



Adolescents with HIV and neurodevelopmental impairment: transitioning towards adult care

T Chawatama¹, S Persand¹, D Melvin¹, A Coomer¹, C Foster¹
¹Imperial College Healthcare NHS Trust

Background

Improvements in anti-retroviral therapy (ART) have resulted in increasing numbers of children with perinatally acquired HIV (PaHIV) transitioning towards adult services. Despite suppressive ART the long term effects of HIV encephalopathy in infancy continue to impact on functioning in childhood, however the neurodevelopmental outcomes in later adolescence are less well characterised.

Aim

To document the incidence of severe neurodevelopmental problems affecting learning and/or mobility in young adolescents with PaHIV cared for at a single centre paediatric HIV clinic and to consider the implications for future independence and effective care in adulthood.

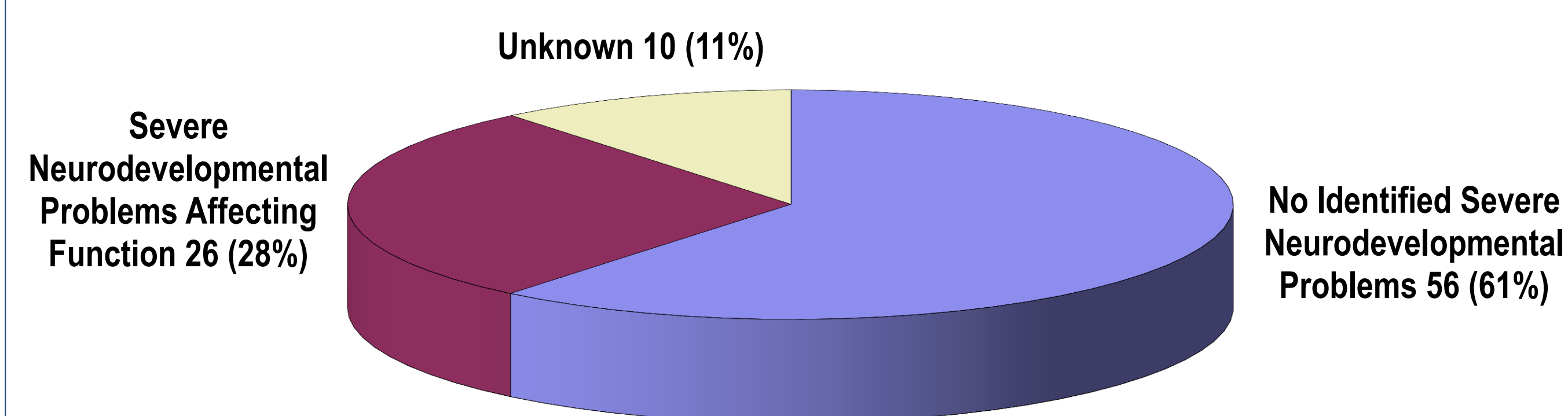
Methods

A single centre retrospective case note audit of adolescents with PaHIV aged 12-18 years identified as having at least one severe neurodevelopmental problem defined as:

- A neurological/motor deficit affecting mobility
- Significant cognitive impairment requiring long-term additional learning support (i.e. a standardised score on age appropriate cognitive test falling > -2 standard deviations below mean or IQ < 70.)
- A neurodevelopmental diagnosis (neurodisability) significantly affecting daily life and performance (e.g. Attention Deficit Hyperactivity Disorder, Autistic Spectrum Disorder.)

