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# LOST IN TRANSITIONS

Current issues faced by adolescents living  
with HIV in Asia Pacific



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# ACKNOWLEDGMENTS

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This report was written by Caitlin L. Chandler and Attapon Ed Ngoksin. The United Nations Children’s Fund’s East Asia and Pacific Regional Office and South Asia Regional Office generously provided funding for this report. The Asia Pacific Regional Bureau for Education of The United Nations Educational, Scientific and Cultural Organization also provided support for in-country focus group discussions that contributed to the report.

We are grateful for the time, ideas and wisdom shared by the many individuals and institutions who contributed to this report. Sincere thanks to Chanthorn Phorng and Vikas Ahuja for undertaking interviews in Cambodia and India. Special thanks to: Dr. Paula Bulancea, United Nations Children’s Fund; Rico Gustav, Asia Pacific Network of People Living with HIV (APN+); Bettina T. Schunter, United Nations Children’s Fund; Justine Sass, United Nations Educational, Scientific and Cultural Organization; Scott McGill, Save the Children; Dr. Annette Sohn, TREAT Asia/amfAR; Jo Sauvarin, United Nations Population Fund; Himakshi Piplani, HIV Young Leaders Fund; and Vermont Aversu, APN+ consultant and a member of Y+ Advisory Group of the Global Network of People Living with HIV.

It would have been impossible to interview so many adolescents, caregivers and medical professionals at the community-level without the help of networks of people living with HIV and community-based organizations who provided introductions. In Nepal, thanks to the entire team at Nava Kiran Plus and the National Association of People Living with HIV, and in particular Sudhir Paky and Nikhil Gurung for their invaluable insights and support during our visit. In Cambodia, thanks to Greg Gray and Chanthorn Phorng. In India, thanks to Loon Gangte and Vikas Ahuja of the International Treatment Preparedness Coalition South Asia. In Lao PDR, thanks to Lao Positive Health Association (LaoPHA), in particular K’ Vieng and his entire team. In Thailand, thanks to TREAT Asia, Raks Thai, and in particular K’ Jom and K’ Na.

Sincere thanks also to the hosts of focus group discussions in four countries, including Pinoy Plus and Youth AIDS Filipinas Alliance in the Philippines; Igat Hope Inc in Papua New Guinea; National Association of People Living with HIV and AIDS and the National Federation of Women Living with HIV and AIDS in Nepal; and Raks Thai Power Teen Peer Support Group in Thailand.

Thank you to the caregivers and doctors who took time out of their busy schedules to discuss their experiences and recommendations with us, including Dr. Virat Sirisanthana and Nurse Nongyao in Chiang Mai; Dr. Saykham and Nurse Linda in Vientiane; Dr. Sos Mary in Cambodia; Dr. Susheil in Nepal; and Dr. JC Dash in India.

And most of all, thank you to the adolescents and young people who shared their stories, ideas and perspectives with us either in-country or at the *My Right to Health* consultation. This report is for you.

## ACRONYMS & TERMS

AIDS	Acquired immune deficiency syndrome
ALHIV	Adolescent/s living with HIV
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral (medications)
CABA	Children affected by AIDS
CBO	Community-based organisation
CRC	Convention on the Rights of the Child
FGD	Focus group discussion
GFATM	The Global Fund to fight AIDS, Tuberculosis and Malaria
HTC	HIV Testing and Counselling
MSM	“Men who have sex with men” or “males who have sex with males” (either term is intended to include adolescents)
M&E	Monitoring and evaluation
NGO	Non-governmental organization
NSP	National Strategic Plan
OI	Opportunistic infection
OVC	Orphans and vulnerable children
PEPFAR	President’s Emergency Plan for AIDS Relief
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission <sup>a</sup>
PNG	Papua New Guinea
PWID	People who inject drugs
STI	Sexually transmitted infection
SRH	Sexual and reproductive health
SRHR	Sexual and reproductive health and rights
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNFPA	United Nations Population Fund
UNICEF	United Nations Children’s Fund
UNDP	United Nations Development Programme
WHO	World Health Organization
YPLHIV	Young person/people living with HIV

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a Also referred to as parent-to-child-transmission or vertical transmission.

