Special Needs in International Adoption

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Objectives

- Who are the waiting children?
- Why are the children waiting?
- General medical overview
- Case presentations
- Q & A

Adoption: for the children

The entire process has to be about the children, not the parents, biological or adoptive. We should endeavor to find the right family for each child, i.e., "Can I parent this child? Do I have the emotional, medical, and financial resources to make this work?"

Risk Factors in International Adoption and Foster Care*

- Prenatal Malnutrition- poverty
- Prenatal Alcohol Exposure- 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, Hospital, or Multiple Foster Placements

*Adapted from University of Minnesota Adoption Clinic

International Waiting Children

- Minor or major health or developmental problems.
- May be older.
- May be correctible or permanent problems.

Waiting children

- 27% of all referrals in 2008
  - 59% of China adoptions
  - 27% of South Korean adoptions
- Incomplete records, diagnoses
  - Sometimes artificial distinction between "major" & "minor" conditions
  - Lack of access to additional information
- All general risks still apply
- Families often allowed *less* time to decide

Waiting Children, Waiting Parents

- Initial information may be inadequate
  - Stale, needing update(s)
  - Additional tests may be needed
- 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

Examples of Special Needs

- Developmental Delay
- Congenital heart disease
- Cleft lip and Palate
- Spina Bifida
- Ear and eye deformities
- Club foot
- Hepatitis B
- Fetal alcohol exposure
- Prematurity
- Hemangioma

Photos and Videos

- The more, the better and more views better, with emotions shown (anger, joy, 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.
- Digital pictures and wave files can be emailed.

Waiting Child Listings

- Special needs orphanage child is a redundant statement.
- Many countries and even more policies.
- Each agency has its own financial arrangements (reduced fees) and its own policies, relating to waiting children.
- Waiting child adoption process usually faster.
- China's waiting child list is transparent and consistent, though not very Hague-compliant or user-friendly.

The Hague Treaty

Training

96.48 (a) The agency or person provides prospective adoptive parent(s) with at least ten hours (independent of the home study) of preparation and training, as described in paragraphs (b) and (c) of this section, designed to promote a successful inter-country adoption. The agency or person provides such training before the prospective adoptive parent(s) travel to adopt the child or the child is placed with the prospective adoptive parent(s) for adoption.

The Hague Treaty

Referrals

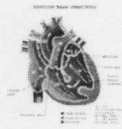
- **96.49 (k)** The agency or person does not withdraw a referral until the prospective adoptive parent(s) have had two weeks (unless extenuating circumstances involving the child's best interests require a more expedited decision) to consider the needs of the child and their ability to meet those needs, and to obtain physician review of medical information and other descriptive information, including videotapes of the child if available.

Making Sense out of the Waiting Child Lists

- Plumbing
  - Heart
  - Circulatory system
  - Genito-urinary system
  - Gastro-intestinal system
- Wiring
  - Brain/Nervous system
- Carpentry
  - Bones, structural support, skin
  - Inherited diseases and combinations of above
- Genetics, syndromes

Plumbing

- Heart



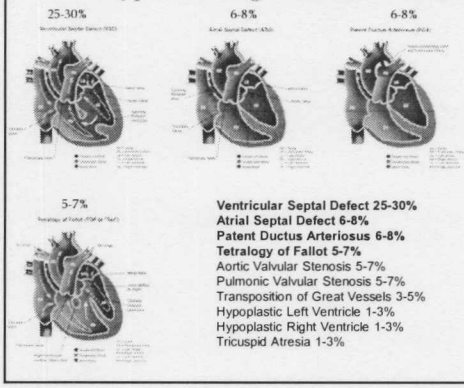
  - Congenital heart problems
    - Correctable, if so, fixed?
    - Increased pressure stress or increased volume stress
    - Decreased oxygen (blue baby)
    - Rate or rhythm problems
- Lung problem
  - Oxygen/ Carbon dioxide
- Blood vessels
  - Tumor, anemia
- Genito-urinary
  - Kidneys, bladder, urethra, internal and external genitalia
- Gastro-intestinal
  - Mouth to anus structural, digestive, endocrine

