



Young people living with HIV and the transition from children's to adult services

Literature review

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NCB's vision is a society in which all children and young people are valued and their rights are respected.

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Contents

Introduction	3
Statistics	5
Policy and guidance on transition	8
Parallels with/learning from the experience of transitions by young people with other chronic illness and/or disabilities	11
Additional transition issues for young people living with HIV and those working with/caring for them	15
Rural (or other) areas with low numbers of young people living with HIV	20
Conclusion	21
Bibliography	23

Introduction

'Transition of care from a paediatric to adult setting is not specific to HIV, but occurs in a number of paediatric specialities...However, there are important differences for young people with HIV which may make this process more difficult'
(Lyll 2007, p.6).

There is a considerable literature on the current issues, perceived deficiencies and models of good practice in effecting transitions from children's to adult services. It is widely acknowledged that support and care at this critical point can be poorly coordinated and geographically patchy in terms of its quality (VSS 2010). Transitions between children's and adult services involve changes in expectations, ethos and often the loss of valued relationships. Young people with HIV share many of the issues, challenges and experiences of other young people with chronic or complex health needs, such as those with diabetes or cystic fibrosis, when making the difficult transition to adulthood and greater self-management of their conditions. Problems with continuity of care, changed expectations by services and professionals, lack of community and social support can result in confusion and anxiety. The continuing need to adhere to irksome or demanding medication or self-care regimes, at the very time when many adolescent young people are seeking to assert their independence, can all combine to make transitions problematic. However the stigmatised nature of HIV arguably creates significant additional difficulties for young people in making their transition to adulthood and greater independence at adolescence.

Before the development of effective treatments children who were vertically infected with HIV were not expected to survive past childhood:

'Accordingly, parents and health care providers often did not anticipate these children would face the conventional challenges of adolescence, including decisions regarding sexual and other risk behaviours'
(Wiener, Battles and Wood 2007, p.471).

Adolescence is a developmental stage widely recognised as being one often characterised by erratic behaviour, emotional turmoil and psychological insecurities as young people seek a secure new identity and acceptance in the adult world. Lewis, writing on adolescence in *Afraid to Say: the needs and views of young people living with HIV/AIDS* (2001) notes that adolescence is a time when the young person struggles to assert their own identity and their independence of adults. The desire to be 'normal' in the eyes of one's peers and to fit in with their expectations can be a strong countervailing force to the advice of adults and professionals. For young people with HIV, as interest in sexual relationships develops, the risk of onward transmission of the virus also requires that they exhibit a higher degree of self-confidence, responsibility and maturity than their peers in negotiating relationships.

Combined drug regimes have fortunately transformed the long-term prognosis for young people with HIV, making the condition a chronic rather than life-threatening one if managed effectively. However, whilst medical advances have been dramatic in terms of controlling and mitigating the effects of the virus on the body, social attitudes and beliefs are more enduring. HIV remains a highly stigmatised condition, resulting in a great deal of prejudice, anxiety, fear and social isolation for those affected by it. The stigma surrounding HIV in turn compounds the difficulties of achieving confident and open transitions in which effective self-management regimes and social adjustment can be achieved. Despite commonalities with other complex paediatric health conditions, from which much can be learned in terms of effective approaches and models of care, there are currently unique social aspects to HIV infection:

'The challenge will be to "normalise" HIV infection and fully integrate it into the spectrum of childhood illness'
(Lewin and Melvin 2001, p.434).

Wilkins, Campbell and Beer (2007), writing on the effective preparation of young people living with HIV when making the transition to adult life, point to several common difficulties experienced by them and their carers. They comment that not many adult physicians are skilled and trained in adolescent care, let alone HIV issues and care. Both parents and young people, who may have developed strong bonds and trusting relationships with paediatric service staff, can struggle with the changed relationships and expectations of adult care services. Transition to adulthood can also mean losing touch with professionals who know how a young person communicates and what, if any, assistance they require (Morris 1999). Young people may have grown accustomed to the more protective ethos of paediatric services and can struggle to grasp and accept the full consequences of greater personal autonomy. Parents and carers can find it hard, often for the best of motives, to accept the decrease in their control and decision-making role. For various reasons strongly related to stigma and the real or perceived risks of disclosure, young people living with HIV may in fact have only recently had their diagnosis fully disclosed to them as they approach adolescence, and young people's individual levels of awareness, understanding and acceptance will vary. Alongside the normal psychological, physical and social pressures attending puberty and adolescence, they will have to contend with having a condition surrounded by stigma. Ideally they need to be gradually prepared for transition and supported to become well-informed as to how to best manage it. In practice the stigma, ignorance and fear surrounding HIV often make this very difficult to achieve, with disclosure and openness delayed to the last moment in too many instances:

'Transition depends on young people being aware of their diagnosis ... The stigma surrounding HIV and its sexual transmission make it very difficult for parents to disclose an HIV diagnosis to a child'
(Wilkins, Campbell and Beer 2007, p.2).