# KEY CONCEPTS

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6. **Adolescent:** Person aged 10 to 19 years, according to the United Nations<sup>1</sup>

**Child:** Under the *UN Convention on the Rights of the Child, 1989*, a child is a person under 18 years of age, unless under domestic law the child reaches majority at an earlier age.

**Young person:** Person aged 10 - 24, according to the United Nations<sup>2</sup>

**Children affected by HIV and AIDS (CABA):** Children living with HIV, and children whose well-being or development is threatened by HIV and AIDS in their families or communities,<sup>3</sup> as defined by UNICEF, UNAIDS and PEPFAR.

**Orphans and vulnerable children (OVC):** Children affected by HIV as a result of living in a household where one or more people are ill, dying or deceased due to AIDS, as defined by UNICEF, UNAIDS, PEPFAR and other partners<sup>4</sup>

**Adolescents who are perinatally infected:** Adolescents who acquired HIV during the gestation, birth or breastfeeding period.

**Adolescents with acquired HIV:** Adolescents who became HIV-positive due to unprotected sex or unsafe injection drug use, and in a very limited number of cases due to unsafe medical procedures.

**Harm reduction:** According to UNAIDS, "Policies, programmes, and approaches that seek to reduce the harmful health, social, and economic consequences associated with the use of psychoactive substances... Harm reduction is a comprehensive package of evidence-informed programming for people who use drugs. The nine components in the package are: opioid substitution therapy; HIV testing and counselling; HIV care and antiretroviral therapy for injecting drug users; prevention of sexual transmission; outreach (information, education, and communication for people who inject drugs and their sexual partners); hepatitis diagnosis, treatment, and vaccination (where applicable); and tuberculosis prevention, diagnosis, and treatment."

**Key populations at higher risk of HIV exposure:** According to UNAIDS, refers to "those most likely to be exposed to HIV or to transmit it - their engagement is critical to a successful HIV response: i.e. they are key to the epidemic and key to the response. In all countries, key populations include people living with HIV. In most settings, men who have sex with men, transgender persons, people who inject drugs, sex workers and their clients... Each country should define the specific populations that are key to their epidemic and response based on the epidemiological and social context."<sup>5</sup>

**IMPORTANT NOTE:** While this report primarily focuses on adolescents aged 10 - 19 years old, it is important to note that many programmes and studies in the region focus and report on youth, aged 15 - 24 years; young people, aged 10 - 24; or other age categories deemed relevant to the local context. Therefore it is sometimes necessary to include relevant information on youth or young people, which may incorporate but are not limited to the age range of 10 - 19. In the report, we use the most appropriate term for the age group we are referring to according to the above definitions.

# EXECUTIVE SUMMARY

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Across the Asia Pacific region, adolescents aged 10 – 19 years who are living with HIV face unique challenges as they transition from childhood to adolescence and into adulthood.

This report aims to document and capture some of the experiences of adolescents living with HIV as they disclose their HIV status, deal with life-long antiretroviral treatment (ART), move from paediatric to adult health care services, navigate sexuality and relationships and build their independent lives. It also seeks to offer insights into some of the unique issues adolescents living with HIV face, such as pervasive stigma and discrimination.

Through a review of available information regarding HIV programs and policies for adolescents, including information obtained from an in-person, youth-led regional consultation “*My Right to Health*”; youth-led focus group discussions in four countries; and in-person interviews with 45 adolescents, medical practitioners, caregivers and social workers in five countries, the report details significant gaps in how communities and governments are addressing the needs of adolescents living with HIV.

It is clear that much can be done to better support adolescents living with HIV to ensure their health and well-being. This report offers a clear call to action for community organizations, networks of people living with HIV, youth organizations, policymakers, programmers, governments, donors and all interested parties working towards adolescent health and rights. Recommendations include:

- The need to invest in **better data, better analysis of existing data, and more operational research**, including the creation of data systems to track perinatally infected children through adolescence and into adulthood; and data that helps policymakers and programmers better understand how they can systematically support those who have acquired HIV during adolescence.
- **Holistic, age-appropriate, confidential and non-judgemental health services** for adolescents living with HIV, including a transition process for adolescents moving from paediatric to adult health care services; more peer support services to address treatment adherence and education, as well as mental health; sexual and reproductive health services and commodities; opportunistic infections management; primary health care; testing and linkages to care for adolescents from key populations; and harm reduction, including opioid substitution therapy for adolescents who use or inject drugs.
- Work to give adolescents living with HIV the **best possible treatment and related care**, including better paediatric formulations from birth; accessible, affordable, optimal and uninterrupted first, second and third line ARVs; the phase out of sub-optimal treatment regimens (such as d4T) that cause difficult side effects; age-appropriate treatment education; and regular access to diagnostics and monitoring tests for HIV, other opportunistic infections and co-infections.

