ Reactive Attachment Disorder
- ◆ PTSD
- ◆ Inherited Psychiatric Disorders
- ◆ Autistic Spectrum Disorder
  - ❖ Sensory Processing Problems
- ◆ Sensory Problems

# Cerebral Palsy

- ◆ Incidence- 2-3/1000
- ◆ Caused by brain damage, affecting muscular control. The extent and location of the brain injury determine the abnormal movements.
  - ❖ 84-90% prenatal injury (prematurity, complicated neonatal course, Kernicterus)
  - ❖ 10-16% infections, strokes, head injuries (accidents and abuse)

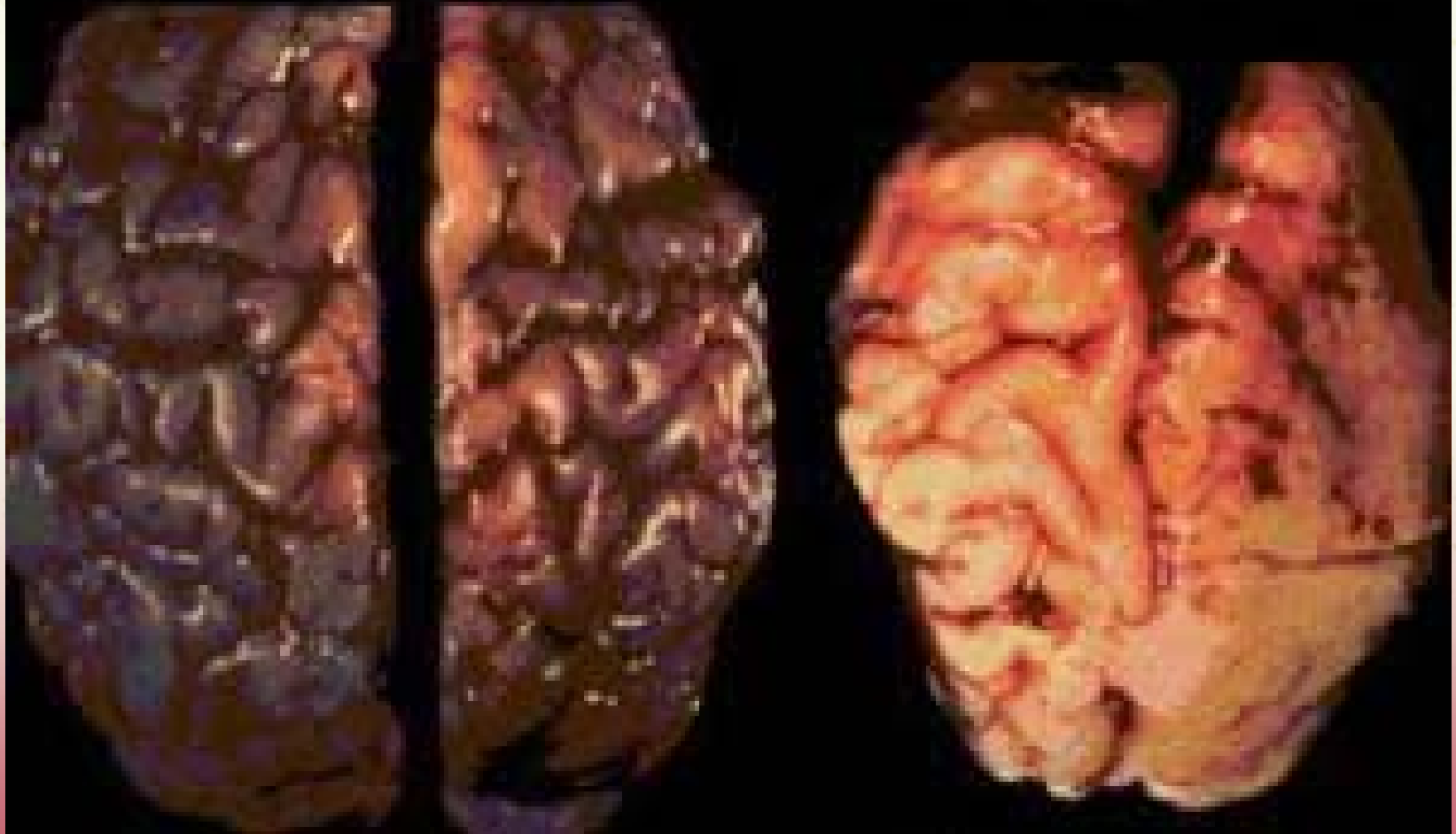
# Intellectual Disability

- ◆ Present in 2-3% of US population (IQ under 70)
  - ❖ 25% have detectable chromosome abnormality
  - ❖ 50% do not have an identifiable cause
- ◆ Down's Syndrome
  - ❖ 1 in 600-800 births
- ◆ Velocariofacial Syndrome
  - ❖ 1 in 700 births
- ◆ Fragile X Syndrome
  - ❖ 1 in 2,000-3,000 male births; females affected, as well
- ◆ Fetal Alcohol Spectrum Disorder
  - ❖ Up to 5% of first graders in US (May, 2009)