Statistics

Figures from the Survey of Prevalent HIV Infections Diagnosed (SOPHID), as published on the Health Protection Agency (HPA) website, state that out of 65,319 people diagnosed as HIV-positive and attending HIV clinics for care in the UK in 2009, some 899 were aged 0-14 years and 2,349 were aged 15-24 years. The HPA's report *Testing Times - HIV and other Sexually Transmitted Infections in the United Kingdom: 2007* states that:

'The number of young adults accessing HIV-related care more than tripled between 1997 (716 [12/100,000]) and 2006 (2,228 [34/100,000]). However, out of the total number of those living with HIV, the proportion of young adults has remained stable: 4.5% (716/16,075) in 1997 and 4.3% (2,228/52,083) in 2006.'

Some of these young adults will have been infected vertically, *in utero*, during birth or via breastfeeding. SOPHID notes that 401 young people aged 16-24 identified as vertically infected with HIV were accessing HIV care in the UK in 2009, compared with 13 in 2000.

According to data from the Collaborative HIV Paediatric Study (CHIPS) a cumulative total of 1,645 children were reported to them by the end of March 2010 with the proportion of the cohort aged 10 years and over having increased year on year from just 11 per cent per cent in 1996 to 65 per cent in 2009. The median age of this cohort was 11.9 years in 2009. In *Growing pains* (2008), Bernard notes the number of young people living with HIV who were approaching transition at the time of writing:

'According to data from the CHIPS (Collaborative HIV Paediatric Study) cohort, last year there were a further 187 teenagers aged 15 or older receiving paediatric care [...] Waiting in the wings are another 418 children aged 11-15...'
(Bernard 2008, p.2).

The cohort of adolescents and young adults who have grown up with HIV and are now moving into adulthood, largely due to improved survival rates following the introduction of effective combination therapies, will need coordinated multidisciplinary support to make the best possible transition from paediatric to adult services:

'with ready access to appropriate advice and support during adolescence and before they become sexually active'
(www.hpa.org.uk - *HIV and other Sexually Transmitted Infections*).

While vertical transmission of the HIV virus through perinatal infection has been greatly reduced, horizontal transmission rates, largely through unprotected sexual activity, have actually increased in recent years. Although horizontally-acquired infections occur more commonly among those aged between 25 and 39, who have accounted for over half of new diagnoses in recent years, significant numbers of young people under 24

years of age are infected horizontally. The following table illustrates how many people under 24 have been infected via different transmission routes since the beginning of the epidemic.

UK HIV diagnoses by transmission route and age group at diagnosis, all years until the end of June 2009¹

Age group (years)	Men who have sex with men		Men infected through heterosexual contact		Women infected through heterosexual contact		Injecting drug users		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
<20	658	1	120	1	847	3	226	4	4,364	4
20-24	4,744	10	906	5	3,698	13	880	17	10,716	10

The *Testing Times* report states that out of 745 young adults diagnosed with HIV in 2006, 13% (96) were classified as having been diagnosed late 'with a CD4 cell count below 200 cells/mm³). CD4 count can indicate time since HIV infection, with a low count being due to the progression of HIV within the body over an incubation period. In another data set, the HPA reports that 57 16-24 year olds diagnosed between 2005 and June 2010 were identified as having been vertically infected (prior to 2005, numbers are much lower). These figures are worth noting for several reasons:

- to understand that the physical impacts of HIV and HIV treatment upon young adults with HIV may vary widely, presenting clinicians in adults' services with different challenges;
- so as not to overlook individuals diagnosed at an older age who may have acquired HIV through vertical transmission but will not have been accessing paediatric care long-term; and
- to challenge assumptions about when and how horizontal transmission takes place: for example, some HIV infections will be a result of child abuse or early sex.

The range of experiences that young adults have of having acquired, found out about and lived with HIV, and of accessing HIV care and support, will be diverse.

The demographics of the young HIV population also changes with age. In terms of sex, both CHIPS and SOPHID report a more or less equal number of male and female patients in follow-up. However, CHIPS reports that

¹ <http://www.avert.org/uk-transmission-route.htm>. Only data relating to those under 24 years is represented here; the percentage figures relate to percentages of total diagnoses in people of all ages. The 'Total' figures include people infected through undetermined routes as well as those infected through other routes (including blood/tissue products and mother-to-child transmission).

around half of all children being followed up in the study were born outside the UK and Ireland, and that 79% of all children in the study are Black African. According to SOPHID, Black Africans accounted for 37% of 16-24 year olds accessing HIV care in 2009. The influence of ethnicity and culture, and also of majority or minority status within the cohort, on the experience of transition for young people living with HIV, therefore, is worth considering.

