Psychology services in management of children and young people living with HIV: Standards for care

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Not just filling in the gaps but making effective connections between health and wellbeing

Thanks

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Psychology is the study of mind & behaviour. It is an academic discipline based on empirical scientific evidence. As an applied science it seeks to understand individuals and groups by establishing general principles and researching specific cases & functions.

perception, cognition, attention, emotion, intelligence, motivation, brain functioning, personality, interpersonal relationships……..

Standards are based on evidence

The National Service Framework for children, young people & maternity services (DoH 2004).

Standard 6

"All children and young people who are ill, or impaired, will have
timely access to appropriate advice and to effective services
which address their health, social, educational and emotional
needs throughout the period of their illness".

BACKGROUND PRINCIPLES TO THESE STANDARDS

Basics of these standards

- Psychological support is delivered by whole range of people caring for children and young people in the MDT
- Uses a service model from other chronic childhood health conditions
- Focus on role of ‘practitioner’ psychologists
- Concordant with adult HIV psychology standards and other UK paediatric HIV care standards

Six core standards

1. Provision of Equal Access to Psychological support
2. Promote Engagement and participation of children, young people and their families
3. Identify Developmental and Psychological needs
4. Support for knowledge, understanding and sharing information about HIV
5. Promote psychological approaches to managing treatments
6. Promote psychological wellbeing in adolescence and during transition between paediatric and adult services

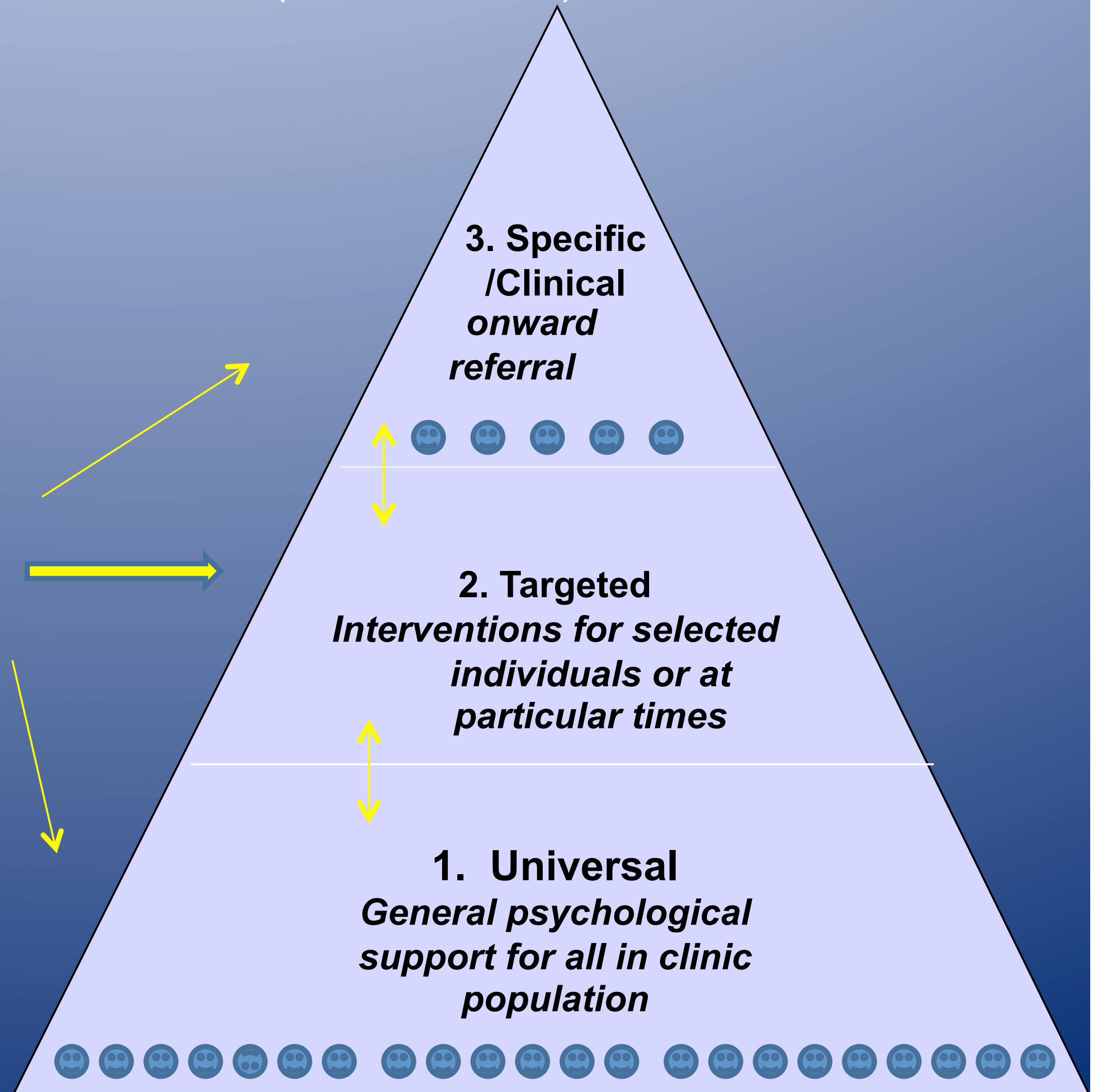
Meeting the standards in paediatric HIV clinics