# FAS: The Bottom Line

Brain of normal baby

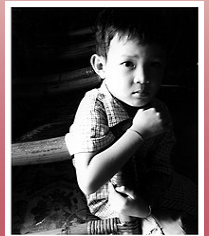
Brain of baby with FAS





# Stress Response Impaired by Prenatal Alcohol Exposure and Orphanage Life

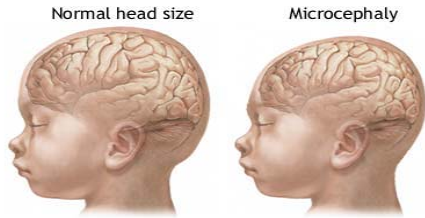
- ◆ Greater PAE was directly related to greater activation of infant stress response systems- Haley, et. al., Alcoholism: Clinical and Experimental Research, Vol. 30, No. 12, 2006.
- ◆ Many studies show abnormal stress responses in neglected orphanage children- hyper-alertness, chronically increased cortisol levels, and abnormal emotional responses.



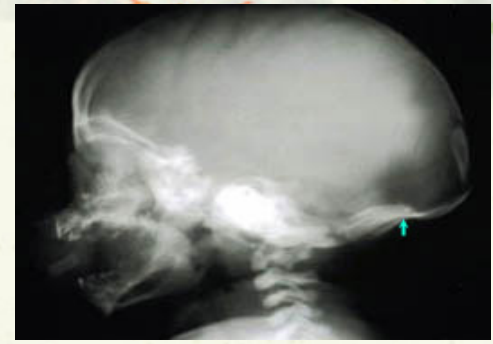
# Developmental Delays

- ◆ Orphanage life accounts for 20-33% delays vs. stated age
- ◆ Excessive delays should raise concerns about untold or unknown issues, including:
  - ❖ Brain injury from many causes
  - ❖ Severe neglect (possibly, before and after coming to the orphanage)
  - ❖ Error in age estimate ( Chinese usually pretty accurate)
  - ❖ Syndromes- usually associated appearance or problems
- ◆ Physical problems more objective, with more predictable outcomes

# Head Circumference



ADAM.



## ◆ Why do we care about head size?

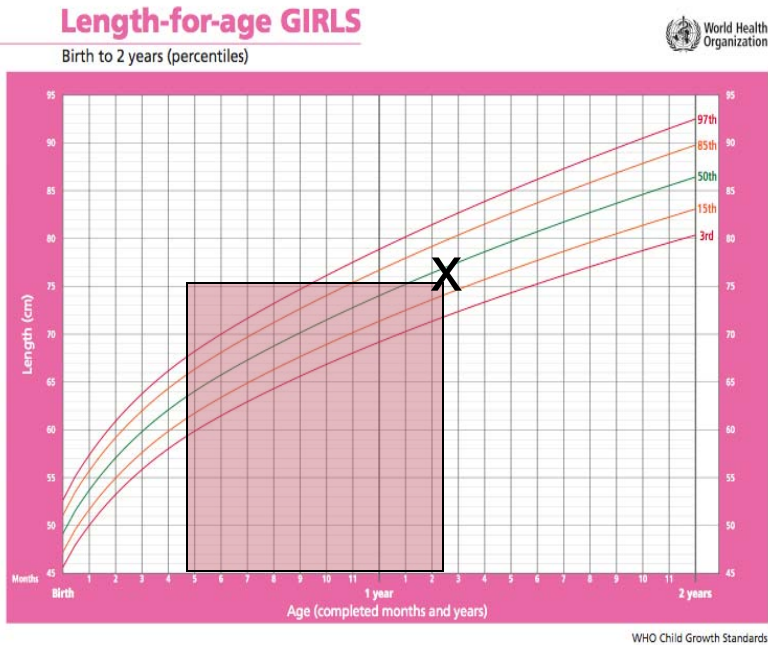
- ❖ Correlates with brain size. Men have larger heads than women, so head size isn't necessarily associated with intelligence.
- ❖ Very small or very large heads are associated with serious problems-syndromes, abnormal brains, developmental and behavioral problems.
- ❖ Malnourished children first lose weight, then height, then brain growth/ head size. Protein malnutrition may affect height more than weight.

# Measuring a Child's Head



- ◆ Angle down from front to back, not parallel to the floor.
- ◆ Multiple measurements a must. The largest circumference, properly done, is correct.
- ◆ Orphanage workers or medical personnel may be rushed, or measure incorrectly.

