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# HIV-AFFECTED FAMILIES: DEVELOPMENTAL CONSIDERATIONS & FAMILY INTERVENTIONS

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# Prevalence of HIV

- Increase in new cases of HIV in women & female adolescents
  - Between 2000 & 2006, no. of women with HIV increased 55%
  - New cases of HIV in females in 2007 = 10,977
  - HIV transmission routes: IVDU decreasing; high-risk heterosexual contact increasing
- Disproportionality in women & female adolescents (per 100,000)
  - Rate for Blacks more than 18 x Whites
  - Rate for Hispanics nearly 5 x Whites
- Incidence of HIV/AIDS in children (under 13)
  - Perinatal transmission declined by 95% in past decade
  - New cases of pediatric HIV in 2007 = 159
  - Racial profile: 67% Black, 15% Hispanic, 13% White

# Childbearing & Child Rearing

- ❑ Women with HIV living longer, healthier, & have a wider range of reproductive choices
- ❑ Decision to have children: 12% conceived/bore post-diagnosis
- ❑ Births in women with HIV/AIDS: 8,650-8,900 in 2006
  - ❑ 30% higher than in 2002
- ❑ In nationally representative sample, 28% of infected adults had children (35,000 families)
- ❑ Women with perinatally acquired HIV disease are of reproductive age & sexually active

# Family Focus

*“HIV is a **family** disease.”*

~

*“Almost inevitably, when you identify an individual with HIV, you will find that other members of his or her family and/or household are also HIV-infected.”*

~

*“For all types of families, across both developed & developing nations, the impact of an individual’s HIV infection radiates across the entire family system.”*

# Concomitant Social Risk Factors in Families

- ❑ Substance abuse (including excessive drinking)
- ❑ Poverty/unemployment/lack of health insurance
- ❑ Unmarried/unstable relationships
- ❑ Intimate partner violence
- ❑ Victims of crime
- ❑ Lack of social support
- ❑ Low educational attainment
- ❑ Poor housing
- ❑ Lack of transportation/childcare
- ❑ Mental health threats & problems



# Circumstances in Neonatal Period

- ❑ Childbirth may be *the* occasion when mother learns of her HIV status.
- ❑ HIV diagnosis is a traumatizing event.
- ❑ Trauma heightened by simultaneous diagnosis of mother & child.
- ❑ Distrust establishment re: diagnosis, treatment & solutions
- ❑ HIV conspiracy theories in minority community
- ❑ Denial of HIV disease
- ❑ Mother/infant dyads at increased risk for impaired bonding

# HIV-related Burdens & Stressors

- ❑ Chronic illness & physical health symptoms
- ❑ Challenging medication regimens
- ❑ Distress re: own health & life expectancy
- ❑ Concerns re: childrens' future & custody
- ❑ Stigma & social alienation
- ❑ Disclosure difficulties (particularly to children)
- ❑ Fears re: spreading HIV infection in the household
- ❑ Depression, anxiety, guilt
- ❑ Uncertainty re: infant's HIV status
- ❑ Special needs/care for diagnosed HIV-infected child

# Opportunities & Protective Factors

- ❑ Childbirth -- often a window of opportunity
- ❑ Mothers may embrace maternal role & want what is best for their infants & families.
- ❑ Mother may be willing to accept help.
- ❑ HIV diagnosis may provide impetus for women to adopt changes in self-care.
- ❑ Opportunity to gain entry & engage other family members.
- ❑ Potential impact on interaction between mother & child.
- ❑ Potential impact on early development & health of infant.
- ❑ Nurturing/stimulating home environment can mitigate negative birth outcomes.

# Duke University & UNC, Chapel Hill Studies

## Developmental Outcomes of Infants of HIV+ Mothers

- ❑ Longitudinal study on parental caregiving of infants of women with HIV.
- ❑ Goal: identify factors that place infants at developmental risk & potential interventions
- ❑ Parental caregivers: Southern, poor, rural, African American, single.
- ❑ Infants: younger than 6 mos. & seropositive for HIV.
- ❑ Variables: **child characteristics** (preterm, gender, HIV status); **caregiver characteristics** (caregiver consistency, education, depressive symptoms); **family characteristics** (conflict, number of children, caregiver partner status); **parenting quality** (positive attention, negative control)
- ❑ Data collection: enrollment (e.g., 3 mos old infant), 6, 12, 18 & 24 mos.