Ferrand, Miller and Jungmann in their article 'Management of HIV infection in adolescents attending inner London HIV services' (2007), report on the results of an audit of young people attending both specialist and generic HIV services in inner London during 2006. Their study found that 45% of the sample reported as being sexually active, with frequent non-disclosure of their HIV status to their sexual partners. This situation is reflected by Bernard's comment that, with increasing numbers of HIV positive children now growing into independent, sexually aware and active adults, both they and those advising and providing health care to them face '*complex challenges not anticipated a decade ago*' (Bernard 2008, p.3).

Policy and guidance on transition

'All young people are to have access to age appropriate services which are responsive to their specific needs as they grow into adulthood'
(Department of Health 2004, p.7).

This aspirational standard for transition is set by the *National Service Framework for Children, Young People and Maternity Services. Key issues for primary care* (Department of Health 2004). However the NSF acknowledges that currently when a young person is transferred from children's services support and care can be poorly coordinated and patchy in quality. It states that multi-agency transition planning for young people is key to providing high quality transition services. *You're Welcome quality criteria: making health services young people friendly* gives best practice guidance and states that services should have specially trained staffed and clear procedures to prepare young people for transition from an early age, with specific attention given to those with chronic, long-term conditions:

'Appropriate staff members are trained to help young people, and their parents or carers, with the transition to adult services from the age of 12 onwards'
(Department of Health 2007, p.8).

Young people should be offered appropriate information and advice, which is easy to understand, to help them make safe choices around sexuality and health. They should also be helped to develop the confidence and skills to negotiate relationships and to delay early sex and resist peer pressure. The Royal College of Nursing's *Lost in Transition: moving young people between child and adult health services* (2008) defines transition as the 'planned and purposeful' movement of adolescents and young adults from child-centred to adult orientated health care systems. Similarly, the Royal College of Paediatrics and Child Health, in *Bridging the Gaps: health care for adolescents* (2003) stresses the importance of careful preparation and planning, of consulting with, listening to and empowering young people in preparing them for this important transition in their lives. Similar points are made in *Bridging the Divide at Transition: what happens for young people with learning difficulties and their families* (BILD 2002). *Transitions: young adults with complex needs: a Social Exclusion Unit final report* recommended the following as principles of service delivery for young adults in transition:

- actively managing the transition from youth to adult services;
- taking the young person's 'thinking and behaviour' into account and building on it;
- involving young adults in designing and delivering services for them;
- the provision of effective information about services;
- information sharing between services;
- offering young people a trusted adult who could both support and challenge them

(ODPM 2005, p.87).

In practice there are longstanding concerns that the transition between children's and adult health and social care services often falls short of the 'seamless' and 'needs-led' ideal set out in guidance. In too many cases it can still more closely resemble the experiences described a decade ago in Morris's *Hurtling into the Void* (1999). This described the anxieties and uncertainties experienced by disabled children and young people during transition and commented on the failure of agencies to work in a needs-led and co-ordinated way. Nearly a decade later, *Transition: Moving on Well*, (Department of Health 2008), similarly acknowledged gaps in provision, with poor coordination and a lack of continuity and follow-up during the transition of young people. It noted that such experiences can have serious consequences for young people in terms of reduced or lapsed adherence to medication and self-care regimes. Reduced or lapsed adherence can in turn have serious consequences for their subsequent and long-term health. It can result in avoidable complications and additional costs to health services, as they seek to address conditions exacerbated by neglect (Department for Children, Schools and Families and Department of Health 2007).

For some groups of young people, such as those living with HIV, chronic health problems, disabilities or mental health issues, their transitions can raise a complex array of issues. These require a multi-agency and holistic response involving careful planning and coordinated support from a range of statutory and voluntary agencies. Both the *National Service Framework for Children, Young People and Maternity Services* (Department of Health 2004) and *Healthy Lives, Brighter Futures* (Department of Health and Department and Department for Children, Schools and Families 2009) emphasise the importance of supporting young people as they move between children's and adult services. Nonetheless, a SCIE research briefing on the transitions of young people with physical disabilities or those with chronic illnesses identified common themes as emerging from the literature on the subject. These common themes included:

- apprehension and anxiety amongst young people as they approach transition;
- issues around the changing roles of families and carers;
- the critical importance of ascertaining young people's views on effective models of care;
- their active participation in shaping services;
- the failure of different agencies to plan and work together

(SCIE 2004).