# Plotting Results On A Growth Chart



- ◆ Locate the child's age on the x-axis (13 months).
- ◆ Locate your measurement on the y-axis (73 cm.).
- ◆ Use the corner of a piece of paper to place your point on the chart.
- ◆ Result is 25th percentile, i.e., 75% of 13 month-olds are taller than this girl.
- ◆ WHO growth charts at [who.org](http://who.org)

# Post Traumatic Stress Disorder



- ◆ Often seen in children with a history of abuse/neglect
- ◆ Increased arousal
  - ❖ Sleep issues, night terrors, hyper-vigilance
- ◆ Fears and aggression
  - ❖ Separation anxiety, fear of the dark, fear of toileting
- ◆ Recollection of trauma
  - ❖ Flashbacks, reenactment through play, nightmares
- ◆ Decreased attention span
  - ❖ Poor concentration, exaggerated startle response

# Inherited Psychiatric Disorders

- ◆ ADD/ADHD
- ◆ Schizophrenia
- ◆ Bipolar Disorder
- ◆ Depression
- ◆ Obsessive- compulsive Disorder
- ◆ Intellectual Deficits
- ◆ In US, approximately 90,000 people are in hospitals being treated for Schizophrenia or Bipolar Disorder, while 200,000 remain untreated and homeless. For these people, alcohol may be their only medication.
- ◆ In China, admitting psychiatric disorder disgraces family.

# Inherited Psychiatric Disorders

- ◆ ADHD- Half of the children born to adults with ADHD will also be diagnosed with it.
- ◆ Schizophrenia- ten times greater risk in families.
- ◆ Bipolar Disorder- eight times greater risk in families.
- ◆ Depression- three times greater risk in families.
- ◆ Anxiety/ Panic Disorder- affects 23 million adults, and there is an increased risk in families.
- ◆ Obsessive-Compulsive Disorder- 17.9% more likely in offspring of diagnosed parents.\*

\* Michele T Pato, et al, Current Psychiatry Reports, 2001, 3:163-168



# Sensory Processing Disorder



- ◆ Abnormal response to normal stimuli
  - ◆ Eating- solids, textures
  - ◆ Clothing- labels, textures
  - ◆ Noises- volume, pitch
  - ◆ Reactions to daily activities
  - ◆ Ritualistic behaviors
  - ◆ Inappropriate verbal responses
  - ◆ Poor interactions, no friends
- ◆ Deprivation can result in disorganized perception
- ◆ May resemble ADHD, with sensory overload

# Sensory Organ Problems

- ◆ Vision
- ◆ Hearing
- ◆ Touch/ Pain
- ◆ Smell/ Taste
- ◆ Balance
- ◆ Fixable vs. Permanent?
- ◆ Partial vs. Complete?
- ◆ Static vs. Progressive?
- ◆ Prognosis?
- ◆ Worst case scenario?
- ◆ Necessary medical specialty resources, therapy available?



# Making Sense?

- ◆ Access to information
  - ❖ Privacy
  - ❖ Fragmented care
  - ❖ Inter-agency communication
- ◆ Medical, psychological, and developmental issues
  - ❖ Prognosis
  - ❖ Parentability
- ◆ Translation of \$20 words into understandable concepts
  - ❖ Medical jargon
- ◆ Adoption pediatrician
  - ❖ Expertise
  - ❖ Consultants and colleagues
- ◆ [aap.org/section/soafc.html](http://aap.org/section/soafc.html)  
>



# **AAP Section on Adoption and Foster Care**

**<http://www.aap.org/Sections/adoption/default.cfm>**



# Understanding the Waiting Child List

## Problems

- ◆ Disorganized
  - ↓ Random categories
- ◆ Excessive complexity
- ◆ Obscure diagnoses
  - Agency reacts to referral diagnosis
- ◆ Scary unknowns
- ◆ Yes, or No, or Maybe

## Solutions

- ◆ Organizing and building conceptual framework
- ◆ Organ system approach
- ◆ Increasing or decreasing severity.
- ◆ Would like to learn more about child, or not.
- ◆ Flexibility

**Making that leap of faith...**





# Special Needs Referral Review Issues

- ◆ Independent physical examinations should be available, before adoption finalized, especially if significant concerns expressed.
  - ❖ Medical records should be available.
- ◆ Additional questions and surprises.
  - ❖ Medical records. Adoption pediatrician and local MD.
- ◆ Additional or repeated blood tests
  - ❖ Risks and additional trauma for the child
  - ❖ Same lab that gave first dubious result?
  - ❖ Will test give essential information, affecting your decision on your referral?



