

## Adolescents and HIV (a paediatric HIV service perspective)

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## Disclosures

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# Acknowledgement

I want to begin by acknowledging and thanking the young people living with HIV and their families who attend our clinics, share their stories with us and generously participate in research, education and peer support

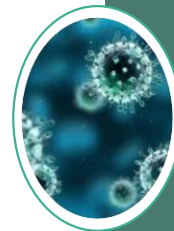


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## Outline

- Adolescents and HIV in Australia
- The paediatric HIV clinic
- Resources for young people in Australasia

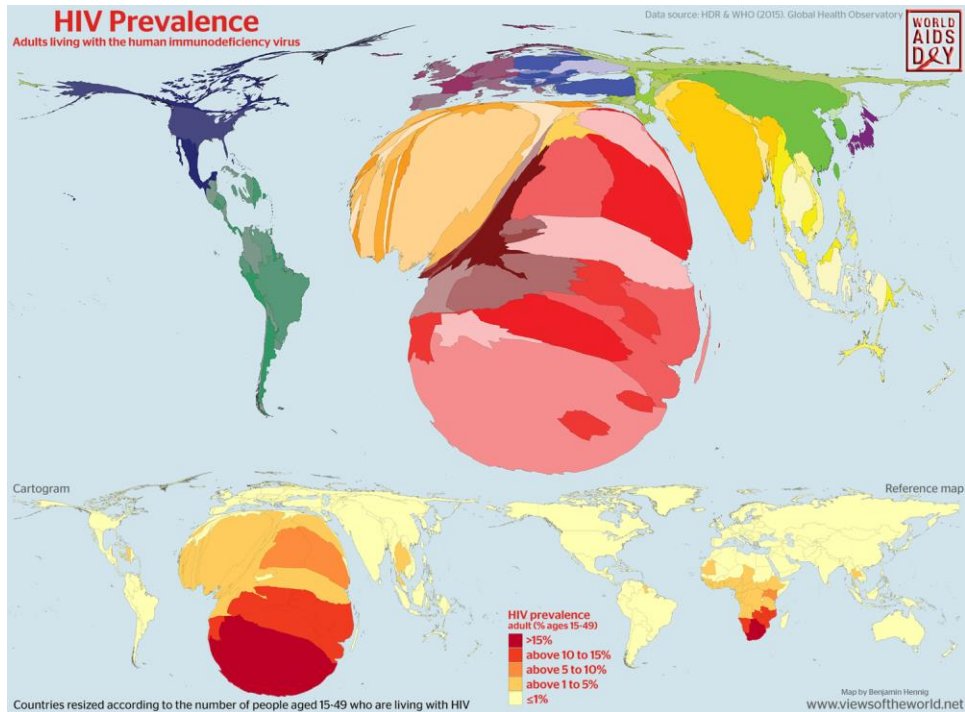


# Adolescents and HIV Epidemiology

## Epidemiology

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- UNAIDS: Overall in 2016 an estimated 2.1 million of those living with HIV were children (<15 years old)
- 160,000 infants worldwide had acquired HIV infection from mother-to-child-transmission of the virus
- Greater than 90% of new paediatric HIV infections occur in Africa



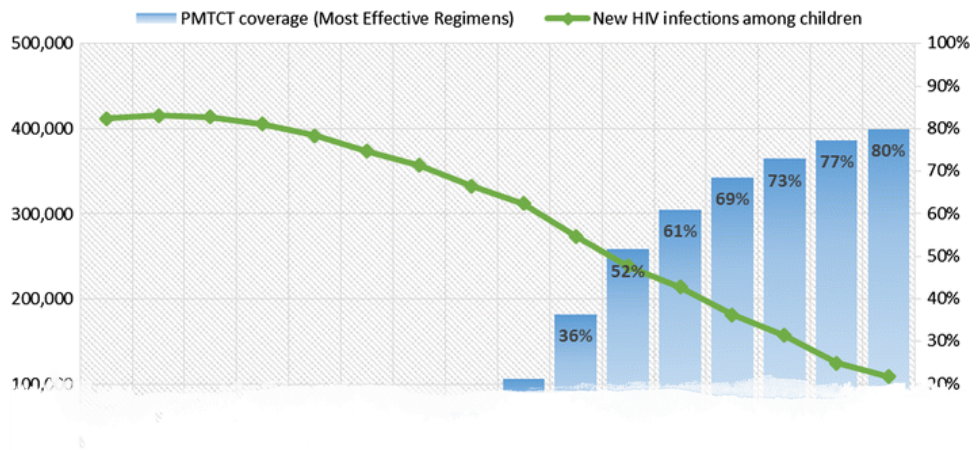
## Mother-to-child Transmission (MTCT) of HIV