Guidance on transition and long term follow up services for adolescents with HIV infection acquired in infancy (Melvin, D and others (2005) states that good practice for transition involves careful individually-tailored preparation and planning which takes account of the individual young person's ability to understand and openly discuss their diagnosis. Support and age-appropriate information should be given at all stages on coping with the practical, social and emotional issues which commonly attend greater independence, including information on sexual health and development. The views and perspectives of the individual young person should be actively sought and

incorporated in the transition plan. Parents and carers should similarly be offered support and sources of further information and advice. As with transition planning for other groups of young people, the transition plan should be regularly reviewed, developed or changed according to changing need or to improve its efficacy for the young person. In line with other guidance and research on the subject of health transitions, Melvin's HIV-specific guidance states that transition should be seen and experienced as a *process* rather than a fixed point in time, requiring a flexible approach and a multi-disciplinary response based on the young person's individual needs, awareness and abilities (see Melvin and others 2005, p.7. see www.chiva.org.uk/publications).

Parallels with/learning from the experience of transitions by young people with other chronic illness and/or disabilities

'It seems to have come all of a sudden – he was a child – now all of a sudden everyone's pulling out and disappearing ... get used to being on your own'
(Abbott and Carpenter 2010, p.27).

The above comment, made by the carer of a young man with Duchenne muscular dystrophy, can too often reflect the individual's experience of transition between children's and adult services. Without adequate preparation it can seem abrupt and be experienced as traumatic. It finds an echo in the quote from a young woman living with HIV who felt that her children's hospital:

'almost literally chucked me out and told me I was too old to go there. And I was crying "where am I to go now?"...it was really scary going into the adults hospital cos I didn't know what to expect'
(Eaton, unpublished, p.58).

Morris (1999) observed that, for young people with high support needs and/or continuing health care needs, the feeling of 'abandonment' and loss of well-established and supportive relationships with paediatric staff could make transition very stressful. Furthermore, a major concern for many adults, both carers and professionals, as they progressively relinquish, or simply lose, control over the daily lives of vulnerable young people, is that they will cease to take best care of themselves. Often this anxiety may be rooted in the adult's own difficulty in allowing their child to move on, grow up and assume an independent, autonomous life. In the case of young people with disabilities, chronic illnesses or HIV however there are additional, specific and legitimate concerns and it is accordingly useful to look at what works best, and what is ineffective, in the provision of transition services to other groups of vulnerable young people with arguably similar issues. According to some specialists in paediatric HIV infection, learning gained from the transition experiences of other young people with chronic health problems has been insufficiently used:

'... knowledge of adherence problems from other chronic illnesses has not seemed to generalize, or forewarn clinicians of the difficulties in expecting young children and adolescents to adhere to complicated and unpalatable pharmacological regimes'
(Lewin and Melvin 2001, p.429).

The literature on diabetes care for young people stresses the critical role of personal responsibility and the self-management role of the individual concerned. Informed awareness, empowerment and active involvement in care are critical to success. This should be based on being given clear, age-

appropriate information on how to most effectively manage one's condition and how to avoid behaviour which might lead to complications:

'Young people cannot be empowered to take control of their own condition if they are not well informed and educated at a level that is appropriate for them as individuals. Information should be available through all media...' (Datta 2003a, p.201).

According to Datta 'all media' should include the internet and education should be seen as a continuous and interactive process. However information alone will rarely be enough at a developmental stage when most young people have many other competing priorities and may be resistant to attempts to make them conform to the advice and guidance of adults. Datta, in the research review *Young People with Diabetes* (2001) observes that many young people fail to attend clinic appointments in the period when their care is being transferred from the children's to the adult diabetes team, and adult care teams may in turn be less active than paediatric teams in following up such non-attendance. Nearly a decade later Owen and Beksine (2008) observed that the lack of pre-planned and supported transitional care for adolescents with diabetes, undertaken at an appropriate time and involving carers and young people can result in many young people 'dropping out' of the adult care system. This can in turn result in health deterioration and increased risk of clinical and psychiatric conditions. They recommended that it be made mandatory to contact all those young people who missed appointments. Similarly, the Royal College of Nursing (2008) recommends that when a young person fails to attend appointments, professionals should explore why, and if necessary consider different methods of accessing them.

In addition it is recognized that young people may require or benefit from different structures and arrangements, retaining some elements of continuity with paediatric services:

'Concern that young people's needs were not being met by a direct handover from paediatric to adult services has encouraged clinicians to develop transfer arrangements that include an element of continuity of care' (Datta 2001, p.2).