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

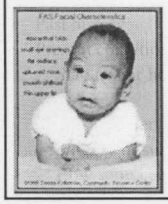
Types of Congenital Heart Disease

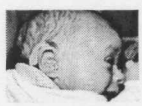


Ventricular Septal Defect 25-30%
Atrial Septal Defect 6-8%
Patent Ductus Arteriosus 6-8%
Tetralogy of Fallot 5-7%
Aortic Valvular Stenosis 5-7%
Pulmonic Valvular Stenosis 5-7%
Transposition of Great Vessels 3-5%
Hypoplastic Left Ventricle 1-3%
Hypoplastic Right Ventricle 1-3%
Tricuspid Atresia 1-3%

Wiring

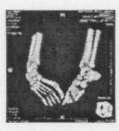
- Brain
  - Structural abnormality
  - Functional abnormality
  - Fixable/ permanent
- Nervous system
  - Spinal cord
  - Peripheral nerves
  - Fixable/ permanent

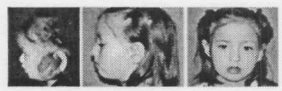




Carpentry

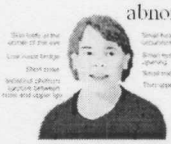
- Bones
  - Intact/ missing
    - Correctable/ permanent
    - Congenital/ acquired
- Structural
  - Skin, soft tissue
  - Connective tissues, muscles
- Skin
  - Defect, tumor, color, texture





Genetics

- Inherited
- Physical (structure and function), psychiatric (structure and function)
- Syndromes
- Identifiable combinations of structural and functional abnormalities



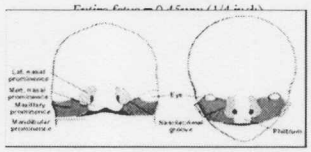
DMG, female, Central China

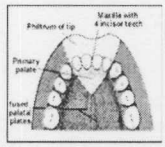
- Diagnosis: Congenital bilateral cleft lip and cleft palate, 3rd degree.
- Children Medical Exam Record from age 9 months. Growth: height 10th percentile, weight 3rd percentile, head circumference <<3rd percentile (all on Chinese growth charts)
- Physical exam reported normal except clefts. Note hearing reported "normal".
- Narrative: Found at 2 weeks of age. Problems reported with feeding and vomiting. "Growth and development were all more delayed than normal children". She remains in orphanage care.
- Cleft lip was repaired at age 8 months.
- Updated growth measurements at age 15 months: height and weight 10th percentile, head circumference still << 3rd percentile. Development at age 15 months: crawls, walks holding one hand only, does not speak.
- Cleft Palate repair was planned in China at age 15 months just after this latest growth and development assessment.

Cleft Lip / Cleft Palate
Definition:

Face:
- 4th week of gestation
- 5 processes merge/fuse

Palate:
- 12th week of gestation
- Fusion of hard/soft palate
- Entire fetus 6-7 cm

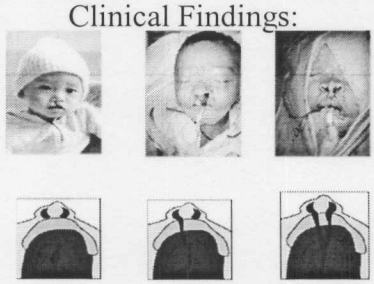




Cleft Lip / Cleft Palate

- **Epidemiology** (What and Where?)
  Common "Special Needs" Diagnosis
  - Deformity is Immediately Obvious
  - Cultural and Practical Decision to Abandon
  - History of Treatment and Acceptance in West
- **Etiology** (What Causes It?)
  - Genetic (more common in Asians)
  - Folate Deficiency
  - Toxins: Drugs/Alcohol/Environmental

Cleft Lip / Cleft Palate
Clinical Findings:



Cleft Lip / Cleft Palate
Treatment:

Multidisciplinary Craniofacial Team
- Audiology
- Speech/Language
- ENT
- *Plastic Surgery*
- Oral-Maxillofacial Surgery
- Dentist/Orthodontist
- Pediatrician/Geneticist
- Genetic Counselor
- Pediatric Ophthalmologist
- Social Work

