Child Development and Developmental Disability

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On behalf of the DDRC [Developmental Disabilities Research Collaborative between UKZN, DoH and DoE, Social Development]
Developmental plight of South African Children

- 43% of population are children <18ys
- 2/3 live in income poverty
- 35% women are HIV+ at ANC
- 2/3 families live off welfare grants
- 25% of U5 children stunted
- 20% of children have lost a parent
- 1/3 do not live with their biological father
- 22% of children spend most of life affected by preventable infections (diarrhoea, RTI)
- 4/10 children have anemia
- 2/3 of children have had at least one helminthic infestation
- 1/3 live with caregivers with mental health distress
- ? Inadequate housing, safety
- ? Substance use (alcohol and others)

Source: SA health gauge, 2006

Source: Kauchali, S & Chhagan, M, 2004
QUALITY OF LIFE OF CHILDREN AND CAREGIVERS

International and National Movements

✓ WHO/UNICEF IMCI and Care for Development
✓ Brain Disorders in the Developing World
✓ Developmental Outcomes of Children on ART (SANAC/PEPFAR)
✓ Early Child Development (UNICEF/World Bank)
✓ Mental Health GAP (WHO)
✓ Early Child Development Indicator (WHO/UNICEF)
✓ Global Autism Public Health Initiative (GAPHi)

UN-CRC (1989) Article 6:
1. States Parties recognize that every child has the inherent right to life.
2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

“No survival without optimal development- two-sides of the same coin” (S Kauchali)
"The conditions under which children are dying are the same conditions under which children are living"
**ECD Knowledge Network**

WHO's Commission on Social Determinants of Health has established the Knowledge Network on Early Child Development to create a global focus on the early years of life. The network is made of scientists, policy makers, civil society organizations and development agencies from across the world. It will identify innovative ways of addressing Early Child Development and inform the Commission of the approaches for fostering leadership, policy, action and advocacy needed to create positive change for children.

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**Investing in the early years of life ensures a better future**

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**Why focus on early child development?**

Universally, there is an increased awareness of the early years as a crucial period for promoting physical, mental, and psychological growth of children and preparing them for lives as capable and productive adults. The course of development depends, critically, on the quality of stimulation, support and nurturance that the child experiences in his or her family, neighbourhood, and care environments. Deficient or unsupportive environments can seriously and irreversibly affect children's development. Evidence shows that early and appropriate policy interventions that address the risk and protective factors for growth, cognitive and social-emotional development of children can improve health, well-being, and competence in the long-term. Despite the strength of the evidence, investments on Early Child Development have been slow, particularly in the poorest countries.

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**Child survival and child development are inseparable**

During the lifespan of the Commission, the network will intensify advocacy on Early Child Development and make recommendations to form part of the Commission's final report in 2008. As part of its focus, the network will:

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**Partnering with WHO on early child development**

WHO will strengthen its advocacy and action on ECD policies and interventions within health programmes at all levels. It will promote the inclusion of child development outcomes on an equal basis to child survival to ensure that children not only survive but also thrive. Recommendations from the network will build on existing strategies and serve to strengthen partnerships with other agencies so that the challenges to children's development can be addressed.
Instead of two separate outcomes of early childhood programs, we should combine improved survival with optimal development into a **single** outcome measure:

Disability-free survival!

Akin to HIV-free survival for PMTCT programs
MONITORING CHILD DEVELOPMENT IN THE IMCI CONTEXT

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Children living with HIV

- Implications for school services
- Psychosocial aspects in care of adolescents
- CHAMP-SA for uninfected youth
Developmental Impairment: Prevalence

Impairment Prevalence by Type

- Gross Motor: 3.2%
- Fine Motor: 20.1%
- Hearing: 11.9%
- Vision: 13.5%
- Speech: 5.7%
- Seizures: 2.9%
- Cognition: 4.4%
- Behavior: 3.0%

Developmental Impairment Present?