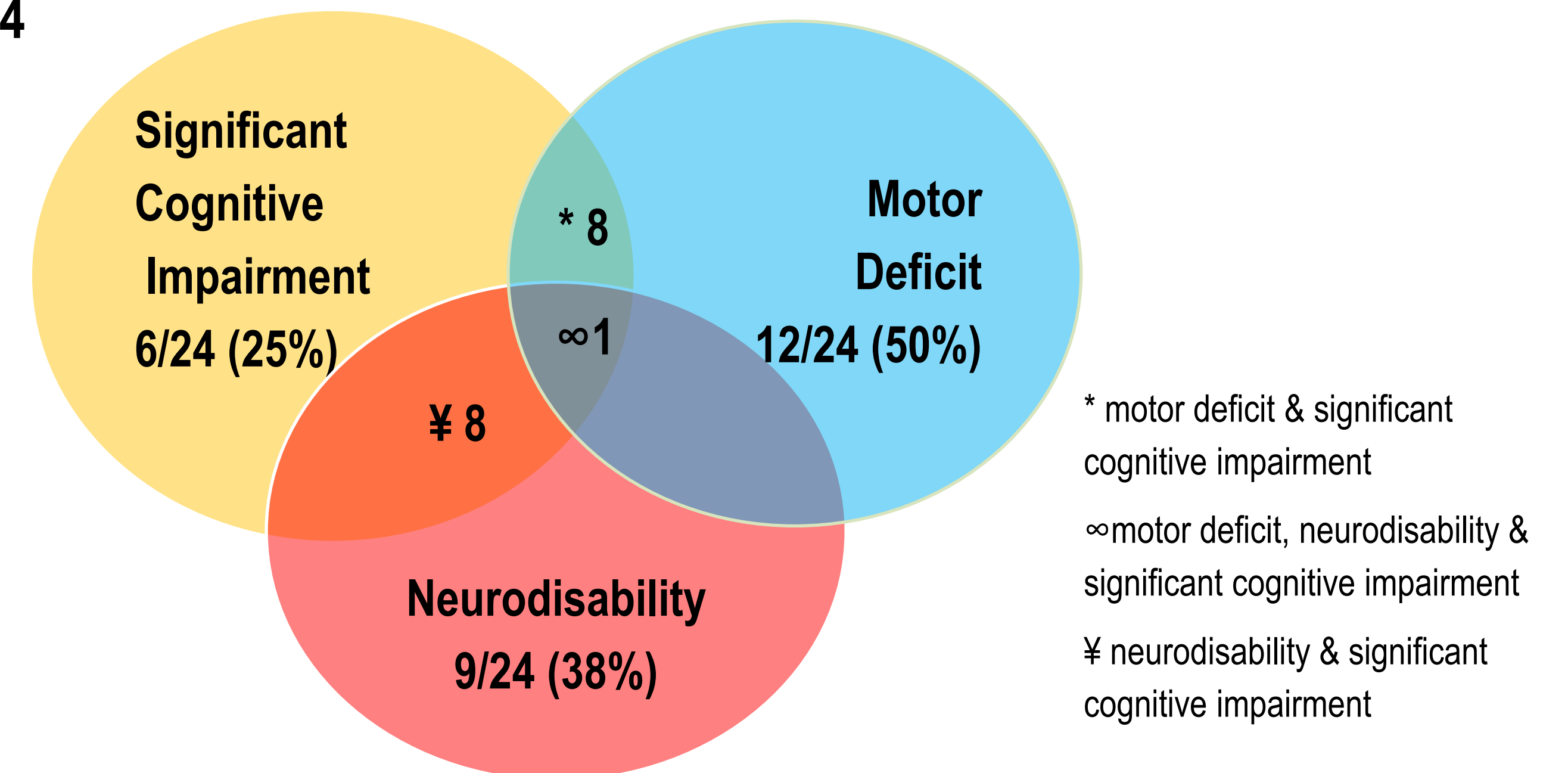
Results

Chart 1: Proportion of Adolescents with Severe Neurodevelopmental Problems



Total Number of Patients = 92
Detailed data available for 24/26 patients with severe neurodevelopmental problems

Chart 2: Subgroup of adolescents with neurodevelopmental problems n=24



* motor deficit & significant cognitive impairment
∞ motor deficit, neurodisability & significant cognitive impairment
¥ neurodisability & significant cognitive impairment

EDUCATION

Mainstream School 21/24 (88%)
Special Needs School with statement for learning 2/24 (8%)
Unknown (schooling overseas) 1/24 (4%)