Developmental Stages of Life
- Children followed from Birth to Age 21 yrs
- Structure vs. Function
- Different Issues Related to Age
  - Feeding & growth
  - Language
  - Hearing
  - Appearance
  - School Issues

Cleft Lip / Cleft Palate Implications:

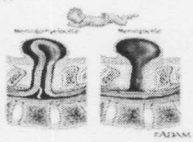
- Short Term
  - General
    - Team evaluation
    - Screen for co-morbidities
      - Cleft related
      - Adoption related
  - Cleft
    - Address feeding issues
    - Surgery (lip, then palate)
  - Ears
    - Treat acute infection
    - Place ear tubes
    - Monitor hearing
- Long Term
  - General
    - Speech
    - Hearing
    - School Performance
    - Growth
  - Cleft
    - Palate function, fistulae, appearance of lip/nares
  - Dental/Ortho
    - Bone grafting, braces, mid-face advancement
  - Genetic Counseling
    - Risk of clefting in offspring

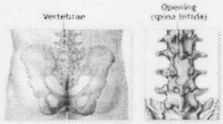
DJX, male, Northern China

- Diagnosis: Meningomyelocele/Spina Bifida
- Children Medical Exam Record from age 2 years: Growth height and weight 25th percentile, head circumference 97th percentile (all on Chinese growth charts).
- Physical exam: normal motor and sensory function of lower extremities, no other identified physical deformities.
- Narrative: Found at about 1 month old with "lump" on lower back. MRI scan indicated meningomyelocele and intraspinal mass. Surgery in Beijing at age 8 months, foster care there-after. Post-operative development reported as normal. Urinary and fecal daytime continence ? at age 2.
- Follow up MRI scan in China reported showed spina bifida and repaired meningomyelocele. Follow up reports showed continence just prior to family travel at age 3 years.
- Postscript: Evaluation by Pediatric Neurosurgeon in U.S. and review of Chinese MRI scans indicate NO meningomyelocele or spina bifida. Lesion presumed to be lumbo-sacral lipoma which was resected without problem. Follow up MRI scan in U.S. pending

Spinal Deformities
Definition:

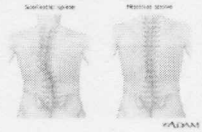
- Spinal Cord Anomalies
  - Meningocele
  - Meningomyelocele





Spinal Deformities
Definition:

- Bony Deformities
  - Scoliosis
    - Congenital
    - Acquired
      - » Ideopathic
      - » Cerebral Palsy
- Midline Low Back Mass
  - Lipoma
  - Teratoma
  - ? Involve Spinal Cord



Spinal Deformities

- Epidemiology (What and Where?)
  - MMC/SB is most common disabling birth defect in the U.S.
  - Open Meningomyelocele fatal (infection) if not closed at once
  - Closed lesions do not require immediate surgery
  - Sophisticated technology (MRI) required for accurate diagnosis
  - Associated defects common
    - MMC/SB: Hydrocephalus ("water on the brain")
- Etiology (What Causes It? When?)
  - –MMC/SB: Folate Deficiency (Neural Tube closes 3rd wk gestation)
  - –Congenital Scoliosis: Underlying Vertebral Abnormality
  - –Spinal Lipoma/Teratoma: Confused Closure of Tissue Layers

Spinal Deformities
Clinical Findings:

- Meningomyelocele/Spina Bifida
  - Pre-operatively: lump on back, rarely scar, want MRI scans
  - Post-operatively: scar on back, ? Operative records, ?MRI
  - Paralysis or weakness of legs (pre or post operative)
    - Unless severe, may be difficult diagnosis in newborns
    - Possible association with club feet at birth
  - Problems of bowel and/or bladder control
    - Must be old enough to diagnosis clinically (age 2-3 years)
    - Can be life-long problem requiring cath program, surgeries
  - Problems with hydrocephalus
    - Requires early surgical treatment (CSF shunt), unusual in IA population as many of these infants do not survive

Spinal Deformities
Treatment:

- Pre-Adoption Evaluation
  - Terminology and translation can be confusing
  - Child may be too young to evaluate gross motor development and bowel/bladder function
  - MRI Scan reports prone to interpretation and translation error
  - Suggest: request original scans for review with specialist in U.S.
- Post Adoption Medical Evaluation
  - Child needs to be seen by Pediatric Neurosurgeon
  - Possible evaluation by Spina Bifida / MMC team (various names)
  - Pediatric Specialists may be required:
    - Pediatric Neurosurgeon
    - Pediatric Urologist
    - Pediatric Orthopedic Surgeon

Spinal Deformities
Implications:

- Short Term
  - IA Medical Evaluation
    - Exam, Labs
  - Evaluation by Ped NS
  - Other Ped Specialists prn
  - Repeat MRI Scan (s)
  - Bladder Urodynamics (?)
  - Latex Precautions
- Long Term
  - Watchful Pediatric Care
  - Specialist Care prn
  - Seek Evaluation for any Neurological Changes
  - Tethered Cord Syndrome is main risk (rx: surgery)
  - Possible Learning Issues
  - Latex Precautions

Mao Xiaolan, born 12/12/00, residing in Guangdong province

- Abandoned at age 3, moved to orphanage.
- Exam done on 12/18/07:
- Height 111 cm (less than 5th percentile)
- weight 18 kg (25th percentile)
- head 51 cm (25th percentile)
- Development appropriate: attends school, language "normal", healthy and adorable

Laboratory studies:

- Hematocrit 37% (normal)
- RPR (syphilis) negative
- HIV negative
- HBsAg: positive
- HBsAb: negative
- HBcAb: positive
- HBeAg: positive
- HBeAb: negative
- AST (SGOT): 35
- ALT (SGPT): 23

Hepatitis B

- Viral infection affecting the liver
- Spectrum of disease
  - –No symptoms/asymptomatic carrier
  - –F atal hepatitis (about 1%)
- Contagious to others via blood and body secretions (not urine or stool)
  - –Ho usehold contacts: do not share food, toothbrushes, drinks
  - –Ho usehold contacts need immunization

Hepatitis B: prevalence

- More common in children adopted from Africa, Asia and Eastern Europe
  - 300 million people worldwide
  - 5 to 7% of children adopted internationally
  - Increased incidence in IV drug abusers, multiple sexual partners
- Most children tested in country of birth
  - Issues of timing, accuracy, sterile technique
- May be acquired prior to birth (from biological mother) or after birth (from contaminated needle)
- Risk to adoptive family, community

Testing for Hepatitis B

- Multiple lab tests:
  - *–HBs Ab*: Antibody to hep B, marker of immunity from vaccine, infection or mom
  - *–HBs Ag:* Indicates infection, acute/chronic
  - *–HBcAb:* Nonspecific marker of acute/chronic or resolved infection; never from vaccine
  - *–HBeAg:* Marker of high degree of infectivity
  - *–HBeAb:* Always indicates infected or immune person; never from vaccine

Tests for Hepatitis B	Results	Interpretation *(from Immunization Action Coalition, www.immunize.org)*
HBsAg HBsAb HBcAB	Negative Negative Negative	Susceptible - needs vaccination
HBsAg HBsAb HBcAB	Negative Positive Negative	Immune due to vaccination or previous disease
HBsAg HBsAb HBcAb	Negative Positive Positive	Immune due to previous disease; not contagious

Hepatitis B: treatment

- Further testing needed to determine degree of injury to the liver
- Referral to gastroenterologist or infectious disease specialist important
  - –M ultiple antiviral treatments under evaluation
  - –So me patients will clear virus spontaneously
- If chronically infected, at long term risk for cirrhosis of liver, liver failure or liver cancer

