Growing up with HIV

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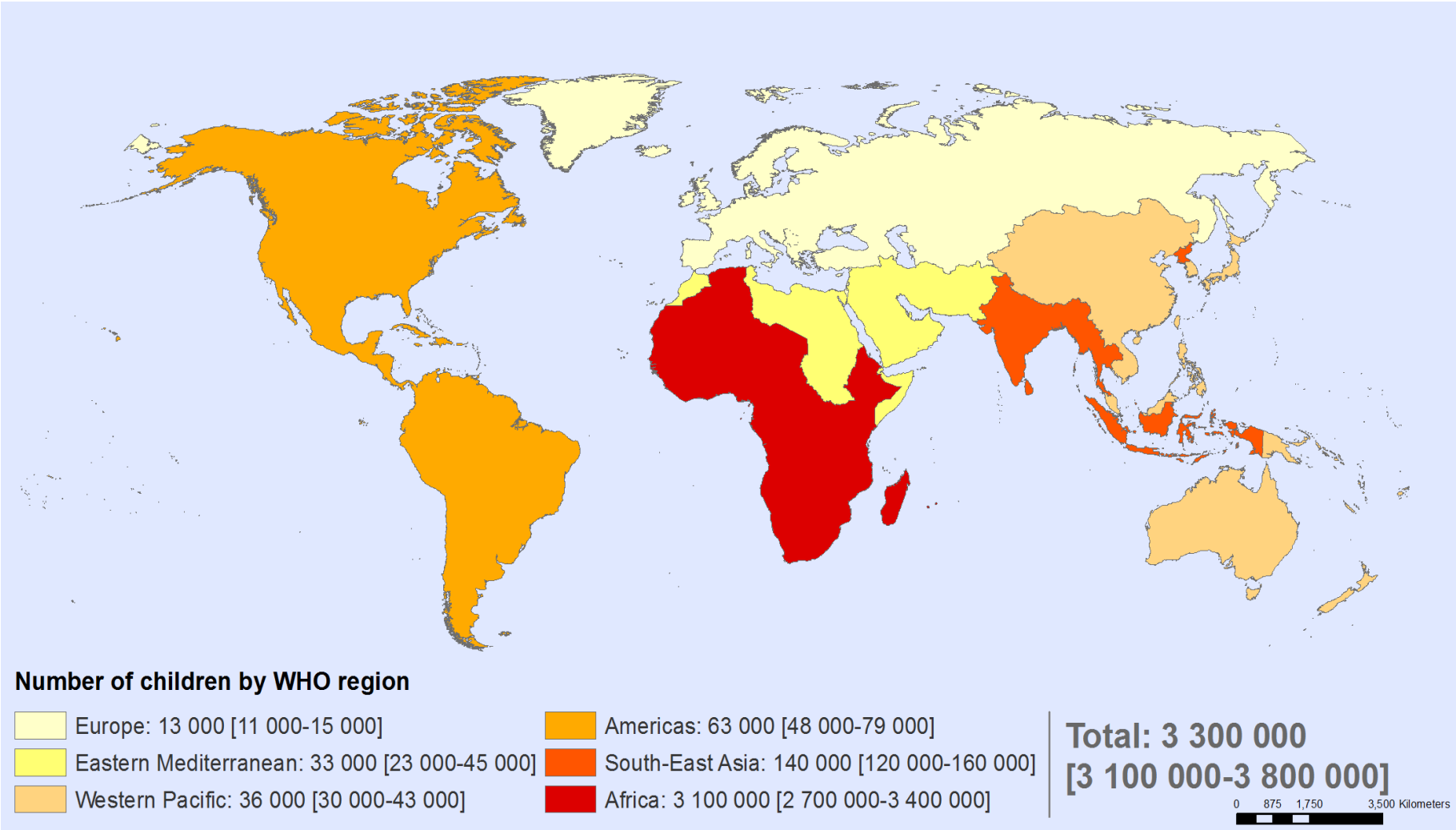
Conflicts of Interest

- Nil

Global burden

- 2011 34 million people living with HIV worldwide
- 2011 3.3 million children living with HIV are under 15 yrs
- In 2007 adolescents and young adults 15-24yr accounted for 45% of new HIV infections worldwide

Children (<15 years) estimated to be living with HIV, 2011
By WHO region



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Data Source: World Health Organization
Map Production: Public Health Information and Geographic Information Systems (GIS)
World Health Organization

World Health Organization

Ageing Cohort Globally

- 2.1 million children <15 yrs

Ferand et al 2010. Survey of children accessing HIV services in a high prevalence setting: time for adolescents to count?