- 67% No
- 33% Yes
Hearing impairment

- 2-fold higher risk with HIV
- Increased risk with TB
- 80% conductive loss
- 20% sensorineural loss
Disability prevalence

• Using ICF-CY based approach

22% Impairment

7% Restriction or Limitation

9% Disability
Conclusions

• Significant burden of developmental impairment (22-33% of population)
  – Important “at-risk” population
  – Most commonly affecting fine motor, vision and hearing domains

• Initial findings for overall disability prevalence considerably high (7%)
  – Exploring analytic approaches to measure disability severity
    • ICF –CY only has severity score for impairments/limitations, or restrictions separately
Seizures: Lifetime Prevalence/1000

• Ever had a seizure 59.1
• Febrile fits 28.3

• Epilepsy* 20.5
• Active epilepsy** 9.4

*Epilepsy: 2 or more unprovoked seizures ever
**Active epilepsy: 2 or more unprovoked seizures with one in the last year
Risk factors for history of any seizures (n=68)

• Prenatal
  – Bleeding in 2nd/3rd trimesters*  OR 2.92 (0.98-8.72)
  – Maternal meds in pregnancy*   OR 2.61 (0.98-6.93)
  – Substance use ns       OR 1.21 (0.47 - 3.12)
  – Preterm (>3 weeks) ns      OR 1.62 (0.62-4.21)
  – Labor > 24 Hours*          OR 1.86 (0.95-3.63)

• Neonatal
  – No cry for over five minutes*** OR 3.66 (1.63-8.21)
  – Taken away from mother**     OR 2.15 (1.11-4.16)
  – Difficulty feeding-first month** OR 3.62 (1.44-9.08)

*=p<0.1    **=p<0.05    *** p<0.01
Behavioral and developmental Factors associated with any seizures n=68

- Delayed walking *** OR 3.85 (1.95 – 7.60)
- Delayed speech ns OR 1.32 (0.46 – 3.77)
- Difficulty feeding self *** OR 6.48 (2.24 – 18.73)
- Any behavior problems ** OR 3.84 (1.25 – 11.79)
  - Aggression ns
  - Shyness ns

*=p<0.1 **=p<0.05 *** p<0.01 ns=not significant
Associations with other impairments

Impairments

- Gross motor
- Fine Motor
- Speech
- Cognitive*
- Hearing
- Vision

*As diagnosed by physician not psychologist
Other impairments associated with unprovoked seizures n=28

- Gross motor**** OR 12.01 (4.74 - 30.42)
- Fine motor *** OR 3.02 (1.41 - 6.47)
- Speech**** OR 5.94 (2.43 - 14.53)
- Cognitive**** OR 10.96 (4.53 - 26.50)
- Hearing ns OR 0.92 (0.27 - 3.09)
- Vision ns OR 1.64 (0.60 - 4.48)

*** p<0.01     ****p<.0001     ns=not significant
Population based studies of seizures in children in LAMICs

- Durkin, Davidson et al. 1993  2-9 yrs old
  - Bangladesh, Pakistan and Jamaica
    - Active Epilepsy  5.2-12.4/1000
    - Lifetime epilepsy  5.8-15.5/1000
    - Any seizure history  17.7-91.2/1000
- Mung’ala-Odera et al. Rural Kenya 2007
  - Active Epilepsy  11/1000
  - Lifetime Epilepsy  41/1000
- Current Study – Peri-urban KwaZulu-Natal 4-5 yrs old
  - Active Epilepsy  9.4/1000
  - Lifetime Epilepsy  20.5/1000
  - Any seizure history  59.1/1000
Role of Academic institutions

• trainers of service providers
• generators of evidence
• proponents of evidence-based planning
• advocates for vulnerable groups
Role of National Professional Associations

• Examples: PANDA and SA ACAPAP
• Training curricula for professionals
• Standard of care, multidisciplinary consensus
• Public education
• Advocacy
• Advisory role: organisation of specialised services within each region.
KZN strategic plan 2010-2014

• Plan for disability and rehabilitation
• Cross-talk with NIP ECD
• Child Development (looking after survivors)
  – Health (‘monitoring and surveillance’)
    • Role: screening (New RTHB), assessments and placements
    • Integration into PHC and IMCI
    • ‘Impact’ measure for INP, PMTCT, HAART
  – Education (‘input’ measure, WP6)
  – Social Development/Welfare (‘safety net’)

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Thank You!