Standard	Psychological Approaches
1. Equal access	1. Psychological thinking included in care for all
2. Engagement & Participation	2. Appropriate to developmental stage
3. Developmental & Psychological needs	3. Screen at key time – coping, learning, emotions & behaviour.
4. Information sharing	4. Address communication & disclosure appropriate to competence and maturity
5. Treatment Adherence	5. Integrating psychological factors into treatment management
6. Transition	6. Addressing independence, identity, sexuality and separation as well as preparing for transfer

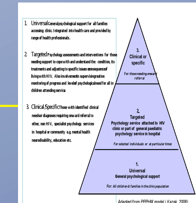
A Service Model

Adapted from PPPHM model (Kazak 2006)

Practitioner psychologists with dedicated paediatric HIV sessions



Practitioner Psychology services



1. Universal

Approaches for whole population

e.g. collaboration, developing protocols, psychosocial reviews, staff consultation, teaching and training etc.

2. Targeted

Direct referrals + Proactive approaches

3. Specific/Clinical

Enabling onward referral to specialist teams

e.g. CAMHS, child development, education, forensic, neuro psychology etc.

THE VALUE ADDED EFFECTS OF A PRACTITIONER PSYCHOLOGY SERVICE

2 case examples

1. THE NEWLY ARRIVED FAMILY

Four siblings from Nigeria (4, 9, 12 & 14y)

Moved to the UK to live with an Aunt (Parents both deceased)

Upon arriving in the UK, three children tested HIV positive

(4, 9, & 14y), all had TB.

General

- Collaborating with MDT over coping with practical as well as health issues (housing, education, managing big pill burden).
- Identifying emotional needs for each child and ‘new’ parent.
- Assessing ‘readiness’ & competence for more knowledge, participation, responsibility etc.
- Keeping in mind uninfected 12 y.

Targeted and Specific

- Adjustment (new life in UK)
- Bereavement and attachment issues
- Different emotions and behaviours at different ages
- Cognitive/learning assessments (9 year had developmental delay)
- Providing age appropriate information about health & HIV
- Medicine taking/ adherence interventions

3 yr old: getting into a routine

14 yr old: sharing responsibilities, understanding diagnosis

2 .THE TRANSITIONED ADOLESCENT

Simon, 18y, just transferred to adult services.

History : perinatal infection, lives with dad(+) and step mum (-ve). Learnt diagnosis from argument with dad (at 13y). Always struggled with medicine taking.

Attendance sporadic. Parents refused any peer support. Family reluctant to engage with psychology.

After transfer to adult service

- Admitted as in-patient
- Psychology involvement : depression and neurocognitive assessment (Moderate depression & good cognition)
- Interventions to promote independence / autonomy (taking responsibility for health and treatment decisions)
- Building emotional resilience, (peer support/ normalising), separating from the family's narrative about HIV , revisiting losses and bereavement
- Introducing new associations around medicines

Thank you for your attention!