# Assessment Instruments (Duke/UNC study)

- ❑ **Depression:** Center for Epidemiologic Studies Depression Scale (CESD)
- ❑ **Family:** Family Environment Scale
- ❑ **Parenting:** Naturalistic observation of behavior
- ❑ **Home environment:** Home Observation for Measurement of the Environment
- ❑ **Child outcomes:** Bayley Scales of Infant Development-2<sup>nd</sup> edition (Mental Development Index & Psychomotor Development Index)
- ❑ **Language:** Preschool Language Scale, Version 3
- ❑ **Adaptive behavior:** Vineland Adaptive Behavior Scale

## Outcomes (Duke/UNC study)

- ❑ **Findings:** Both parenting quality & consistency of primary caregiver influenced developmental outcomes.
- ❑ Positive attention from caregiver – strongest/most consistent relation to outcomes.
- ❑ Higher mental, motor & adaptive behavior scores associated with more positive attention & more negative control.
- ❑ Infants with changes in primary caregiver had lower motor & adaptive behavior scores
- ❑ Development of infants related to their caregiving environments

## Duke/UNC Outcomes (cont.)

- ❑ High % of mothers at risk for depression.
- ❑ Depression re: feelings of stigma, perceptions of health, health problems
- ❑ Chronically depressed mothers -- less protective toward infant, less positive interactions, lower quality of home environment.
- ❑ Mothers denied their illness, avoided dealing with it, visited health care providers sporadically.
- ❑ Mothers put children's need 1<sup>st</sup> & focused on their maternal role to the exclusion of own needs/health.

# South Carolina Nursing Study

- ❑ Evaluated mother-infant interaction in southeastern U.S. in presence of maternal HIV infection.
- ❑ Compared groups of mother-infant dyads: HIV+ and HIV- mothers
- ❑ Goal: Determine whether maternal HIV infection was associated with differences in quality of mother-child interaction.
- ❑ Quality of interaction: Nursing Child Assessment Teaching Scales (NCATS)
- ❑ Maternal, child & environmental factors: interview form, CESD Scale & Bayley Infant Neurodevelopmental Screener.
- ❑ Findings:
  - No significant difference in mother-child interaction between the HIV+ and HIV- groups. (Both groups below normative samples.)
  - Despite more depression with HIV+ mothers, no significant influence on mother-child interaction scores between groups.

# Promising Practices for Family Intervention

- ❑ Provide more information about HIV diagnosis & emotional support.
- ❑ Promote the physical and emotional health of mothers.
- ❑ Provide realistic, optimistic information about child's health trajectory.
- ❑ Support ethnically appropriate parenting.
- ❑ Assess role/ability of father & grandparents (for alternate care).
- ❑ Assess infant's status using developmental screening tool.
- ❑ Identify developmental milestones/timeframes for achievement.
- ❑ Discuss caregiver perceptions of infant's capabilities.
- ❑ Observe infant/parent interactions.
- ❑ Encourage/support family efforts to care for the infant.
- ❑ Encourage verbalization of feelings by parent/family member.

# Cultural Context for Interventions

## □ African-Americans

- Interventions that stress a “family ecological” approach rather than a “person-centered”, approach will reducing psychological distress and family-related hassles.
- Social network (extended family, community members, friends) often serves as powerful source of support.
- Increase ethnic pride and knowledge of historical barriers; promote positive self-esteem and self-worth.
- Empower African American women to be directly involved in prevention and intervention programming.

## □ Latinas

- Service strategies that reflect universal Latino cultural values/beliefs (honor family)
- Help in coping with the perceived stigma of the disease.
- Addressing traditional cultural beliefs that pose barriers to disclosure.
- Counteracting mothers’ beliefs that they have not lived up to ideal motherhood.
- Introducing infant massage as an alternative to breast feeding.