~ 25,000 Zimbabwean children - 25% 10-14yrs

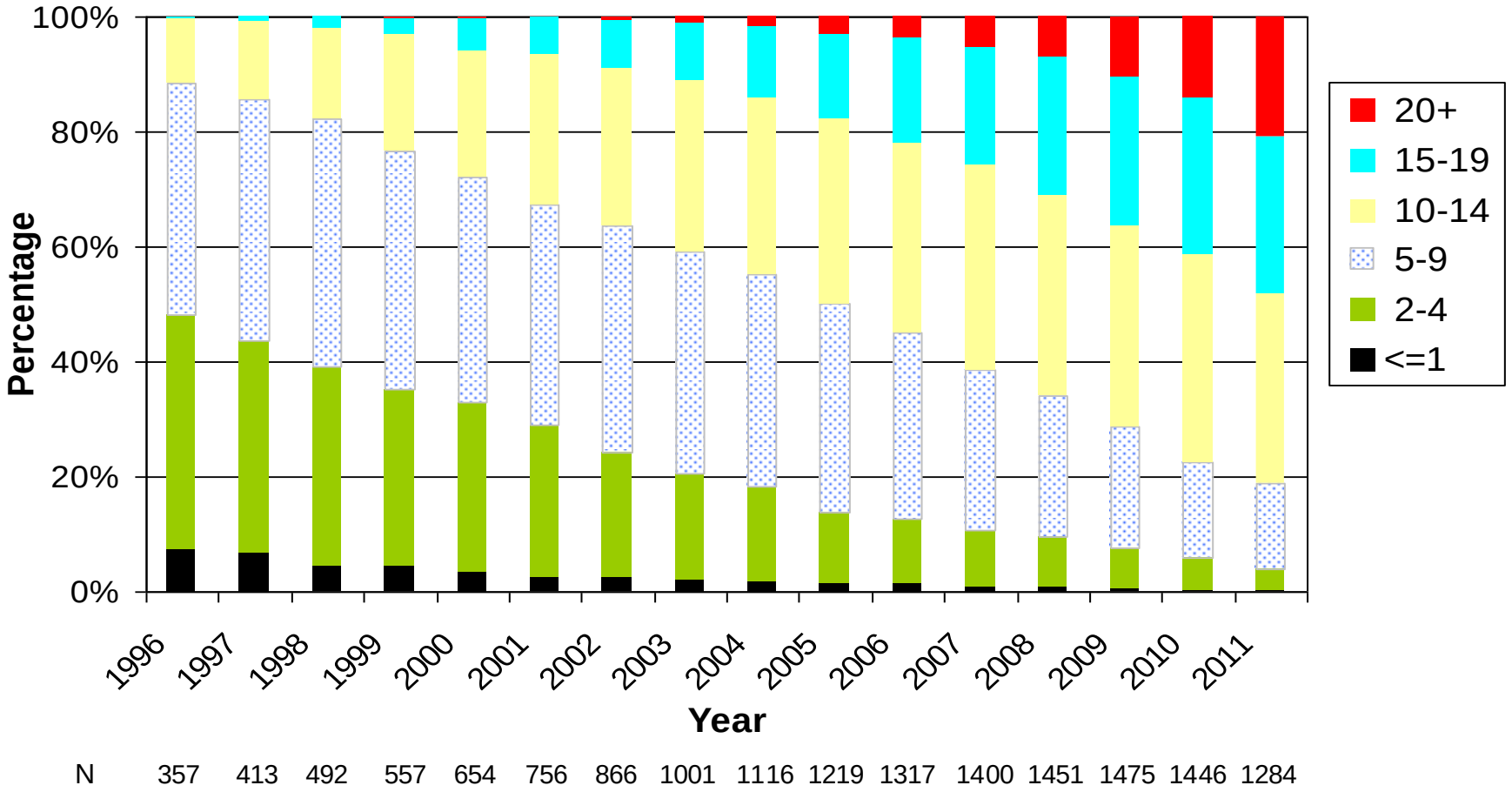
17% 15-19yrs

CHIPS UK Data March 2010

- **1,645 children**
- **520 aged15+**
- **206 transferred to adult care**

Median age HIV infected European paediatric cohorts >10yrs

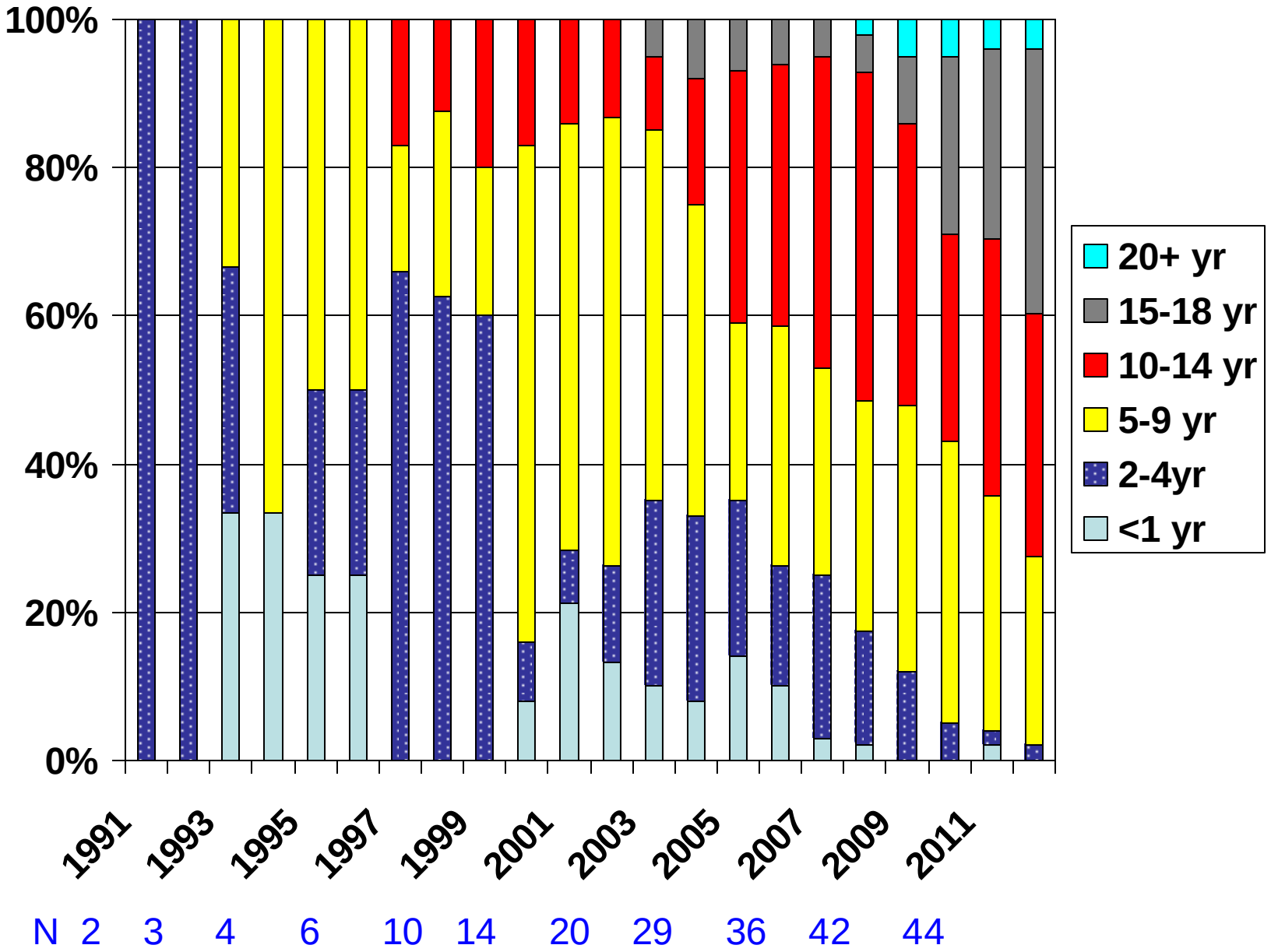
Age* of children including those transferred to adult care by year, 1996-2011

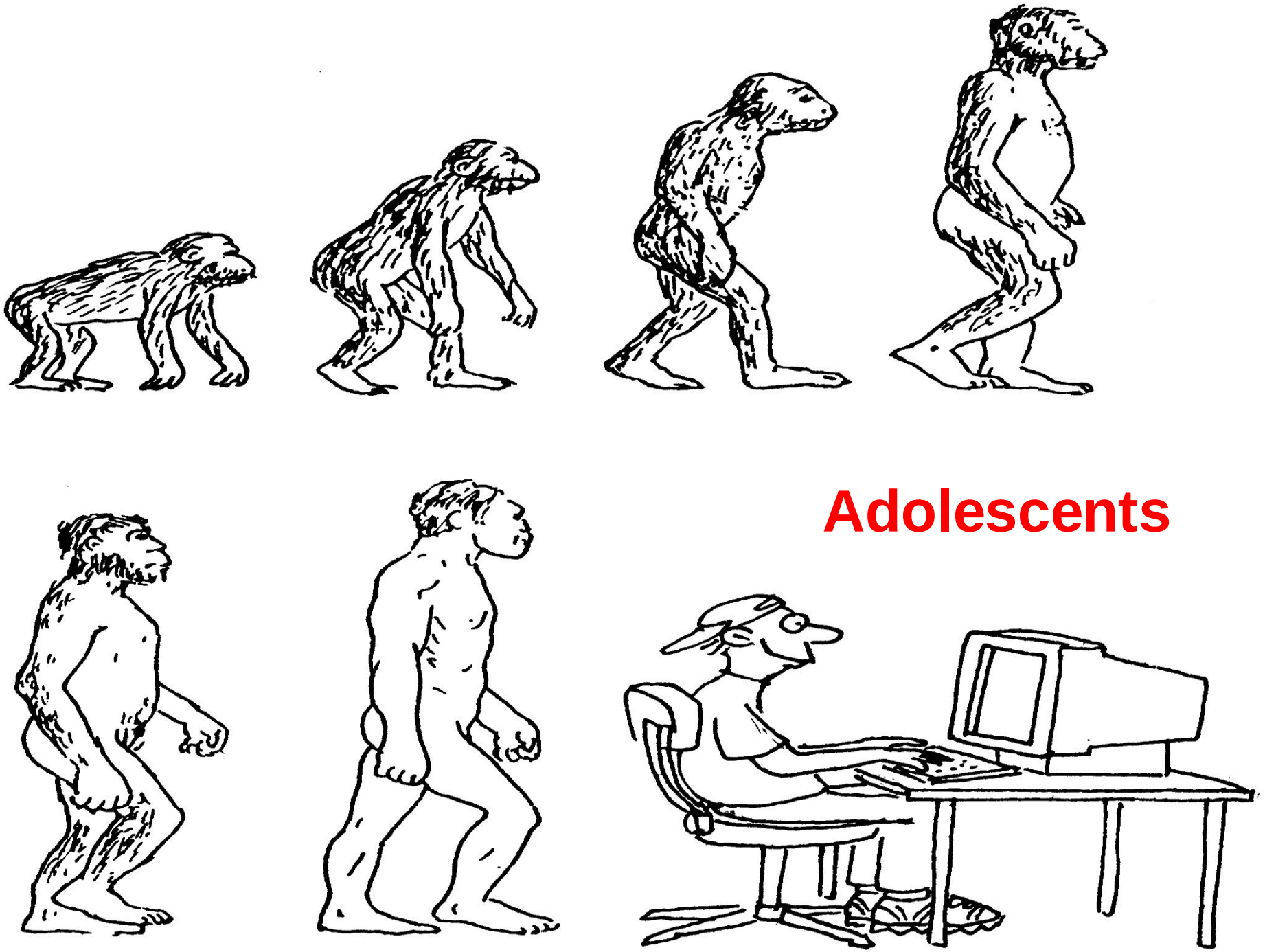


Data are for all children and young people in CHIPS (excluding those who have died or who are lost to follow-up) as well as young people in CHIPS who have transferred to adult care