Such arrangements included joint clinics run by both paediatricians and adult physicians, allowing the young person to get to know the members of the adult care team without immediately losing all contact with paediatric staff. They may well have developed trusting relationships with the latter, built up over many years of attending paediatric services since childhood. It is suggested that joint clinics be run at times convenient for the young people and separate from other clinics, with specialist nurses available to offer advice. Datta (2003b) concluded that the specialist diabetes nurse's knowledge of young people and their families put them in a strong position to offer appropriate advice, ensuring the young person's active involvement but without demanding too much of them.

Kurtz and Hopkins (1996), in their early work on transition for the Royal College of Physicians, noted that young people may be put off attending clinics where there are either much older or much younger patients. They recommended that clinics be organised 'as far as possible' according to the age and interests of patients. Optimal practice in primary and hospital care is to provide access to a multi-disciplinary team incorporating a paediatrician with expertise in the specific illness, a specialist nurse with knowledge and experience of the condition's management and support, and a paediatric dietician and psychologist. Increasing the likelihood of successful transitions requires informal, flexible and individualized approaches to prepare adolescents for adulthood and adult services, based on the needs of the young person rather than the needs of the service (Royal College of Nursing 2008, Soanes and Timmons 2004). This is a point re-iterated throughout the research:

'Flexibility in the transfer process is important both for personal and developmental reasons and should take account of a young person's stage of physical development, emotional maturity and stated requirements' (BDA in Datta 2001, p.2).

The same points about the need for flexibility and a proactive multi-disciplinary delivery of services are made in the article 'Adolescents with Diabetes: a Health Action Zone project' (Cuttell 2004). Cuttell also states the need for health professionals to seek continuously to motivate adolescents, encouraging them to take responsibility and gain confidence in self-managing their health conditions.

McDonagh, addressing the topic of transitional care for young people with chronic illnesses and/or disabilities at a national conference convened by the Department of Health, the Royal Colleges and the Department for Skills and Education in 2006, identified the following as the key principles or components which should underlie *any* model of care. Transition care for young people with chronic illnesses and/or disabilities should be:

- an active future-focused process
- young person centred
- inclusive of parents /care-givers
- multidisciplinary and interagency.

In addition preparation should start early and it should:

- involve paediatric and adult services in addition to primary care
- provide co-ordinated, uninterrupted health care which is age and developmentally appropriate
- be culturally appropriate
- be comprehensive, flexible and responsive
- be holistic, with medical, psychosocial and educational/vocational aspects
- involve skills training for the young person in communication, decision-making, assertiveness, self-care and self-management

- enhance the young person's sense of control and interdependence in health care
 - maximise life-long functioning and potential
- (from McDonagh 2006, p.3).

McDonagh's list echoed the findings of an earlier multi-method review carried out for the NHS in order to identify the key components of practice for promoting continuity in the transition from child to adult care for young people with a chronic illness or disability. This earlier review emphasized the importance of factors such as:

- specific service provision;
 - development of self-management skills;
 - supported psychosocial development;
 - involvement of young people;
 - peer involvement; support for changed relationships with parents/carers;
 - provision of choice;
 - provision of information and focus on the young person's strengths for future development
- (from Forbes and others 2001, p.91).

Noting that there are various models of transitional care provision, McDonagh's presentation concluded that there was '*no robust evidence to support one model over another*'. She saw a need for more rigorous evaluations, as distinct from descriptive or subjective user accounts in assessing the relative effectiveness of various models. Nonetheless, some components of effective transition services *within* the various models were, in McDonagh's view, supported by stronger evidence, notably the value of young people meeting their adult doctors prior to transfer and of them having a key worker for case management. The value of training health professionals in adolescent health was also supported by evidence. Young people prioritised the qualities of honesty, respect, confidentiality and competence in medical staff whereas adults emphasised the importance of caring, communication and competence. As indicated above, McDonagh called for more research into, and objective evaluation of, models of good practice and their relative value and outcomes. She felt that more robust evidence was urgently needed as to the barriers to effective transitional care and the relative merits (including cost-effectiveness) of various models of good practice and service provision. Accordingly McDonagh emphasised that:

'... Such research must involve young people and their families and/or carers as well as paediatric and adult care providers in health, education social services and the voluntary sector if a true picture is to be realised' (McDonagh 2006, p.20).