- This is the mechanism of infection for the vast majority of children with HIV

Without intervention the rate is between 25-40%

Rate of transmission is influenced by clinical status of the mother

- (importance of anti-retroviral medication during pregnancy)



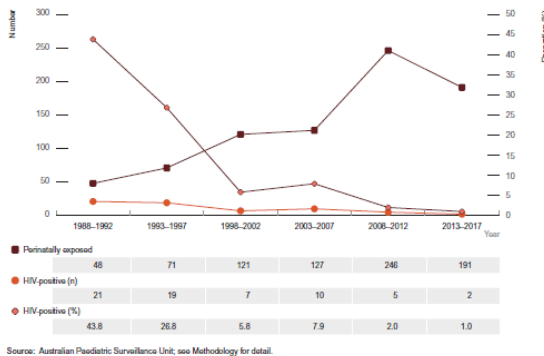
Trends in percentage of pregnant women living with HIV receiving effective antiretroviral medicines for PMTCT and new HIV infections among children 0–14, 21 sub-Saharan African Global Plan countries, 2000–2015

Idele P, AIDS Behav 21:S23–S33 2017 (UNICEF Data)

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## Australian Epidemiology

Figure 1.121 Number of Australian-born children perinatally exposed to HIV and proportion HIV-positive, 1985–2017, by year of birth



In Australia and other resource rich settings, parent to child HIV transmission has become an exceptional event

## Adolescents and HIV

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- Differing definitions
  - Not children, nor adults
  - In 2016: an estimated 2.1 million ALHIV, 84% living in sub-Saharan Africa\*
  - Many epidemiological surveys divide estimates into  $<15$  and  $\geq 15$  – this leaves 10-19-year-olds stranded on the margins of both sides
  
- Risk factors for sexual/other transmission of HIV in adolescence
  - 2 main groups:
    - Perinatally-infected adolescents
    - Adolescents with new HIV infections

## Adolescents with perinatal infection

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- Diverse health and family experiences, in addition to service use, different from adolescents 15-24 with newly-acquired HIV
  
- Issues may include:
  - Potential multi-generational HIV
  - Immigration and/or adoption
  - Parental loss
  - Stigma and secrecy
  - Adolescents have been attending paediatric clinic since infancy
    - Long-term medication use
    - Disclosure and support: young person, family, peers, others
    - Growth, sexuality, education and employment



# The Paediatric HIV Clinic: Australia



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## HIV services at Sydney Children's Hospital, Randwick



The Paediatric Human Immunodeficiency Virus (HIV) Service at Sydney Children's Hospital, Randwick works with children, families and pregnant women living with HIV.

Sydney Children's Hospital is the state-wide lead in the management of Paediatric HIV. It is the only service of its kind in Australia to provide medical management, psycho-social support, research, consultation and education to children and families affected by HIV.

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## Paediatric and Adolescent HIV Clinics

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- Various models exist:
  - Paediatric and adolescent; standalone adolescent; family clinic model; multidisciplinary clinics; shared care (paediatrician or adult HIV service)
  
- Staffing:
  - Medical practitioner (Often paediatric HIV/ID specialist)
  - Nurse
  - Social worker
  - Dietician
  - (Pharmacist)



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## Care for ALHIV

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- HIV care and medication:
  - Medication adherence
  - Viral load suppression and maintaining immunological fitness (blood tests)
  - Monitoring for side effects, other infections
- General health and development:
  - Growth, activity, weight
  - Schooling, vocational aims
- Disclosure
- Sexual health
- Transition to independent care and adult health services



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## Transition to adult services – paediatric perspective (1)

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*"We monitor where our kids are at and where our families are at. So if they're not attending clinic or if they're non-compliant with their medication, we really try to build those relationships and re-engage them.*

*But the worry [is], will a young person get lost in an adult system where things, where clients are treated differently, where services put the onus back onto the client to take responsibility for their appointments and don't chase up patients?"*

Paediatric care clinician (nursing and allied health)



Newman et al, AIDS PATIENT CARE and STDs  
Volume 28, Number 7, 2014

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## Transition – paediatric perspective (II)

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*"These children we know for many years and... so, over that time, you really build up a bond and you get to know the family very well, and the issues about medications and life, and things change during that period, and then they're growing up and moving on."*

Paediatric care clinician (medicine)

*"You know, being here thirty years, I've seen all of them grow up. So it'll be sad. I hope they'll be all right."*

Paediatric care clinician (medicine)