Starship Children's Hospital HIV clinic data

Age of children including those transferred to adult care by year, 1991-2012




Adolescents

Time of change:

Downside: Increases in

- Challenging behaviours
- Disaffection with school
- Risk taking –drugs, alcohol etc.
- Pregnancy & STD's
- Depression
- Self harm

Upside: opportunities for

- Friends
- Relationships
- Freedom
- Creativity: music, clothes, dance
- Developing identity and control
- Excitement and fun often without responsibility

Adolescence

The Youth2000 Survey Series

Dr S Denny and Adolescent Health Research Team

10 YEARS OF THE YOUTH HEALTH AND WELLBEING SURVEYS: WHAT HAVE WE LEARNT?

1. National Secondary School Student Surveys
   - 2001 - 9,699 adolescents
   - 2007 - 9,107 adolescents
   - 2012 - 8,500 adolescents

2. School Climate Surveys
   - 2007 School Climate
   - 2012/13 School Climate

3. Alternative Education Surveys
   - 2009 - 335 adolescents
   - 2000 – 268 adolescents

4. Teen Parent Unit Survey
   - 2006 - 220 adolescents

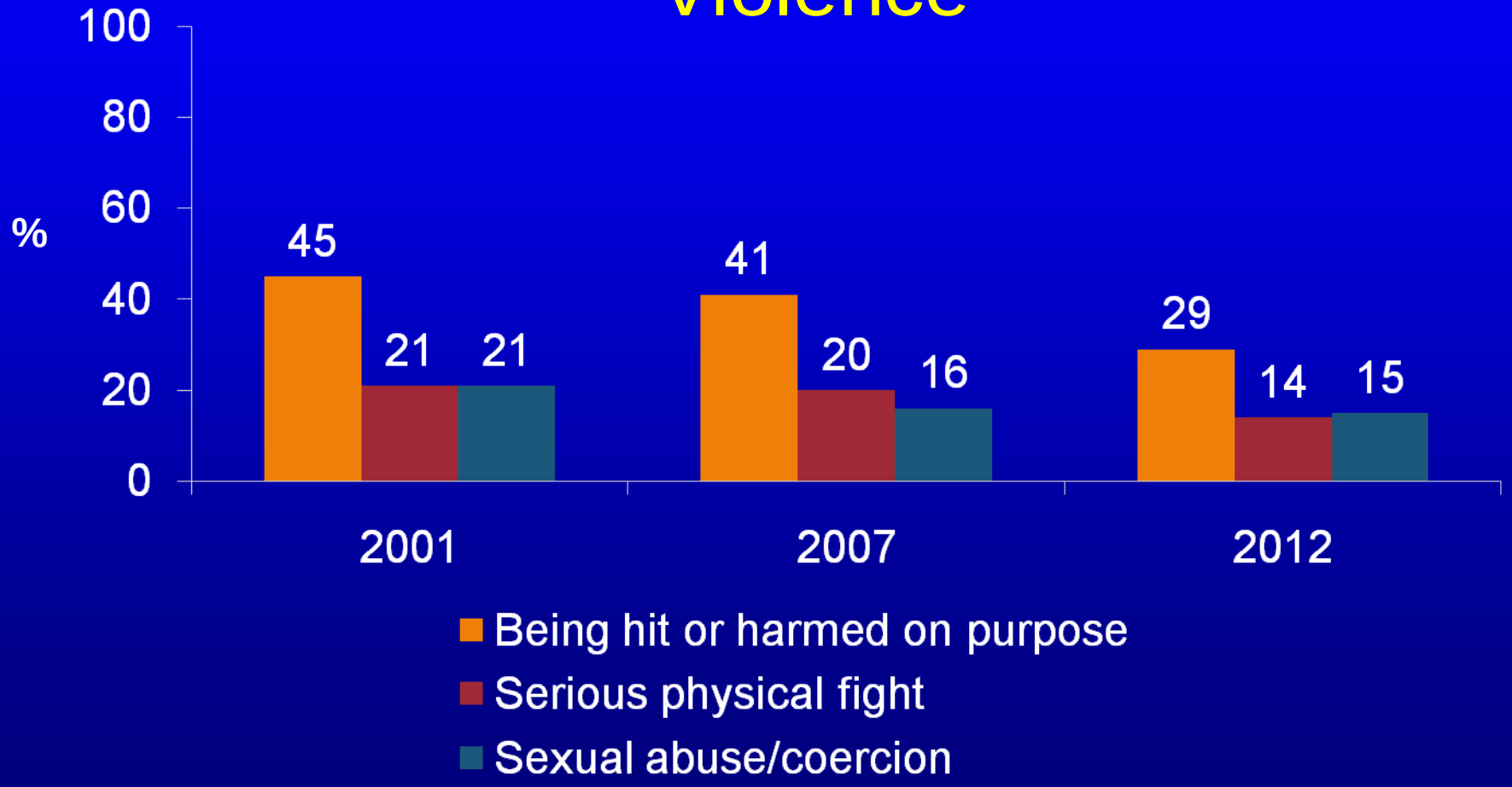
5. Wharekura Survey
   - 2007 – 22 kura and 677 taiohi*

www.youthresearch.auckland.ac.nz
School of Population Health, University of Auckland