Additional transition issues for young people living with HIV and those working with/caring for them

CHIVA (the Children's HIV Association of the UK and Ireland), an association of professionals committed to improving standards of care of children infected with or affected by HIV, has developed practice guidance and standards of care for infants, children and young people living with HIV. The *CHIVA standards of care for infants, children and young people with HIV* include standards dealing with managing disclosure (3.4), adherence support (3.5) and transition and optimal adolescent care for young people born with HIV (3.6). The latter standard confirms the relevance of following generic national guidance and in line with such guidance it re-iterates the need for an individualised transition plan, with a lead person to coordinate transition in both paediatric and adult services. Health and sex education, including the negotiation of safe sex and relationships should be integral to the transition plan and it refers professionals to further CHIVA guidance '*Sexual Health for Young People with Perinatally acquired HIV*' (HYPNet/CHIVA 2009).

Miles, Edwards and Clapson, in *Transition from paediatric to adult services: experiences of HIV-positive adolescents* also found that the components of effective transition were well-established from guidance and practice in many other areas of chronic disease management. The authors agreed that such guidance and practice might well be equally applicable to young people living with HIV, but added that HIV also presented additional and unique issues.

'The adolescent with HIV may have to face HIV associated stigma, issues surrounding new sexual opportunities, forced disclosure and the potential or actual loss of lifetime carers...'
(Miles, Edwards and Clapson 2004, p.305).

Stigma and disclosure

While more effective treatments do mean that HIV *could* now be seen as essentially 'just another chronic condition' requiring effective management, in practice the highly stigmatised status of HIV within our society still sets it apart from other chronic conditions (Geballe and Gruendel 1995, Bor and Elford 1998, Lewis 2001, Tisdall and others 2004, Ely 2006). This stigma generates additional anxieties and fears for young people already vulnerable due to their health issues, and may make the task of those promoting their health and well-being more complex and problematical.

Lewis (2001) states that the operation and internalisation of stigma are major obstacles to disclosure and to the timely accessing of services and support. Challenging stigma, breaking it down and educating people is a major goal for service providers and those with whom they work, including parents and young people. However Eaton, in her research for '*The Rights and Responsibilities of Children and Young people Living with or Affected by HIV/AIDS in Britain*', noted that, although such young people have a

uniquely valuable contribution to make in terms of challenging prejudice and stigma, fear of adverse social consequences can prevent this in some cases:

'... a lot of times you can stay quiet because you might think 'OK, they might ask me how do I know too much...'
(Eaton, unpublished, p.50).

Nonetheless other young people felt strongly that young people living with or affected by HIV should be encouraged to participate and contribute their insights in challenging prejudices, educating others and in improving services:

'young people need to have a voice and input in what is needed, cause there's no-one in a better position to say what young people need than young people themselves'
(Eaton, unpublished, p.59).

Talking to Children about their Health and HIV Diagnosis offers guidance to health care teams involved in the care of children and young people living with HIV in the UK. It makes clear that disclosure of the precise nature of the diagnosis is a pre-requisite for effective preparation for self-management. However it also acknowledges that communicating the exact nature of this condition to children and young people must be a flexible and gradual process, which takes account of differences in personal characteristics, maturity and the particular circumstances, the cultures and contexts of children's and parents'/carers' lives. Eaton found that young people and their families may have very well-founded concerns around confidentiality, social reactions, stigma and personal safety issues, which those seeking to work with them need to be aware of:

'because our community, you know, HIV is very taboo. And it's like people gossip ... say nasty things about it. So, for her, to have a child going through that, it's, it's heartbreaking for her'
(Eaton, unpublished, p.63).

Such gossip can contain very nasty things indeed:

'the reason you don't come to school is because you're dying, you've got AIDS'
(Eaton, unpublished, p.46).

Nonetheless the CHIVA guidance asserts that, whatever their cultural background, the process of involving and sharing knowledge is helpful to children and young people, provided they and their carers are supported:

'There is general agreement that conversations about health should start early so the naming of the diagnosis can occur before transfer to secondary school (for most children)'
(Melvin, Donaghy and Conway 2008, p.4).

The above guidance recommends how to best manage disclosure in stages which do not overwhelm the young person but which still openly respond to common anxieties about managing medication, confidentiality and sexual health concerns. CHIVA guidance and standards offer quality benchmarks and advice on allaying common fears about the condition, the future and even fears of dying prematurely. *Talking to Children about their Health and HIV Diagnosis* and *CHIVA standards of care for infants, children and young people with HIV* say the aim should be to re-assure and empower the young person to take more responsibility for their own health.

Other guides such as *'Where do I start? Talking to children with HIV about their illness'* also advises parents to take a step by step, age-appropriate approach to disclosure. They see such disclosure and talking about the diagnosis as pre-requisites for preparing the young person for adult life:

'Tell them what they need to know piece by piece. They don't need to know everything at once'
(Waugh and others 2003, p.6).