Hepatitis B: short and long of it

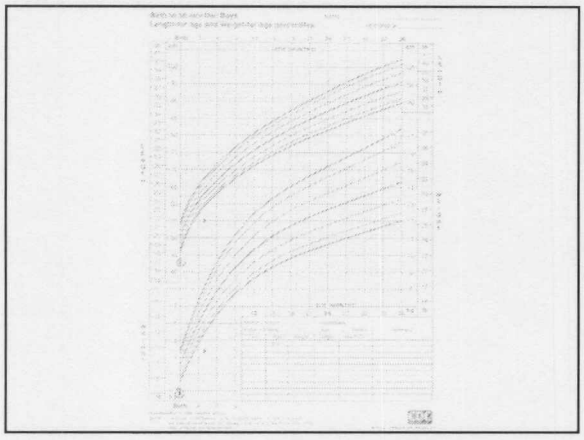
- Prognosis depends upon age infected
  - Infant: 90% develop chronic hepatitis
  - Toddler: 20-30%
  - Older than age 5: 2-10%
- Children need repeat testing every six months, including liver function tests
- *To tell, or not to tell…*
- *All* children adopted internationally need repeat testing for Hep B six months after arrival
  - Also retest for Hep C, HIV, TB exposure

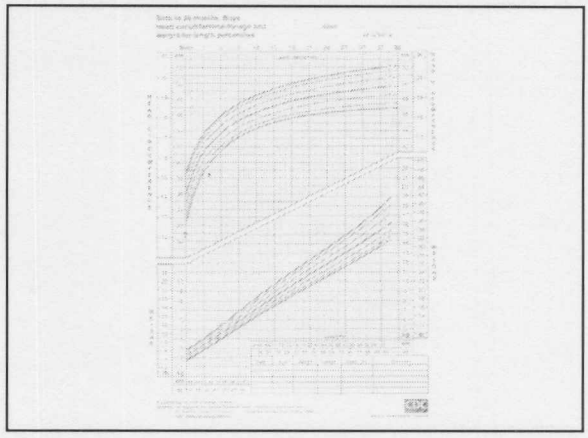
Hepatitis C: quick plug

- Viral infection, similar to Hep B
  - –Spr ead by blood, body fluids
- No current vaccine
- Similar pattern of distribution
  - –I V drug abuse, Asian, African countries
- No vaccine or treatments available
- 85% of infants clear virus from birth mom
- Tests usually done: Hep C Ab, PCR

Juan, 6 mo old from Guatemala

- Bio mother - 24 yo, third pregnancy, no PNC
- Prematurity UK – no resp distress or jaun
- Foster care soon after birth
- Foster mother reports - difficult to feed, 1 ounce every 4 to 5 hours most days
- Growth points: b wt ~ 4 lbs, l ~ 17 in, hc ~ 12 ¼ in.
- 4 months: wt ~ 9 ½ lbs, l ~ 21 ½ in, hc 15 1/8 in.
- No developmental info available.

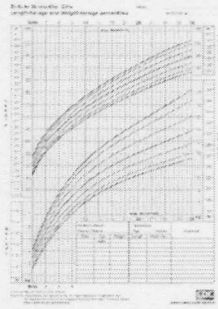


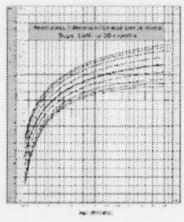


Failure to thrive

- "Description applied to children whose current weight or rate of weight gain is significantly below that of other children of similar age and sex" (from NIH website)
- Ethnic growth standards may "normalize" malnutrition; not usually recommended
- Standard growth charts:
  - Weight, length/height: www.cdc.gov/growthcharts
  - Premature birth: http://www.adoptmed.org/storage/Preemie%20Growth%20Chart%20-%2026wks-1yr.pdf
  - Head circumference chart: http://www.pediatrics.emory.edu/divisions/neurology/hc.pdf

Growth and Growth charts





Failure to thrive: prevalence

- One of most common diagnoses from referrals or at arrival
- Lack of stimulation will often compound growth failure
- Etiology is often multifactorial

Failure to thrive: etiologies

- Environmental (non-organic): no underlying chronic medical condition
  - –B irth family issues: homelessness, unemployment, poverty
  - –Or phanage/foster care issues:
    - Propped bottles, lack of stimulation during feeds
    - Nutritional issues: feeding problems, inadequate/inappropriate nutrition, ethnic variations in diet, toxin exposures, recurrent illness
    - Effects of stress on mental health: depression, PTSD, results of physical neglect