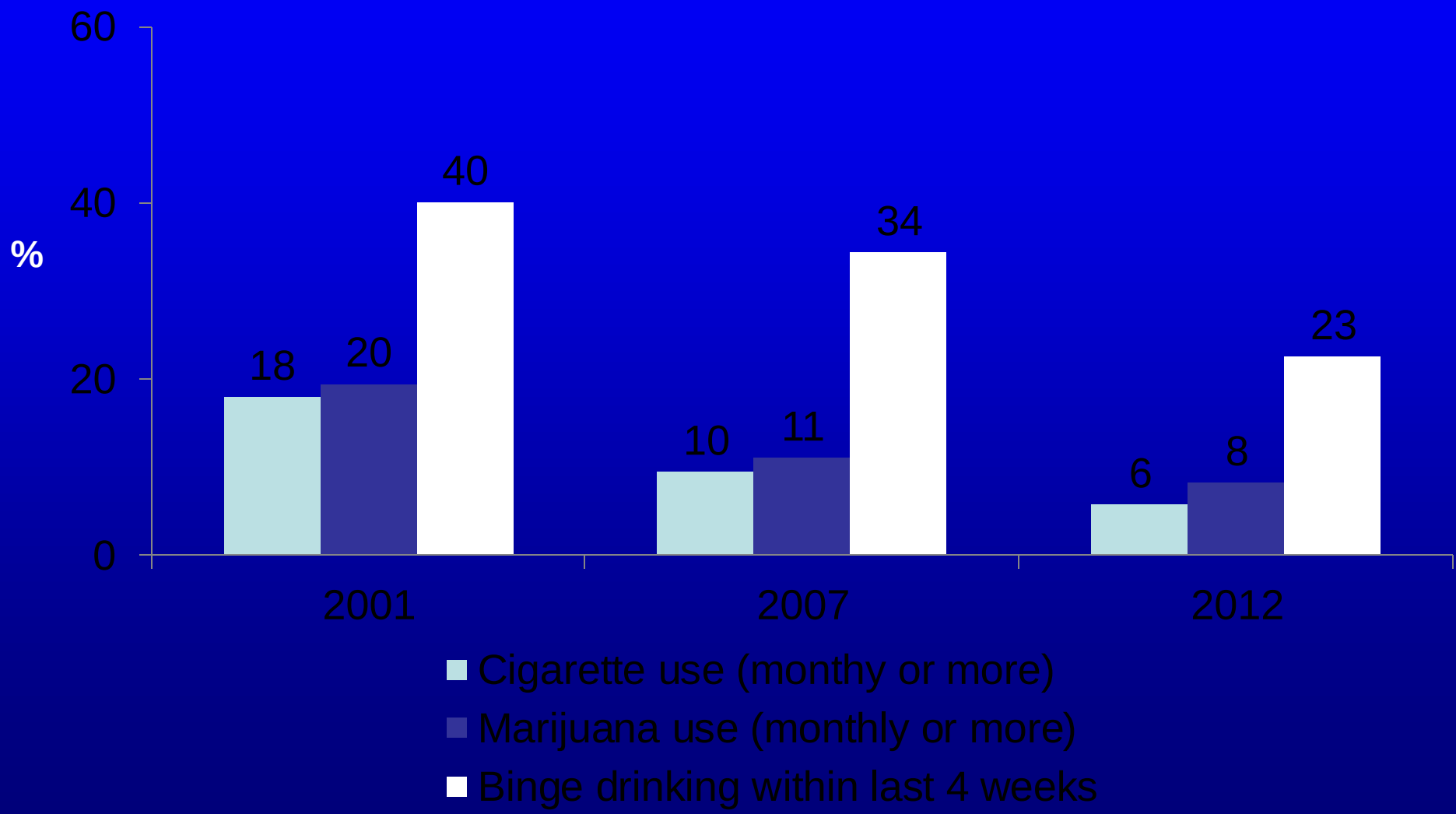
*confidential report

The Youth 2000 survey series

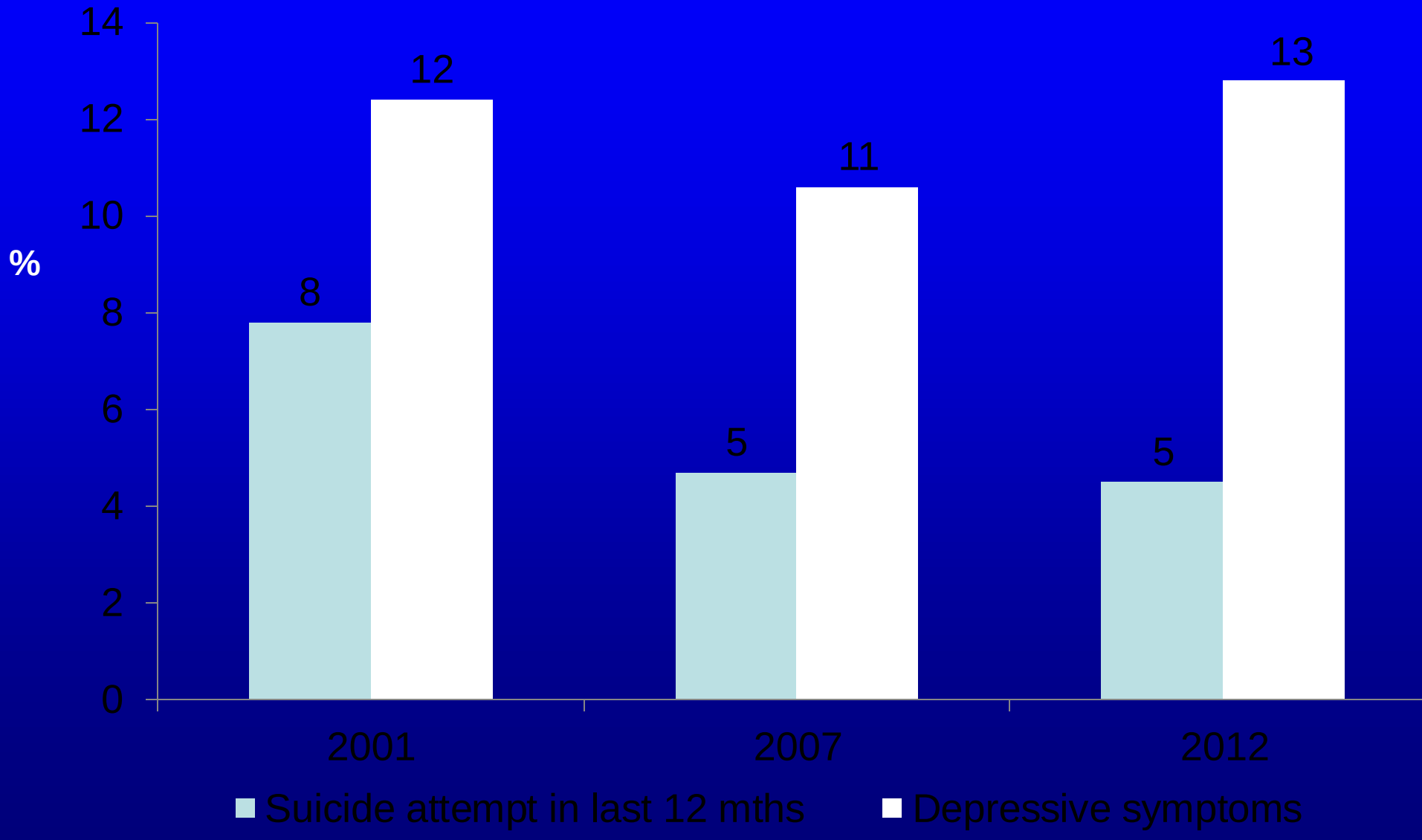
Violence



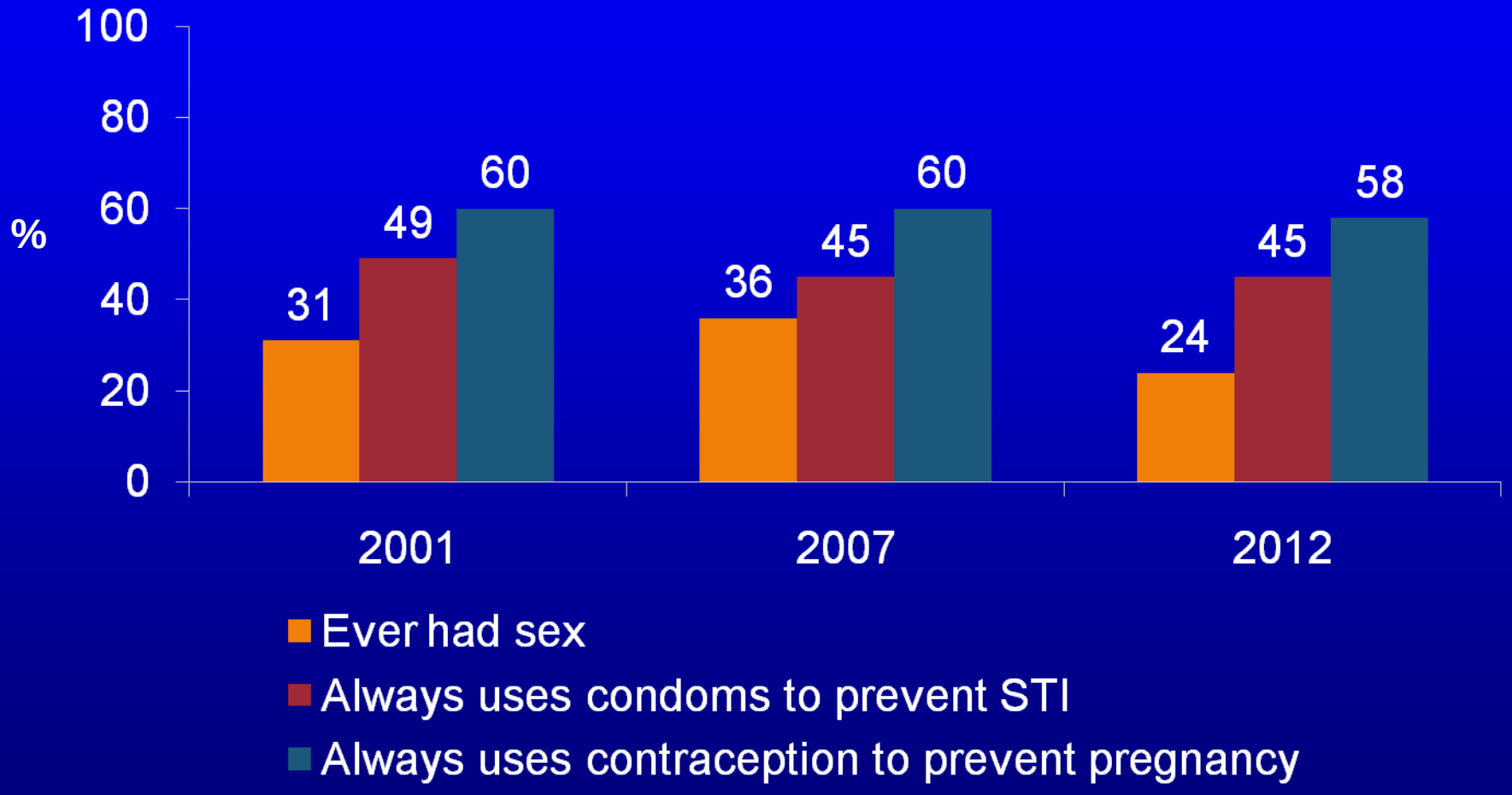
Substance use



Suicide attempts & depressive symptoms



Sexual and reproductive health



Greater rate of risky behaviours in youth with chronic conditions

- 2002 Swiss multicentre Adolescent survey 7548 16-20yr olds 760 with chronic illness vs 6493 healthy controls