Where do I start? advises care in choosing the times and places for gradual disclosure, appropriate to the young person's age and level of maturity. The place should allow for privacy from interruption and allow time for questions and reassurance. It emphasises the importance of talking openly and being honest. It points parents and carers to where they can find support and information, for example from statutory health and social services and other agencies in the voluntary sector.

The CHIVA standards (3.4) and their guidance *Talking to Children about their Health and HIV Diagnosis* both confirm the professional consensus that disclosure should be a process which takes place over time, not a single event. It should involve a multi-disciplinary team approach with a lead worker co-ordinating work around disclosure with the family and young person.

Adherence

'Carrying an awareness of illness around can be something adolescents try hard to reject and forget As infected young people grow older and reach adolescence, finding ways of encouraging adherence requires medical care which complements rather than clashes with their lifestyle'
(Lewis 2001, p.84).

The increasingly unstructured lifestyles which some young people adopt during adolescence, with peers rather than adults assuming dominant guiding roles, can result in a breakdown in the self-discipline, responsibility and consistency required for medication and sexual health regimes to be effective. These may be experienced as onerous, unreasonable or simply disregarded. Exploring one's sexual, social and emotional needs may well seem far more pressing concerns besides which the seemingly distant health consequences may appear relatively unimportant or 'a risk worth taking'. For example, thinking ahead and remembering to take medication

with you if you may be staying out over a long period, a health requirement which also carries the social risk of other people accidentally discovering one's HIV status, can seem onerous for some adolescents who just want to 'get on with their own lives'. Moreover, as already indicated, young people living with HIV are required to be more disciplined and responsible than their peers with other chronic conditions:

'Adherence is the single most important factor in successfully treating HIV, and yet the optimal adherence required for anti-HIV therapy (95%) is much higher than levels that might be adequate for treating other long-term conditions'

(National AIDS Trust 2008, p.9).

Ely (2006) states that fall out in adherence amongst adolescents with HIV is particularly high, a finding confirmed in several other sources (Lewis 2001, Goode and others 2003, Lewin and Melvin 2006).

Talking to Children about their Health and HIV Diagnosis and CHIVA standards of care for infants, children and young people with HIV also reinforce the importance of impressing on young people the need for maintaining adherence to medication and self-care regimes. Standard 3.5 of the CHIVA Standards state that the success of antiretroviral medication is dependant on adherence to therapy and that without a high degree of adherence to the regime of treatment, drug resistance can develop rapidly. Young people and their parents/carers will need support and advice and should be able to discuss with health staff the medication, possible side-effects and how to handle any issues which might impact on adherence (such as the presence of others not aware of the young person's diagnosis).

Sexual health and preventing transmission

As already mentioned, mother to child perinatal transmission rates have been greatly reduced in Britain due to the availability of effective perinatal treatment with antiretroviral drugs, elective caesarean section delivery and the avoidance of breastfeeding (Ely 2006). However transmission of HIV through heterosexual contact is now the largest single transmission route with significant numbers of adolescents infected in this way.

Brown, Lourie and Pao, in their review of literature on children and adolescents living with HIV and AIDS noted adolescent-specific factors in risk-taking behaviour, such as cognitive immaturity and developmentally 'normal' exploratory learning behaviour. Factors such as impulsivity, the effects of distress and adverse life experiences, all common in this group, may compound such behaviours. Brown, Lourie and Pao found that studies indicated the need for targeted programmes of sexual health education which commonly seek to increase awareness of risk and susceptibility and strengthen the desire for safety. More contentiously they argue that:

'... more appropriate goals for infected adolescents are to increase empathy and the desire for responsible behaviour'

(Brown, Lourie and Pao 2000, p.88).

Desirable as empathy for others might be, as a clinical nurse specialist cited in *Growing Pains* pointed out, adolescents living with HIV have so many challenges, emotional needs and anxieties to cope with in a stigmatising society. If adults with no major traumas, health concerns or other insecurities to report find it hard to discuss sex and relationships with their prospective partners, how much more difficult is it likely to be for adolescents with HIV negotiating their very early relationships?

'It's difficult for adults, and it's even more difficult for young people that don't necessarily have the kind of skills to negotiate safer sex. You can provide all the safer sex education, but actually they need to have the confidence to carry it out'

(Susan McDonald in Bernard 2008, p.6).

Over a decade ago Crosby, writing in *Combating the illusion of adolescent invincibility to HIV/AIDS* (1996), expressed the optimistic view that the spread of the virus could be greatly reduced by targeting prevention programmes to adolescents with high-risk behaviours. Clearly this remains an aspirational and challenging area of sexual health promotion.