# Referral Questions Worth Asking

- ◆ What is this child's history in care, and prior to entering care? In all previous placements- why did each one fail?
- ◆ Does he/she laugh, cry, play, and exhibit good eye contact, when interacting with adults?
- ◆ Does he/she show signs of rocking or other self-stimulating behaviors?
- ◆ Was the child abandoned or removed from his/her parent's home- abuse? neglect? Why was the child removed? Parents alcoholic or psychotic?
- ◆ Siblings? Relationship with this child? Availability?



# Photos and Videos



- ◆ More better and more views better, with emotions shown (anger, joy, and attitude).
- ◆ Close-ups of noted medical conditions helpful.
- ◆ Look for unusual features
  - ❖ FAS, Down's Syndrome, Cleft lip and palate
- ◆ Look at extremities, hands and feet
  - ❖ Deformities, appearance, evidence of movement, e.g., clenched fists, stiff muscles.



# Waiting Children, Waiting Parents

- ◆ What can I/we handle?
  - ❖ Financially
  - ❖ Time investment/ transportation
  - ❖ Family dynamics
  - ❖ Future considerations
- ◆ What resources are available?
  - ❖ Insurance coverage
  - ❖ Access to necessary specialists
  - ❖ Community support network
  - ❖ Respite





# The Children

- ◆ Waiting because of correctible or permanent physical or developmental problems.
- ◆ Initial information may be inadequate
  - ❖ Stale, needing update(s)
  - ❖ Additional tests may be needed
- ◆ What resources will be needed to bring the child home, and fix the problem?
  - ❖ Defining the problem
  - ❖ Assessing resources available
- ◆ Can I/we parent this child?

# Working With Doctors, After You Arrive Home

## ◆ Child Advocacy

- ❖ DCFS
- ❖ Protective Services
- ❖ Community medical resources

## ◆ Medical Home

- ❖ American Academy of Pediatrics encouraging community-based pediatricians to become primary care-coordinators for special needs children
- ❖ Primary care “home”

## ◆ AAP Section on Adoption and Foster Care





# Love may not be enough...



- ◆ Acknowledging the differences will foster a child's self-respect.
- ◆ Support groups (friends, email) may help.
- ◆ Educate the educators about adoption issues.
  - ❖ Stages of adoption, racial and cultural identity, difficult school assignments.
  - ❖ Celebrate holidays (e.g., Chinese New Year)
- ◆ Model positive adoption language.
  - ❖ “real parents”, avoid unnecessary questions, refer to adoption only when pertinent.

# Cultural Identity



- ◆ A child with a special need, who looks different from her/his parents and her/his peers, needs a positive, persistent cultural identity.
- ◆ Keep your child's homeland culture alive
  - ❖ Makes him/her feel special in positive way
  - ❖ Encourages positive adoption attitudes at school/daycare.
  - ❖ Gives more holidays to celebrate for siblings and classmates.
  - ❖ Gives adoptive parents chance to work together/ network.
  - ❖ If not, some day, he or she will ask, "Why not?"
- ◆ So, join FWCC, etc., then take part in festivals, cook special foods, decorate your home, educate your child's school, and, have fun with your son(s) and daughter(s). Celebrate differences!

# Chinese American Service League, Chicago



# Reunions, Roots Trip, Culture





# Adoption is all about the children

There are no guarantees with any child who joins a family, whether through birth or through adoption. Children deserve prepared and educated parents who will have the strength and determination to stay committed for a lifetime.



# Suggested Readings

- ◆ Beneath the Mask, Understanding Adopted Teens, Case Studies & Treatment Considerations for Therapists and Parents by Debbie Riley, M.S. with John Meeks, M.D., C.A.S.E. Publications, 2005. ISBN- 13: 978-0-9711732-2-4.
- ◆ Handbook of International Adoption Medicine by Laurie C. Miller, MD, Oxford Press, 2004. ISBN- 0195145305.
- ◆ Wanting a Daughter, Needing a Son by Kay Ann Johnson and Amy Klatzkin, Yeong & Yeong, 2004. ISBN- 0963847279
- ◆ Adopting the Hurt Child by Greg Keck and Mary Kopecky, Pinion Press, 1998. ISBN- 1576830942.

# For More Information:



- ◆ [www.gwca.org/why\\_great\\_wall/waiting\\_child\\_program](http://www.gwca.org/why_great_wall/waiting_child_program)
- ◆ [www.adoptivefamilies.com](http://www.adoptivefamilies.com) (excellent website with all kinds of resources, plus subscription info)
- ◆ [www.emkpress.com/userguide.html](http://www.emkpress.com/userguide.html) (great parent guides with helpful information)
- ◆ [www.adoptionlearningpartners.org/](http://www.adoptionlearningpartners.org/) (wonderful online courses, some of which are free!)
- ◆ [www.fwcc.org](http://www.fwcc.org)
- ◆ [www.jcics.org](http://www.jcics.org)
- ◆ [www.aap.org/section/adoption](http://www.aap.org/section/adoption)