• Daily smoking	OR*	1.18 (1.01, 1.38)
• Illegal drugs		1.23 (0.94, 1.60)
• Early sexual debut		1.26 (0.97, 1.63)
• Eating disorder		1.26 (0.93, 1.71)
• Violent acts		1.29 (1.06, 1.56)
• Antisocial acts		1.35 (1.14, 1.59)
• Alcohol misuse		0.99 (0.83, 1.17)

- more likely to report 3 or $\geq$ 4 simultaneous behaviours

* Adjusted for age, gender, academic track, parents education, health perception and depression

JC Suris et al, 2007

Case: 17 yr old

Diagnosed at 2yrs

CD4 420 (26%) VL 307,000

- Mother HIV +, sib HIV -, father left

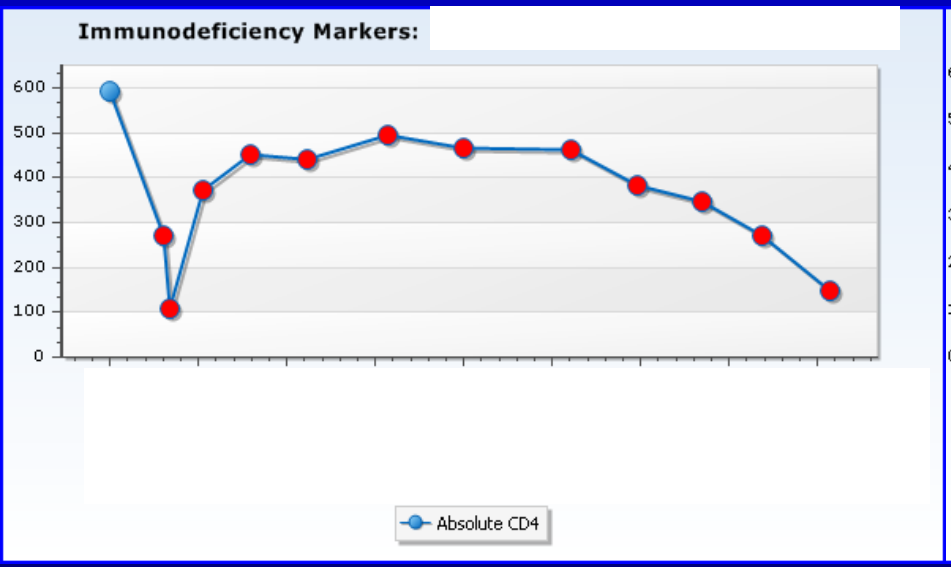
- "family is under considerable stress and turmoil"
- "happy child but very overactive"

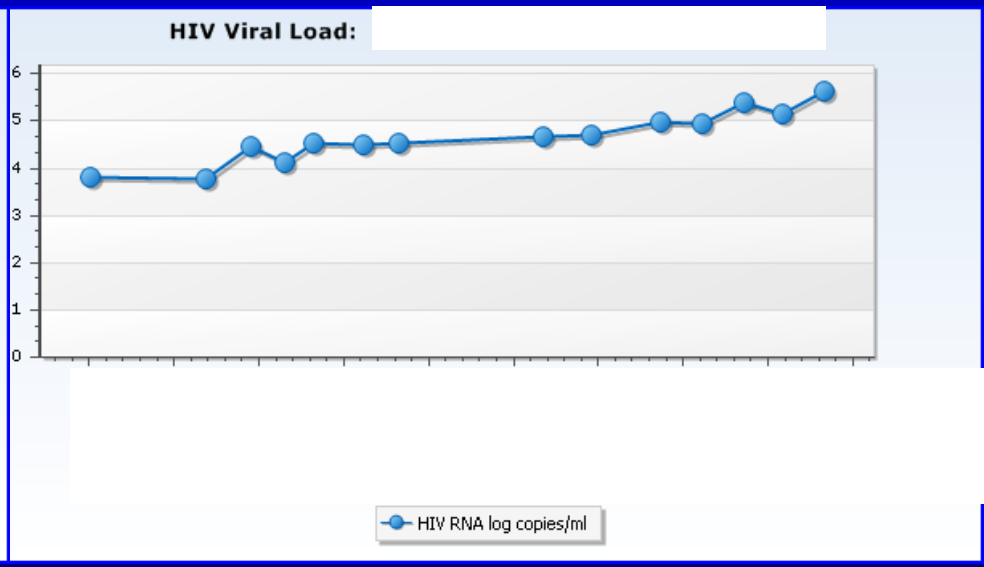
- Zidovudine, lamivudine, nelfinavir started
- "excellent adherence" CD4 1510 VL 39750
- Recurrent fever - antibiotic prescription not filled " on too many drugs already"

- CD4 1140 (44%) VL 57000
- Move to live with extended family
- Counselling, significant behavioural/financial difficulties

Progress

- Few health issues, good attendance at clinic
- “Excellent” drug adherence reported
- Number of different ART combinations, CD4 1175 (31%) VL 69 (183, 8710, 19000)
- Stopped ART, multiple behavioural/adherence issues
- Community & hospital social supports offered





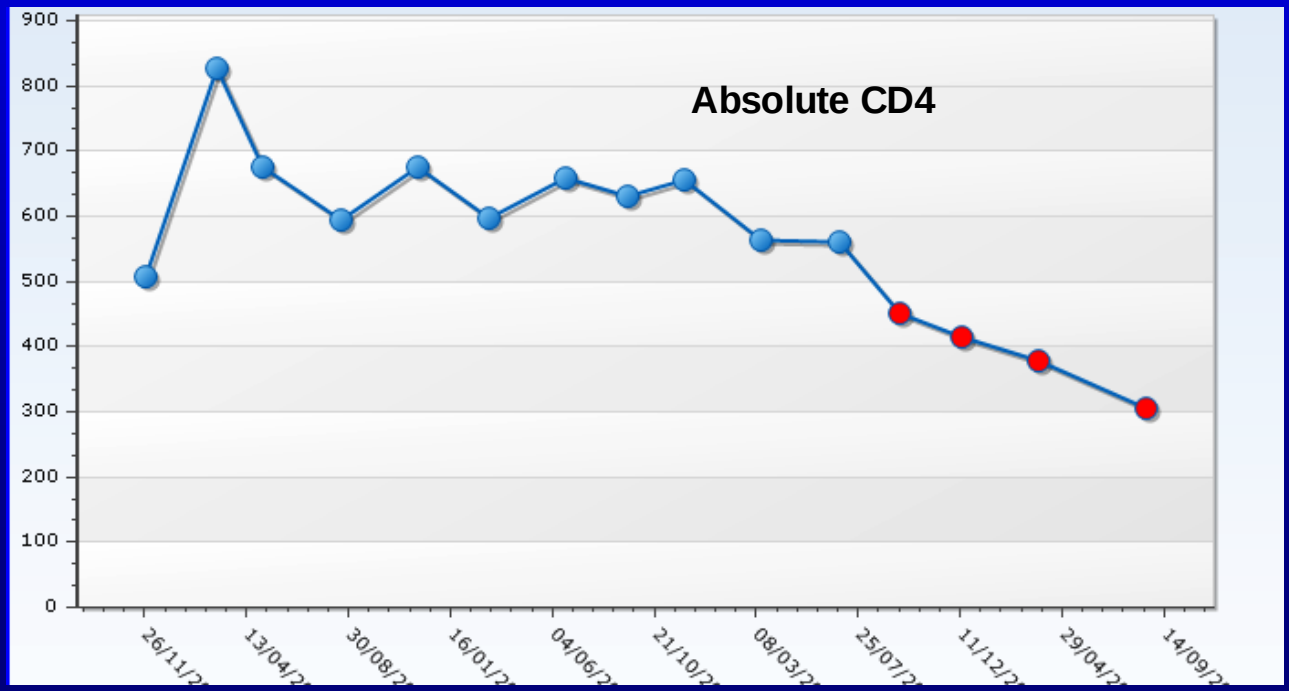
Case: 17years

- Transitioned to adult care
- CD4 declining 147x 10^6/l, VL>100000 off ART, multi-drug resistant virus
- HAART restarted