Rural (or other) areas with low numbers of young people living with HIV

Issues of stigma and isolation, and lack of access to specialist advice and services or the opportunity to talk to other adolescents sharing one's concerns, can be particularly acute for those living outside London or the big conurbations, especially in rural areas where numbers with diagnosed HIV are very low. According to *Growing Pains* (Bernard 2008) only three HIV clinics have set up transitional services – St Mary's in West London, Great Ormond Street/Mortimer Market in Central London and St George's Hospital in South London. As Maria Phelan points out in the same publication, since only around 60 per cent of HIV positive young people access HIV care in London, such services need to be extended in some way to cover those living in the regions – including extremely vulnerable asylum seeking children 'dispersed' by government immigration policy away from the capital and their potential informal support systems in communities there.

Guidance developed by the Royal College of Physicians of Edinburgh, *Think Transition: developing the essential link between paediatric and adult care* (RCPE 2008) recognised the specific issues confronting remote/rural healthcare services and considered various strategies – for example managed clinical networks supported by specialist centres, or the use of devices such as 'telemedicine' – to access expert remote regional advice and support.

Conclusion

Without preparation, knowledge and support the transition of young people living with HIV between children's and adult services can be made even more difficult than for other young people with chronic conditions requiring ongoing care. The very different ethos and clientele of children's and adults' clinics and services can come as a real shock to adolescents and may lead to them dropping out of their essential care regimens. Miles, Edwards and Clapson's study (2004) found that many young people interviewed were simply not prepared on transition for the predominantly gay male population they encountered at adult clinics and were disappointed at not seeing other adolescents there. Moreover Miah, writing in *Talking with Children, Young People and Families about Chronic Illness and Living with HIV* (2004), says that many young people often feel they cannot freely ask questions about their medication and that, even if they do so, the language which adult services professionals use in response can be either patronising or too technical. They can feel disempowered when talking to clinical or medical professionals. Young people may have been attending paediatric units for most of their childhood and feel the loss of these long-term relationships with more child-friendly staff keenly:

'Whereas with my old doctor I could tell him anything I wanted 'cos I've known him for a long time and so therefore it's just getting the confidence to like start up'

(Miles, Edwards and Clapson 2004, p.310).

Ely, in *Looking After HIV: considering the needs of HIV positive looked after children* (2008) found that there was a widespread lack of awareness and understanding about HIV amongst health and social care staff who are not HIV specialists. She also found a lack of specialist advice, support and training for many young people, for their parents and carers, and also for the professionals and social care staff working with them. Widespread misinformation and stigma prevented young people from seeking and receiving the support they need, leaving them isolated at a highly vulnerable time. Professionals, carers and organisations struggled to fully appreciate the impact of stigma and the psychological and emotional issues arising for a young person from an HIV diagnosis. Professionals and social care workers often lacked access to training and the clear organisational guidance necessary to help them in resolving the ethical and risk-management dilemmas and tensions sometimes presented. Issues such as information sharing and the duties and limits of confidentiality could be problematical for staff, as could risk management concerns, for example how to proceed where an adolescent with whom they work is known to be putting partners at risk through engaging in unprotected sex.

Guidance on transition and long term follow up services for adolescents with HIV infection acquired in infancy states that good practice for transition involves applying the following principles throughout the process:

- Preparation (gradual to allow the young person and family to prepare themselves and including an individually tailored transition plan)
- Progress will be limited by the extent of the young person's awareness of, and hence their ability to fully understand and openly discuss their HIV diagnosis. Their level of awareness and its impact on decision-making needs regular review
- Support for both the practical and emotional issues arising with greater independence
- Identifying how to provide new information e.g. on sexual development and sexual health
- Providing systematic evaluations as well as needs led approaches
- Regular evaluations of the young person's perspective, views which should be incorporated as an essential element in transition plans
- Provision of support to parents/carers during the transition process (see Melvin and others 2005, p.7. see www.chiva.org.uk/publications).

As with other guidance and research on the subject of transition, the above guidance states that transition should be seen and experienced as a process rather than a fixed point in time, requiring a flexible approach and multi-disciplinary response based on the young person's individual needs, awareness and abilities. Phelan, in Bernard 2008 highlights four key areas where young adults infected early in their lives need particular support:

- Communications: good communication between paediatric and adult services
- Life skills work to enhance self-esteem and the confidence to independently negotiate safe sex and relationships
- Care management – coordinating mental, psychological and behavioural aspects in young person's care
- Peer support and support for the family support network in 'letting go'.

'You can't just expect young people to handle the leap on their own, there needs to be something in place.....young people might need more time than other adults'

(Maria Phelan in Bernard 2008, p.7).

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