Chart 3: Subgroup of 21 Adolescents in Mainstream School

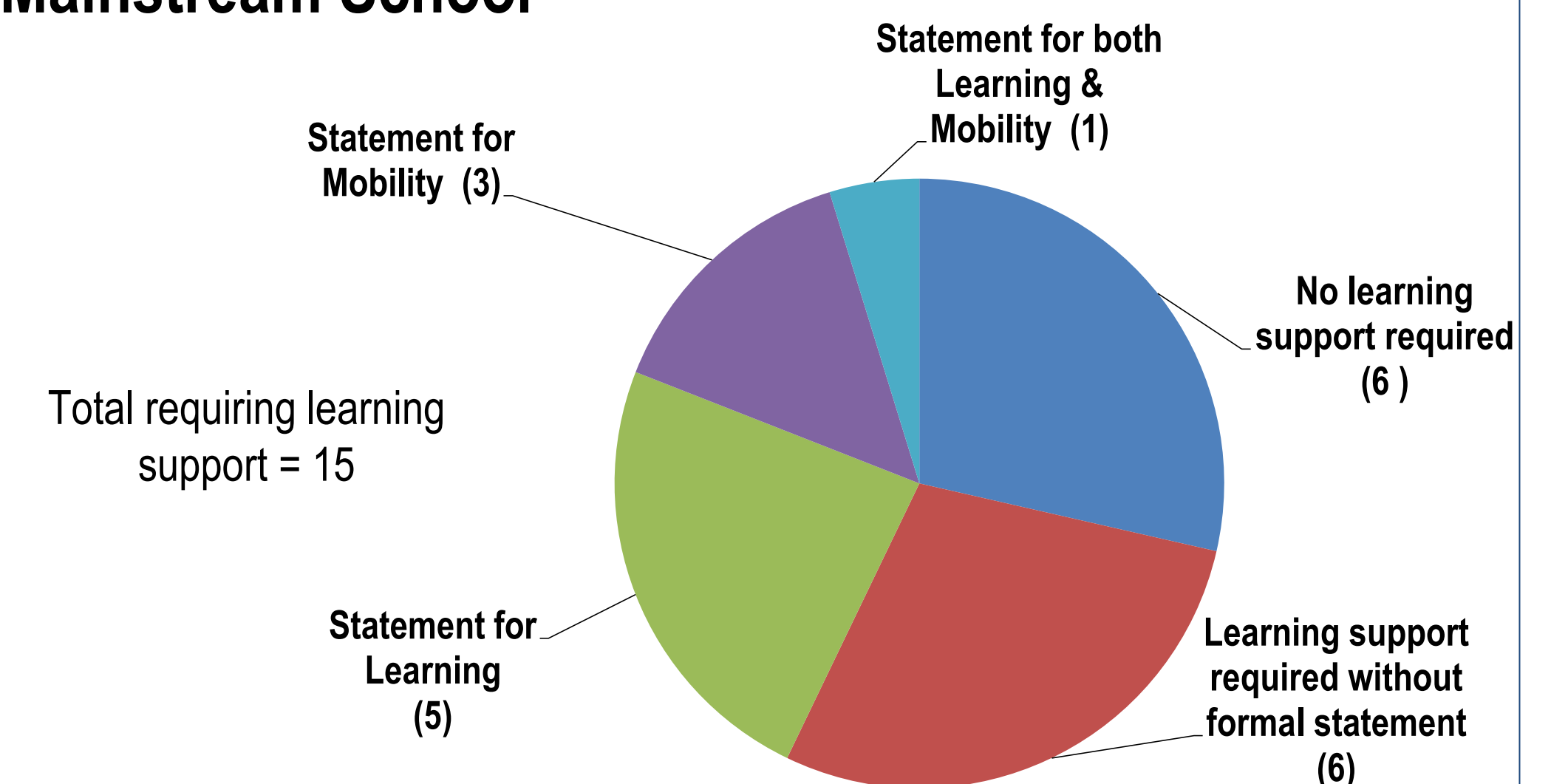


Table 3 On-going Specialist Input (outside the Paediatric HIV clinic MDT)

Speech & Language Therapy	2/24 (8%)
Audiology	1/24 (4%)
Physiotherapy & Occupational Therapy	6/24 (25%) 3 use walking aids
Continence Problems	11/24 (46%) Mostly nocturnal enuresis
Child & Adolescent Mental Health Services	1/24 (4%)

Conclusions & Implications for Future Care

Despite suppressive ART, more than a quarter of HIV infected adolescents in this cohort have significant neurodevelopmental difficulties which require extra services or support to manage learning and/or mobility demands of everyday life. The incidence of severe neurodevelopmental problems is higher than expected when compared to the general population (severe cognitive impairment 6/92 (6.5%) compared to 2-3% in the general population {1}).

Neurodevelopmental issues are longstanding and will persist following transition to adult services affecting young peoples' decision making/capacity, relationship/sexual health education, employment and independent living. They will continue to require coordinated multidisciplinary health and social care.

Whilst this audit focuses on the most severe cases, others in the cohort may have more subtle learning, developmental or psychological difficulties which, although not severe enough to warrant a formal clinical diagnosis, will affect their ability to manage their health. These adolescents are also likely to require extra support after transition.

Reference

1. Wechsler, D. (2004) Wechsler Intelligence Scale for Children Fourth UK Edition (WISC-IVUK). London: Harcourt Assessment/The Psychological Corporation.

Table 1 Patient Demographics n=24

Gender	Male 18 (75%) Female 6 (25%)
Median Age	14 years (IQR 13-16)
Ethnic Origin	Black African 19 (80%) Black Caribbean 1 (4%) Mixed 2 (8%) Asian 1 (4%) Caucasian 1 (4%)
Country of Birth	UK 11 (46%) African Country 12 (50%) Americas 1 (4%)
Main Carer / Living Situation	Both parents 4 (17%) Single Parent 15 (62%) Other family member 1 (4%) In alternative care 3 (12%) Semi-independent 1 (4%)

Table 2 HIV Diagnosis & Treatment

Median Age at Diagnosis	3 years (IQR 1-4)
Nadir CD4 count	14% (IQR 4-19)
Currently on ART	22 (92%)
Current median CD4 count	884 (IQR 656-1043) (CD4 counts of 2 patients off ART 479 & 656 respectively)
Adherence issues in last 12 months	Yes (16%)
Level of knowledge of HIV status	Told HIV diagnosis 17 (70%) Partial (HIV not yet named) 7 (30%)