- Poor school attendance
- Binge drinking
- Marijuana use
- Sexually active
- Left home, no fixed income

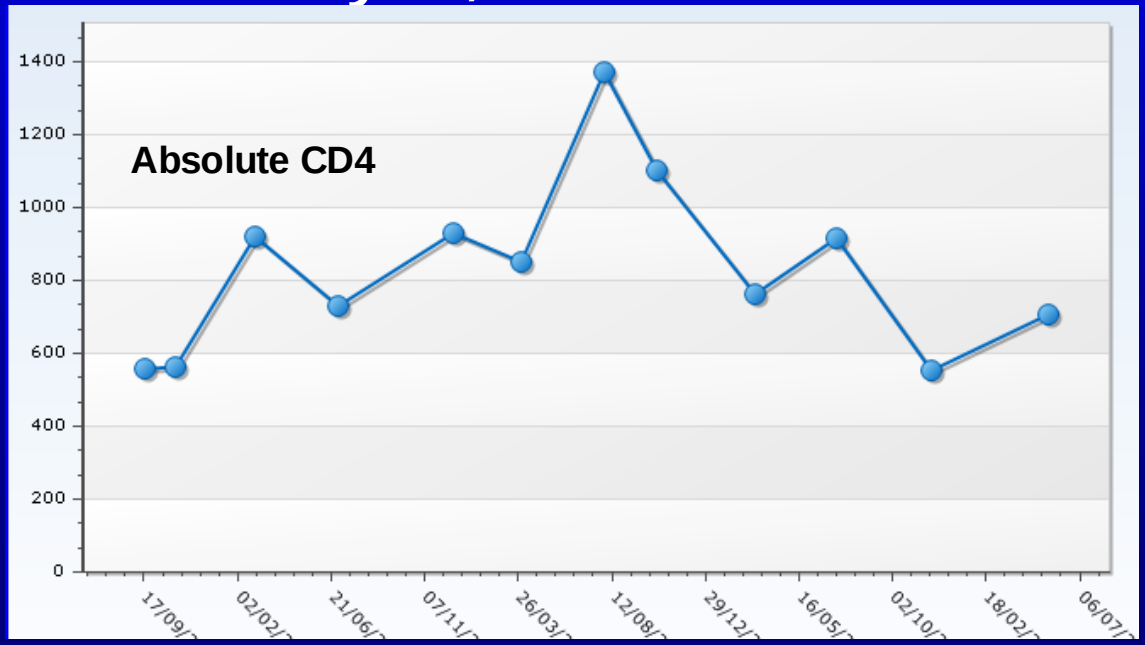
16yr old

- Diagnosed 9 yr old CD4 663x10^6, VL4226 copies/ml
- No antiretrovirals started
- Stable clinical course until recently

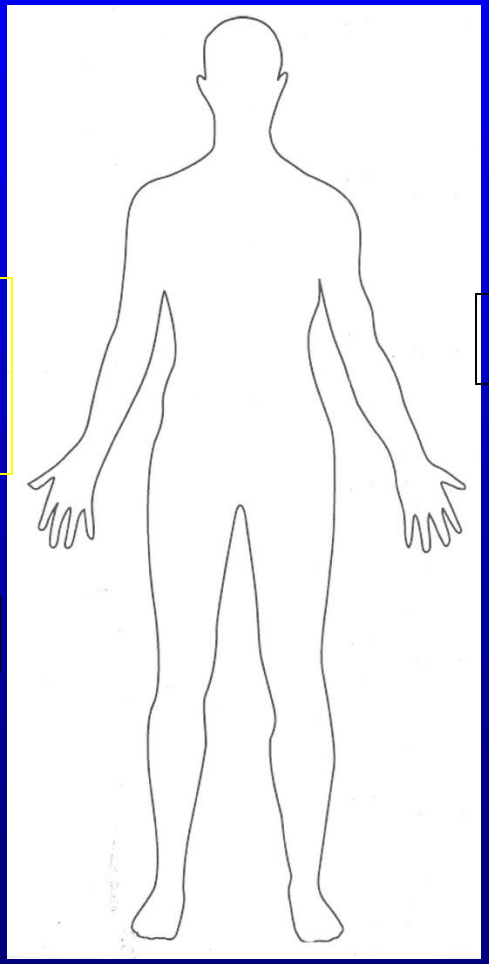


18 yr old

- Diagnosed 3yr old, CD4 713 x10^6 (18%), VL67370 copies/ml (log 4.8)
- HAART started ZDV, 3TC, nevirapine
- No significant illnesses, fully viral suppressed for 14 yrs, remains on same ARTs



Unique situation of children being born with a transmissible disease and a chronic life-limiting disease



Multigenerational illness

Negotiating first (and every) relationships/SI with an STI

Complex psychological needs

Cultural adjustments

Stigma and secrecy

Chronic ill health in childhood

Immigration, poverty, employment

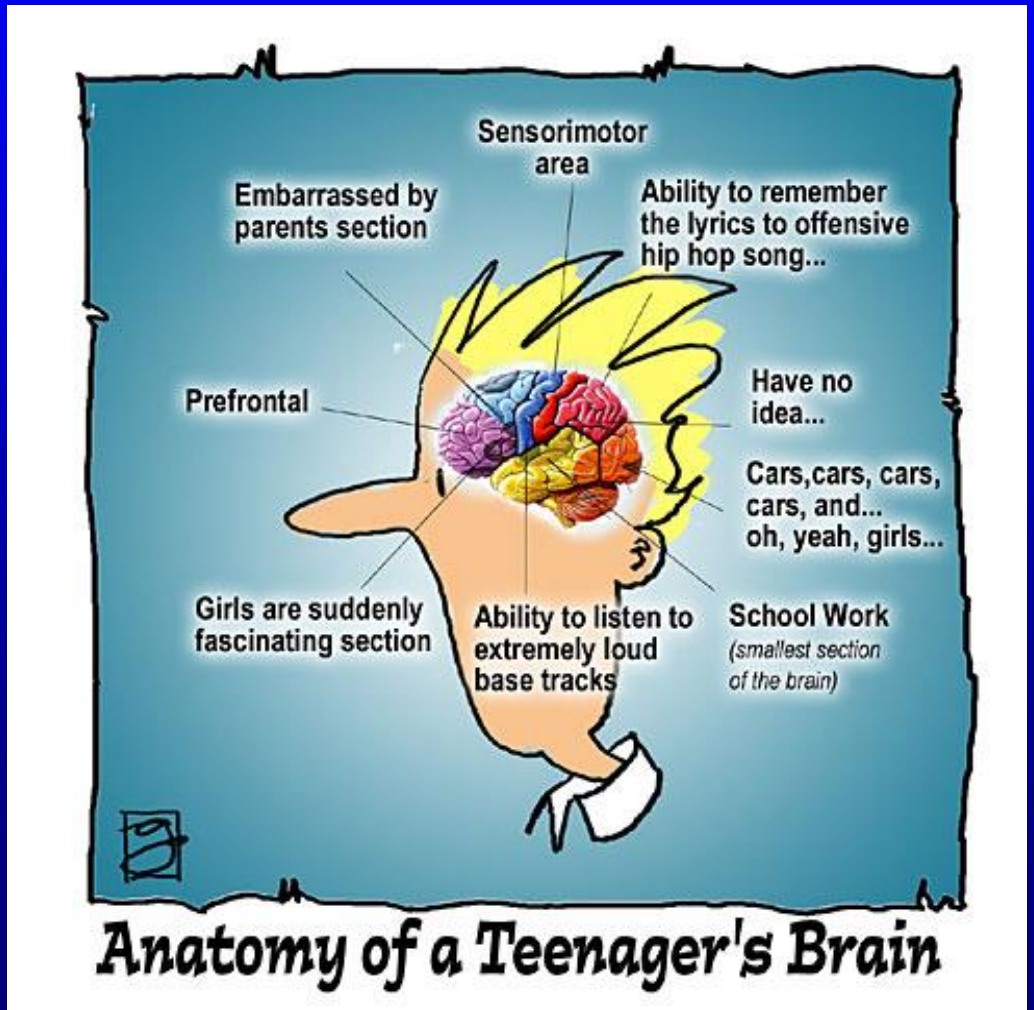
Adherence to medication

Longterm S/E HIV and ARVs - MDR

Prefrontal cortex maturation - 3rd decade

- impulse control, planning, emotional regulation
- Prefrontal cortex: decision making/ reasoning/impulse control matures into early 20s

