Paediatric HIV
-Developmental Aspects

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Normal Development

Development occurs with sequential acquisition of skills in four different areas

- Gross Motor
- Fine Motor
- Language
- Psychosocial

*Language development most approximates cognition*
Normal Development Principles

• Development is a continuous process
• The sequence is the same but the rate varies between children
• The sequence is set in each field, but each field is not necessarily parallel
• Development is related to the rate of maturation of the CNS
• No strict line between normal and abnormal
Developmental Delay

normal progress

rapid progress needed to catch up
Developmental surveillance

- Flexible, *longitudinal*, continuous and *cumulative*
- Identify at risk children
- 5 components
  - Parental concern
  - Developmental history
  - Observation
  - Identify risk/protective factors
  - Document accurately (process and findings)
Developmental screening

- “a brief assessment procedure designed to identify children who should receive more intensive diagnostic assessment.”

- identifies children in need of further evaluation, enabling early intervention

- AAP: all children should be screened using a standardized test during well-child visits at 9, 18, and 24 or 30 months.
Twelve to 18% of US children have a developmental disorder, fewer than 30% of these children are identified by clinician judgment before entering school.

Developmental screening can boost this identification rate considerably.
## DEVELOPMENTAL SCREENING

<table>
<thead>
<tr>
<th>Vision and Adaptive</th>
<th>Hearing and Communication</th>
<th>Motor Development</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Always Ask</strong></td>
<td><strong>Can your child see?</strong></td>
<td><strong>Does your child do the same things as other children of the same age?</strong></td>
</tr>
<tr>
<td>Baby follows close objects with eyes</td>
<td>Baby responds to sound by stopping sucking, blinking or turning</td>
<td>Child lifts head when held against shoulder</td>
</tr>
<tr>
<td><strong>6 months</strong></td>
<td>Baby recognises familiar faces</td>
<td>Child turns head to look for sound</td>
</tr>
<tr>
<td>9 months</td>
<td>Child’s eyes focus on far objects</td>
<td>Child turns when called</td>
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<tr>
<td></td>
<td>Eyes move well together (No squint)</td>
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</tr>
<tr>
<td>18 months</td>
<td>Child looks at small things and pictures</td>
<td>Child points to 3 simple objects</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Child uses at least 3 words other than names</td>
</tr>
<tr>
<td>3 years</td>
<td>Sees small shapes clearly at 6 metres</td>
<td>Child speaks in simple 3 word sentences</td>
</tr>
<tr>
<td>5-6 years: School readiness</td>
<td>No problem with vision, use a Snellen E chart to check</td>
<td>Speaks in full sentences and interact with children and adults</td>
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</tbody>
</table>

**Refer**

Refer the child to the next level of care if child has not achieved the developmental milestone. Refer motor problem to Occupational Therapist/Physiotherapist and hearing and speech problem to Speech therapist/Audiologist if you have the services at your facilities.
Developmental disabilities

- Many presentations, aetiologies and independent variables.

- There is no strict line between normal and abnormal.

- In South Africa clinicians are often faced with children exposed to multiple risk factors
  - biological, environmental, social, genetic.

- Multiple risk factors can amplify each other.
Africa has two thirds of the world’s people living with HIV/AIDS, around 150,000 child deaths per year.
Physician density in countries

The INVERSE CARE LAW: Those who need care the most are the least likely to receive it (Tudor-Hart 1971)
• Access to ART (National)
• 2002: 2.1% of newly diagnosed children
• 2007/2008: 36.9% in that year.
• The Western Cape: newly diagnosed children commenced on ART being 96.1% in the 2007/2008 year.

• [www.ci.org.za](http://www.ci.org.za) (children’s institute)
• Patterns have changed very little
• UNICEF 2011 report (sub-Saharan Africa):
  – Number of children 0–14 years old receiving and estimated to need antiretroviral therapy and percentage coverage
    – 387 500 (1 840 000)
    – 21%
• Sub-saharan africa carries the burden of 87% of the world’s HIV+ children
• **HIVE** refers to the disease, damage or malfunction of the brain caused by HIV-1.
  – Static HIVE is an unchanging, less threatening type of encephalopathy, whereas,
  – progressive HIVE gradually becomes more destructive over time.

• Currently, HIVE is classified as a stage 4 AIDS-defining illness (WHO) reflecting the severity of the disease.
Clinical course of HIV encephalopathy

• Antiretroviral treatment has been proven to prolong survival rates of children suffering from HIV/AIDS by promoting normal growth and development (Smith et al 2006).

• ART has dramatically decreased the rate of HIV/E in the United States from 35-50% to less than 2% (Van Rie et al 2008).
The effects of HIV in our context have been established, but the less quantifiable effects on morbidity, including cognitive function and behaviour is less defined.
Local experience

• HIV/Neuro clinic
  – Established 2008
  – Bimonthly
  – Review of new children:
    • 58% new children seen had clinical definition of HIVE
    • None previously diagnosed!
clinically

- 77% had delayed early motor milestones and
- 67% had delayed early language milestones

- 59.6% microcephaly
- 73% long tract signs (mostly spastic diplegia)
Additional CNS diagnoses/issues

• 21% had had at least 1 seizure
• 71% parents/caregivers reported behavioural problems

• 44% had active ear problems
  – 7 Acute otitis
  – 16 Chronic suppurative otitis media
• Schooling and disclosure
  – With very few exceptions, our children with school difficulties had not disclosed HIV status to the schools
white matter hyperintensity related to HIV encephalopathy.
(a) Bilateral deep white matter hyperintensity, which is periventricular and symmetrical.
(b superior extent of the leukoencephalopathy involving the centrum semi-ovale.
(Andronikou et al 2004)
Slow progressors

- Children vertically infected with HIV
- remain clinically and immunologically stable for a long period
- receiving no or minimal therapy (defined as single or dual nucleoside therapy) before the age of 10 years
- maintained CD4 counts above 25%
• In South Africa, as many as 35% of all infected children are believed to meet criteria of slow progressors.