Newman et al, AIDS PATIENT CARE and STDs  
Volume 28, Number 7, 2014


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## Transition – practical aspects

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- Graduated process
  - Increasing involvement in young person in independence and healthcare self-management
  - Identify adult service and involve in transition process
  - Alternating supported visits prior to transition
  - (Ongoing contactability to assist adult service and young person post-transition)

## Resources for young people in Australasia



## Education and peer support

- 3 camps run by SCH HIV Service
  - **Teen Camp\***
  - Primary Camp
  - Family Camp
- \* 28 participants aged 11 to 18 years old from Australia and New Zealand
- 11 SCHN Volunteers
- 2 Nurses
- 2 Social Workers
- During the camp: health education, peer support, activities+++
  - *Funded by donations, highly valued by young people, families and services*



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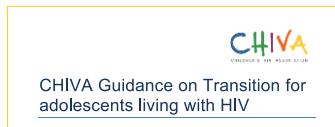
2018 TEEN CAMP PROGRAM				
Saturday	Sunday	Monday	Tuesday	Wednesday
	7.15 am Wake Up & Shower	7.15 am Wake Up & Shower	7.15 am Wake Up & Shower	7.15 am Wake Up & Shower
	8am Breakfast	8am Breakfast	8am Breakfast	8am Breakfast & Bags out of lodges
10am Volunteers & Flights Arrive	8.30 am Support Group Blue Group	8.30 am Support Group Blue Group	8.30 am Support Group	9 am Support Group Farewell
	8.45 am Dual Flying Fox Green Group	8.45 am Archery Green Group		
	10.30 am Morning Tea	10.30 am Morning Tea	10.30am Morning Tea	10 am Bus departs
12 pm Bus departs	11 am Support Group Green Group	11 am Support Group Green Group	11 am MEGA High All Board Challenge or Powerfan	11.30am Arrive at airport & check into flights
2.15 pm Arrive onsite Briefing	11.15 am Dual Flying Fox Blue Group	11.15 am Archery Blue Group		
2.30 pm Lunch	1 pm Lunch	1 pm Lunch	1 pm Lunch	Packed Lunch
3.00 pm Camp Introductions Name Tags (SCH)	1.45 pm Vertical Play Pen or Drumming	1.30 pm Mega Crate Stack	1.30 pm Support Group	1pm -4pm Airport Flights Depart
	3.30pm Afternoon Tea	3.30pm Afternoon Tea	3.30pm Afternoon Tea	
4pm-5 pm Ice Breakers (site)	4 pm Free time & sports kits	4 pm Free time & sports kits	4 -5 pm Team Turtle Games	
6 pm Dinner	6 pm Dinner	6 pm Dinner	6 pm Dinner	
7 pm Evening Games (site)	7 pm Bush Cooking & Campfire	7 pm Disco	7 pm Trivia	
9.00 pm Supper & Group Meeting	9.00 pm Supper & Group Meeting	9.00 pm Supper & Group Meeting	9.00 pm Supper & Group Meeting	
9.30 pm Quiet time & Staff Meeting	9.30 pm Quiet time & Staff Meeting	9.30 pm Quiet time & Staff Meeting	9.30 pm Quiet time & Staff Meeting	
10.30 pm Lights Out	10.30 pm Lights Out	10.30 pm Lights Out	10.30 pm Lights Out	



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## Further information and useful resources

- SCH HIV Service:
  - <http://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/immune-deficiency-and-hiv/sch>
- Printed materials and internet resources for ALHIV:
  - UK Children's HIV Association (CHIVA): <https://www.chiva.org.uk/guidelines/tr/>
- General adolescent healthcare and transition resources:
  - Trapeze <http://www.trapeze.org.au>



## References:

- Kirby Institute: HIV in Australia Annual surveillance short report 2018
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- Newman et al, Bridging Worlds, Breaking Rules: Clinician Perspectives on Transitioning Young People with Perinately Acquired HIV Into Adult Care in a Low Prevalence Setting AIDS PATIENT CARE and STDs Volume 28, Number 7, 2014
- Slogrove, Amy; Sohn, Annette The global epidemiology of adolescents living with HIV: time for more granular data to improve adolescent health outcomes; Current Opinion in HIV and AIDS: May 2018 - Volume 13 - Issue 3 - p 170–178
- UNAIDS Facts Sheet 2016. <http://www.unaids.org/en/resources/fact-sheet>



## Further acknowledgements

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    - Adam Bartlett
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    - Louise Dolahenty HIV SW
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- Adult HIV service and other clinician partners  
Children, young people and families