Infantile encephalopathy- hypertonic diplegia



Chronic HIV exposure

Social factors – deprivation, malnutrition, isolation

Longterm exposure to ART + in-utero exposure

Neurocognitive and Psychiatric Outcomes

- 81 adolescents median age 15 yrs
- Weschler IQ - normal range
- Psychiatric illness 48%, multiple 18%
- Learning disability 42%, learning support 38% (16% mental health hospitalisation)

BUT if prior AIDS: Lower IQ (p=0.002)- below average range

19x multiple psychiatric diagnoses

4x mental health treatment.

Wood S et al. AIDS 23, 1859-1865, 2009

Psychiatric Hospitalisations

- PACTG219C prospective cohort study of -1808 HIV-infected, 1021 neg children
- 25 <15yrs hospitalised for psychiatric reasons
- 6.17/1000 person-years cf general paed population 1.7/1000 person-yrs

- Over all ages 32 hospitalised –
  - depression (16) and behavioural disorders (8), suicide attempt/ideation (6) most common

- 15 multiple hospitalisations, median age of first hospitalisation 11 yrs

Gaughan et al Pediatrics 2004

Adolescent History taking - peer and self HEADSS adolescent screening tool

- Home - Living
- Education and employment - Social services
- Activities - youth offending
- Drug use, alcohol, smoking, other
- Sexuality
- Suicide/Depression- mental health and self harm

Medical Issues

1993

2012

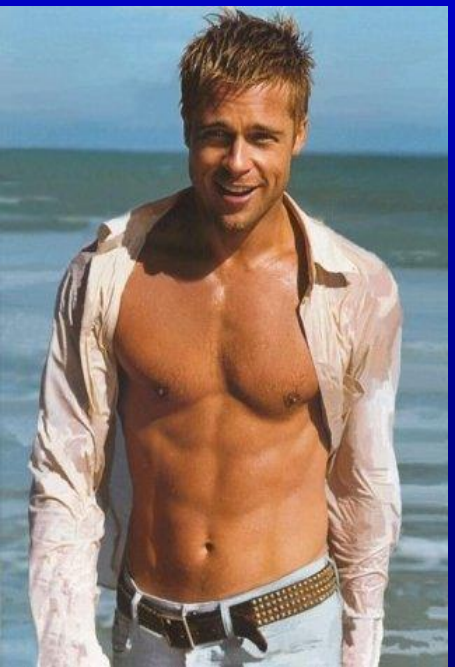
Medical Issues

Multidrug resistant virus

Increased risk of cancers

Adherence

Long exposure to ART/HIV



Metabolic abnormalities:
body image
bone density

Mitochondrial toxicity

Delayed puberty/short stature

Paediatric adherence impact on adult life

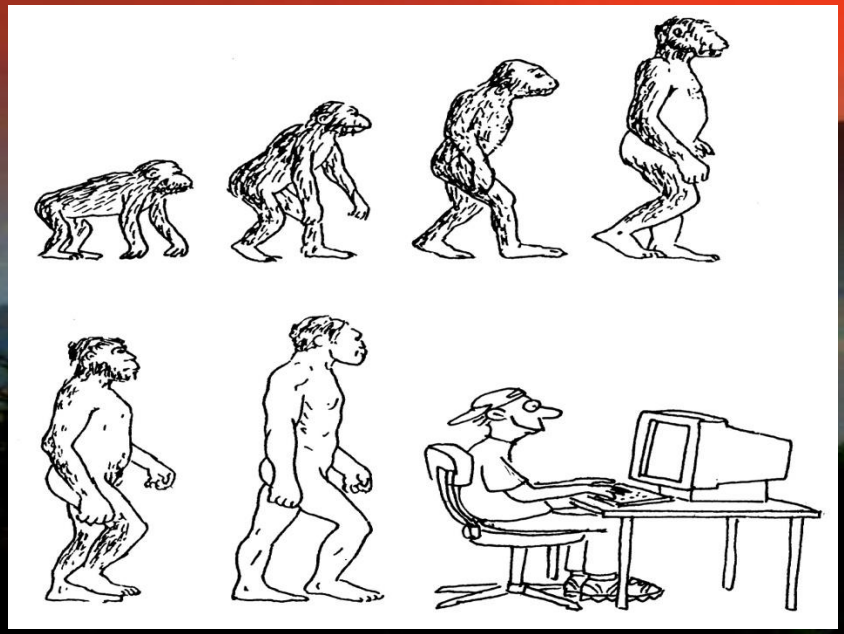
- Case note review of young people 18-25yr, receiving both paeds and adult care – 34 paHIV

	Good paediatric adherers n=15	Poor paediatric adherers n=19
CD4 <200 at last follow up	0	9
Virology	(1) rebound (14) VL<50	(2) VL<50, CD4 >200 for >50% of time on ART
AIDS diagnosis (death)	0	4 (2)

Poor adherer - reported >10% of ART doses missed

Good adherer > 90% ART doses taken

BHIVA 2011 Kent et al



EDWARD DULLARD.
KILKENNY, IRELAND.

Evidence in chronic disease

- **Renal transplantation: 35% lost graft within 36 months of transfer**
  Watson A 2000
- **Congenital heart disease: 1 in 5 deaths "avoidable"**
  Somerville J 1997
- **Diabetes: 10-69% no medical f/up after paediatric care**
  Pacaud D 1996, Frank M 1996, Kipps 2002
- **Better attendance when young person has met adult team prior to transfer**
  Kipps 2002

Transition

"Transition:getting it right for young people" *www.dh.gov.uk* *2007*

'A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems'

Age appropriate approach flexible to individual needs of the adolescent


Resilience
Coping strategies
Independence
Social supports

Transition Process

- Occurs over years
- Partnership between:
  - Young person
  - Carer
  - Paediatric & Adult Multi disciplinary team services
- Tailored to the individual young person, recognition of maturity of the child
- Encourage to develop autonomy and self management skills with dedicated team responsible for transition
- Parents need to handover care, allow teenager to become the decision maker

Need for acknowledgement of the individual

Acknowledging HIV

Knowledge & opportunities

Appropriate involvement of parents/caregivers

Appropriate supports offered/privacy

Acknowledge sexual activity/drug/alcohol use

There's more to life than HIV

Not to much information

Enabling independence and respecting confidentiality

Not assuming sexual activity

Encourage autonomy & self esteem

Models of Transition

- Several models for transitioning young people to adult services
  - Family clinics: integration
  - Specialist services: handing over
  - Specialist services: separate youth clinic