# The Health Federation of Philadelphia Family Centered Home Visitation Program

**Goal:** Strengthen families' abilities to provide safety, permanency & context for healthy development and well-being.

**Approach:** Combines trauma specific interventions with infant mental health & child development services. Culturally competent & accessible services delivered by multidisciplinary team, using a home-based model, in collaboration with hospital and community-based organizations.

**Population:** Low-income families infants & toddlers (0-3) infected/affected by HIV/AIDS, HIV positive pregnant and parenting women (age 13 & older), other family members/caregivers.

**Services:** Child development, parenting support, mental health intervention, health & nutrition monitoring, referrals (e.g., EI, CPS, education, legal, & community service)

**Research:** LSP Health Care Literacy Cluster; KIPS; Edinburgh Postnatal Depression Scale, Epidemiological Studies Depression Scale; SHIF

# The Health Federation of Philadelphia Family Centered Home Visitation Program (cont)

## □ Outcomes:

- 86% of families have alternative caregivers for children
- 80% of families utilized appropriate health care services (prenatal, pediatric, HIV care)
- 84% of parents/caregivers demonstrated satisfactory quality of parenting behavior adapted to their children's needs
- 97% of infants/toddlers showed satisfactory social-emotional development
- 48% of women/caregivers showing symptoms of depression improved
- 94% of parents/caregivers provided satisfactory home environment (safety, permanency, child well-being)
- 82% of families accessed family/community resources for meeting material, concrete needs

# The Family Center

## Early Support for Lifelong Success

**Goal:** Assist children living with HIV+ parent in achieving age-appropriate developmental milestones & educational goals

**Approach:** 18-mo intervention targeting well-being, school readiness & safety of infants & young children perinatally exposed to HIV.

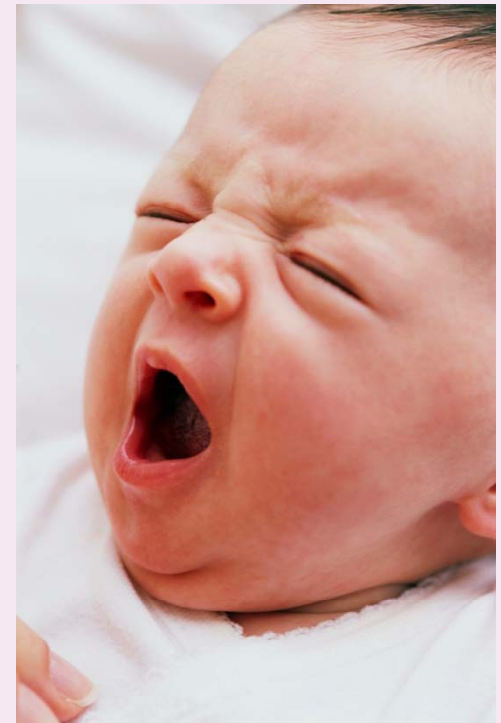
**Population:** HIV+ mothers or caregivers & their children aged 0-7 years in NYC

**Services:** Families w/ kids 0-5: early intervention services; Families w/ kids 4-7: educational advocacy services; Parents/caregivers: child development & parenting education; Content-centered workshops, classes, and programs; Play therapy for kids 2-7 experiencing trauma/loss. Referral services, permanency planning services, HIV medical case management, recovery groups for substance-using women

**Research:** Descriptive evaluation design, pre/post. Comparisons among naturally-occurring groups (i.e., HIV solely vs. HIV/ATOD caregivers). **Child outcomes:** placement in appropriate educational settings; decreased internalizing and externalizing behaviors. **Parent/caregiver outcomes:** Increased knowledge about their children's development; maintenance/improvement of physical & mental health; increased access to supportive services; reduced stress & depression

# Gaps in Research & Services

- Need for more **research** focusing on early intervention/child development for young children 0-5 in families affected by HIV/AIDS
  - Better HIV treatment outcomes may result in changing needs of population.
- Need for more **interventions** with a focus on early child development/attachment
- Need for **rigorous studies** that utilize control groups



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