• Little information is known about this group of individuals in terms of neurodevelopment.

Local experience: Slow progressors

- Pilot study
- Aged 6-16 years
- Asymptomatic, perinatally HIV-infected
- The results indicate that cognitive function and white matter integrity as defined by DTI is significantly altered amongst asymptomatic HIV positive children
• despite a child being described as asymptomatic
• HIV infection still has an impact on the CNS
• Causing deficits in certain cognitive domains
• importance of investigating specific cognitive domains
• Asymptomatic children may have been classified as such due to their scores on global measures
Behavioural Assessment

• 1/3 parents, teachers say children ‘hyperactive’
• Consider all causes especially emotional, child’s environment
• Observation, collateral
• In pre-schoolers, behaviour = cognitive level
Behavioural Disturbances among HIV infected children

• asymptomatic participants experienced difficulty at school
• such as repeating grades, attending special classes and having problems with schoolwork
• parents or caregivers reported internalizing behaviours in the clinical range
• behaviours included somatic complaints, withdrawal and depression
Relations between poverty, stunting, child development and school achievement

Poverty

- Primary caretaker
  - Stress/depression
  - Low responsivity
  - Low education

- Poor care and home stimulation

- Nutritional deficiencies / infections

- Stunting

- Poor cognitive, motor, socio-emotional development

- Poor school achievement

Future

• Roll-out of ART to both children and adults with HIV has improved the outlook for children in South Africa

• BUT

• Often unable to disclose to the school, parents are reticent to seek help for children with LD’s

• Unsupported in a system which is focusing on their medical needs, not adequately recognizing their cognitive and behavioural problems.

• More and more children with HIV are reaching school-going age with the improved treatment accessibility
• More adult spectrum of HIV related CNS compromise (HAD/HAND spectrum) needs to be actively sought

• Psychiatric disturbances likely also under-recognised and under-reported
  – Especially adolescents (Mellins et al 2009)
Conclusions

- HIV still a significant clinical problem in South Africa
- Not being diagnosed well
- Often cognitive and behavioural manifestations
- Co-morbidities present in many of our children
- Non-disclosure putting children at greater risks
Take home message

• Head circumference at birth and 6 monthly thereafter
• Do a neurological exam
• Developmental screen/surveillance
• Ask about behaviour
• Ask for school reports (encourage grade R)
• Treat epilepsy (beware interactions)
• Manage behaviour: consider medication
• Remember SE’s of ARV’s (nb EFV)
• Check ears (and test hearing)...

• Milestone charts in rooms
  – Reference for parents
  – Reference for you!

• What to do before referring
  – Motor delay -> physiotherapy +- OT
  – Language -> Hearing, SLT
## Screening tool...

### RED CROSS WAR MEMORIAL DEVELOPMENTAL SCREENING TOOL PILOT: MARCH 2012

1. Please tick milestones achieved and warning signs observed at clinic visit closest to screening age.
2. Please refer patients with 2 or more gross motor item delays/warning signs to Physiotherapy (local clinic).
3. Please refer all patients with 2 or more fine motor item delays/warning signs to Occupational Therapy (local clinic).
4. Discuss any patient with concerns regarding vision with Eye Clinic: 021 658 5540 (RXH).
5. Please refer patients with speech delay for a hearing test at Red Cross Children’s Hospital as well as Speech Therapy: RXH Audiology: 021 658 5539.

<table>
<thead>
<tr>
<th>Age in months</th>
<th>Head Circumference (cm) + percentile on HC chart</th>
<th>GROSS MOTOR</th>
<th>Fine Motor</th>
<th>Communication</th>
<th>Social</th>
<th>Warning Signs: PLEASE TICK IF PRESENT</th>
<th>Action Taken: PLEASE TICK</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Crawls Sits alone Pulls to stand</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>No head control Not sitting Fisting</td>
<td>Physio referral OT referral</td>
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<tr>
<td></td>
<td>Points to objects</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>Hand preference Persistent Reflexes</td>
<td>Speech referral Hearing Vision test</td>
</tr>
<tr>
<td></td>
<td>Holds small object in each hand</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>Head Circumference &lt;3P or &gt;97P</td>
<td></td>
</tr>
<tr>
<td></td>
<td>baby: mama or dadda without meaning</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>No visual fixation Squint No response to sound</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Babble: understands “bye” and “no”</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Waves bye, shakes head for “no”</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Holds and eats biscuit or chips</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stranger anxiety</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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</tbody>
</table>

### Notes:
- Please ensure all milestones are recorded accurately.
- Warning signs should be followed up with further assessment.
- Follow-up plans should be documented in the patient's medical records.
Figure 2: Differing trajectories of brain and behavioural development as a function of exposure to risk and protective factors.

The cumulative effect is illustrated by the progressive strengthening (darker lines) of the trajectories over time.

Walker et al, Lancet 2011
Thank you