Failure to thrive: etiologies

- Organic failure to thrive:
  - Premature birth
  - Drug/alcohol exposure prior to birth
  - Genetic syndrome
  - Neurological disorder, developmental delay
  - Gastrointestinal illnesses
    - feeding disorders, reflux, chronic diarrhea, cystic fibrosis
  - Cardiac, renal, endocrine
  - Infectious diseases (especially HIV, helicobacter pylori)
- Lack of stimulation will increase effects of any growth failure

Failure to thrive: clinical findings

- Underweight
- Short stature
- Small head
  - –W ith mild malnutrition head growth is spared
  - –Pat tern of growth important
    - Linear vs. drop-off
- Usual correction: for each 3-4 months in orphanage, expect 1 month growth delay

Failure to thrive: treatment

- Adequate nutrition is key
  - Free access to food
  - Consider supplementation if weight gain is not progressing well
    - Pediasure, increased calories, tube feedings
- Consider medical evaluation if not catching up within six months (at the latest!)
  - Do not assume all growth delay is due to institutionalization
  - Refer sooner if feeding dysfunction, mental health issues

Failure to thrive: evaluation

- **Heme:** anemia (especially iron deficiency)
- **GI**: reflux, lactose/milk protein intolerance, hepatitis, celiac disease, malabsorption, cystic fibrosis
- **Infectious**: parasites, TB, HIV, H. pylori, bacterial overgrowth
- **Renal**: urinary tract infection, renal tubular acidosis
- **Endocrine**: growth hormone deficiency, pituitary problem, hypothyroidism
- **Behavioral**: oro-motor sensitivity, PTSD, abnormal hunger axis
- **Miscellaneous**: lead poisoning, zinc deficiency, psychosocial growth deficiency

Adapted from Laurie Miller, M.D., The Handbook of International Adoption Medicine, *2005*

Failure to thrive: evaluation

- History and physical, growth chart
- Calorie counts
- Stool tests (parasites, stool culture, H. pylori)
- Bone age x ray
- Sweat chloride for CF
- Chest x ray
- Renal ultrasound, urinalysis
- Blood tests:
  - Complete blood count
  - Renal function tests
  - Liver function tests (including albumin)
  - Thyroid function tests
  - Calcium, phosphorus
  - Random growth hormone
  - Anti-endomysial/anti-gliadin antibodies for celiac disease
  - Helicobacter pylori

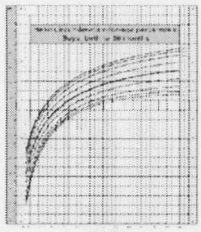
Adapted from Laurie Miller, M.D., The Handbook of International Adoption Medicine, *2005*

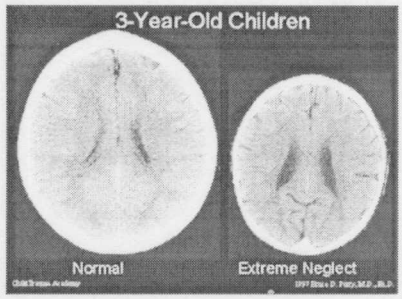
Failure to thrive: short and long term issues

- Increased risk of cognitive delays
- Increased risk of behavioral problems
  - –I nattention, distractibility, memory issues
  - –Ol der children may hoard, overeat
- Increased risk of infection, immune issues
- Children in more stimulating environments tend to do *better.*
- Many children catch up quickly
  - –Ol der girls at risk for earlier onset puberty

Growth failure: microcephaly

- Small head = small brain.
- Etiologies:
  - Brain abnormality.
  - Infection in utero (CMV, Herpes, German measles).
  - Genetic syndromes.
  - FAS, preterm birth.
  - Severe neglect, malnutrition





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

Microcephaly

- Etiology may be malnutrition, prenatal infection, drugs/alcohol, trauma, neglect, genetic
- Long term effects:
  - –I ncreased risk of growth delay
  - –I ncreased risk of developmental delay
  - –G reater the discrepancy from normal, greater the risk of cognitive delays
- Recheck head size if decrease in size