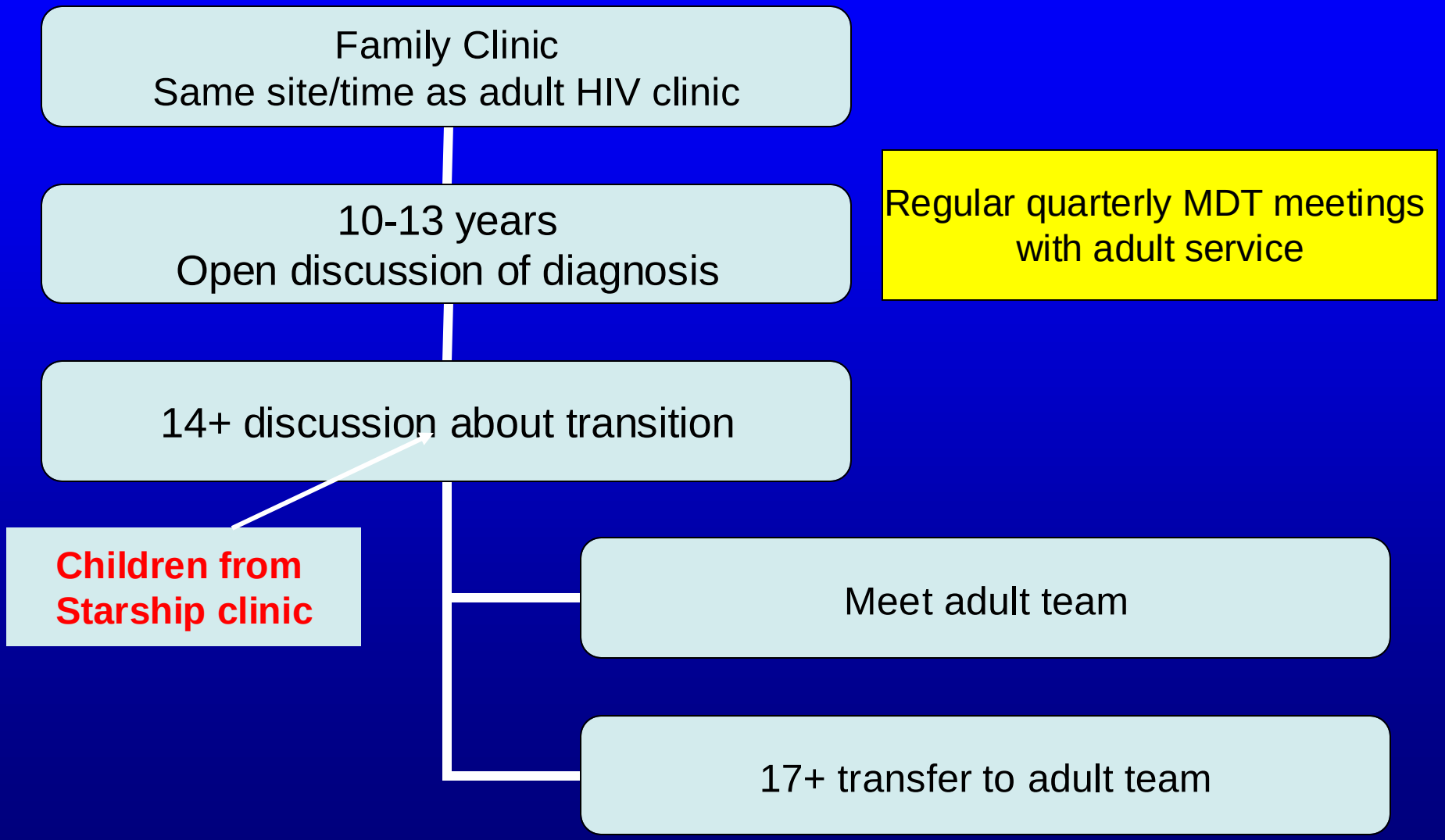
- Model chosen will depend on variety of factors – resources, numbers

Transition plan

- Full review of clinical history
- Identify other assessments/resources needed
- Update on knowledge of HIV and confidentiality
- Sexual health discussion
- Parents/caregiver support
- Discussion on where/when/who
- Introduce to adult service providers
- Shared/joint meeting with staff
- Handover for other services

NHS working party, 2006; Persson, Newman 2012

Transition at Starship Children's Hospital



Transition at Starship Children's Hospital

Benefits:

- family-centred care
- 1 hospital visit per family
- family issues can be dealt with
- easier transition

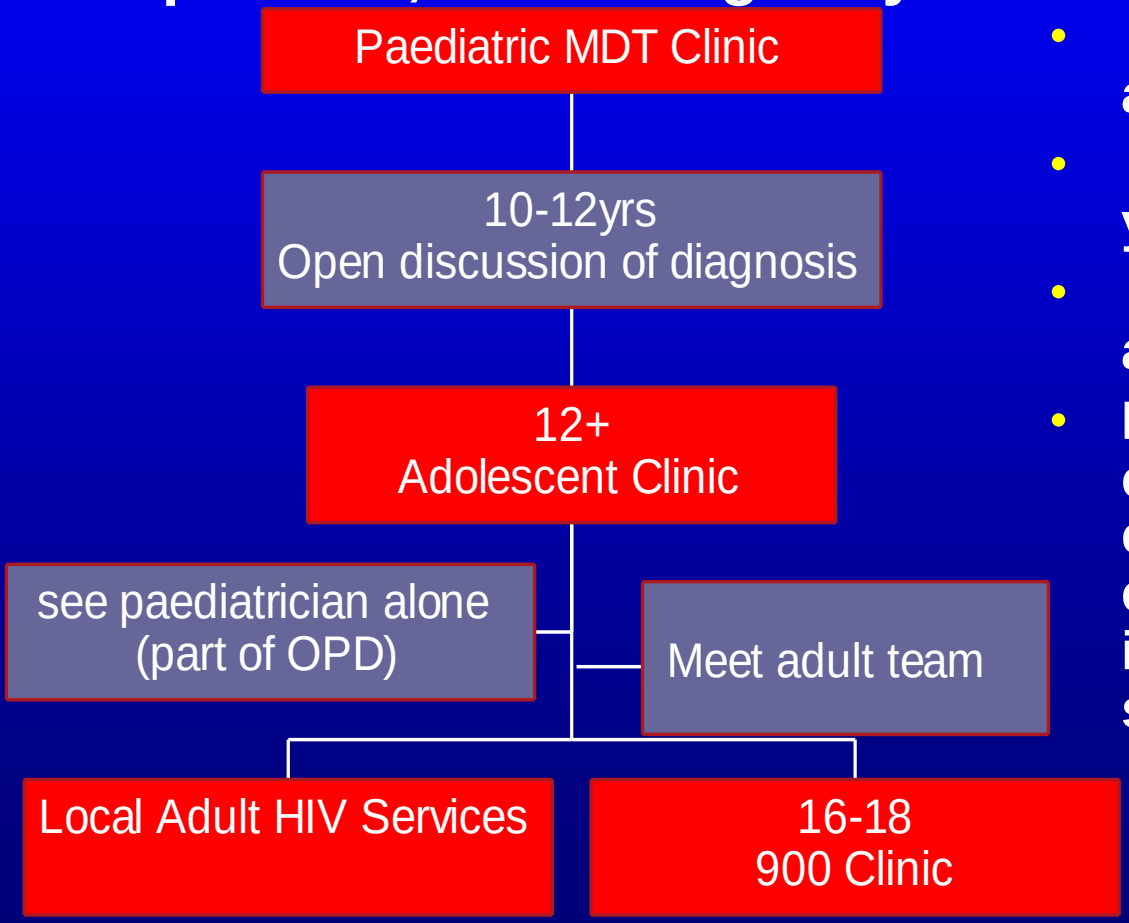
Disadvantages:

- longer duration
- adult clinic not setup for children
- child can disrupt adult visits
- confusion over clinic sites for other clinic visits

Transition care services for young people

Questionnaire on transition,

21 patients, median age 19yr



- **68% transition positive effect on their health/well-being**
- **95% felt their transition was an easy process**
- **All were happy with their young person OPD care**
- **1/3 happy with their care as adult inpatients**
- **Being treated as an individual, comprehensive management explanations and encouragement to develop independence were cited as strongly important**

Bundock et al AIDS Pt Care and STDs 2011

Health outcomes following transfer to adult services

- Retrospective 2006-11, n = 58, median age 20 (17-24),

- 20% severe immunosuppression (CD4 <200)
- 25% admitted - 4 due to ODs, OIs (2),CVA (1)
- 2/58 died (end stage disease,& sepsis, declined ART)
- High rates of co-morbidity, including depression
- Despite attending for MDT follow up there is a small group of young people who remain off ART with low CD4 counts

- But not all bad news:

  85 % of those who take ART are undetectable


Resilience, confidence, hope

Conclusion

- HIV is a chronic disease of childhood with a varied path
- Transitional Care should be planned, purposeful and positive - there is no “right way”
- Need to maintain engagement in health care and acknowledge the complexities of adolescence
- HAART is good, Adolescents are great

Starship
CHILDREN'S HEALTH

Acknowledgments

- Dr Caroline Foster, 900 Clinic, Dr Hermione Lyall, St Mary's Hospital, London
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