- Ensure access to **sexuality education that meets the needs of adolescents living with HIV** and work to address the anxiety, fear and complex emotions some adolescents living with HIV face around sexuality and their reproductive options through counselling, peer support and role model programs.
- Help create a better social environment for adolescents living with HIV through: supporting the **disclosure process** from caregivers to children at younger ages; more age appropriate **livelihood opportunities** for older adolescents living with HIV; **safe housing** for adolescents without families or stable living arrangements; and policies and programs to **turn schools and education settings into safe spaces**.
- Enable adolescent **leadership and participation; supporting peer-led interventions or pairing emerging adolescent living with HIV leaders with more experienced or older PLHIV leaders;** and strengthen community systems to allow adolescents living with HIV to develop their skills and capacities in research, service provision and advocacy.



# INTRODUCTION

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An estimated 35.3 million people are currently living with HIV around the world. UNAIDS estimates that in 2012, globally, there were 2.1 million adolescents 10 - 19 living with HIV.<sup>6</sup>

In Asia Pacific, an estimated 230,000 children under 15 years of age were living with HIV in 2012, with approximately 25 percent of them receiving antiretroviral therapy (ART).<sup>7</sup> The paediatric HIV epidemic is entering the next phase of its evolution in the region, as children infected from birth enter adolescence and face new challenges. These adolescents living with HIV are now dealing with the complex social, economic, mental and developmental consequences of life-long HIV and ART. Having been infected before development of their immune systems and experienced in many cases sub-optimal ART options and formulations, they are facing the transition from complete dependence on their guardians to becoming their own caregivers.

At the same time, other adolescents in Asia Pacific are acquiring HIV through unprotected sex or drug use that involves contaminated injecting equipment. According to UNAIDS 2013 estimates, approximately 58,000 new HIV infections occurred in adolescents aged 10 -19 in Asia Pacific in 2012.<sup>8</sup> Many adolescents in the region lack the information, education, services and supportive environment to prevent HIV transmission. A significant number of countries in the region have age of consent laws that prevent the majority of adolescents from independently seeking HIV testing and counselling - a key gateway to HIV prevention, treatment, care and support. As a result, late diagnosis of HIV infections and poor health outcomes among adolescents living with HIV are common.<sup>9</sup> In addition, key populations at higher risk - such as adolescent males who have sex with males, adolescents who sell sex, and adolescents who inject drugs with contaminated injecting equipment - face additional challenges to HIV treatment, care and support. Due to the legal environment that criminalizes their behaviour in many contexts, these adolescents often do not seek out health services due to fear of prosecution for their behaviour; stigma and discrimination from health care providers; and absence of specific health services to meet their needs such as harm reduction for adolescents who use drugs and healthcare for adolescent transgender people. In addition, adolescents from key populations at higher risk may experience homelessness, unemployment and financial insecurity, lack health insurance, and be more vulnerable to harassment or verbal or physical abuse by law enforcement, clients (in the case of adolescents who sell sex) and even within families.<sup>10</sup>

Health and development experts broadly recognize adolescence as a unique time of transition, during which a person's access to health, education and other social services including social protection is critically important. Although there is considerable information from Sub-Saharan Africa, Western Europe and the United States, few studies in the Asia Pacific region have focused on the attitudes, knowledge and coping mechanisms of adolescents living with HIV. There is currently no global surveillance system to track children living with HIV over time; as a result there is no available information about how many children infected at birth are surviving into adulthood. It is also difficult to know how many adolescents 10 - 19 in Asia Pacific are living with HIV overall or how many are accessing treatment.

In addition, it is important to note that many regional health programmes and studies focus and report on children aged 0 – 15, adolescents aged 10 – 19, youth aged 15–24 years, and/or young people aged 10 – 24.<sup>b</sup> Different countries have their own understandings of children, adolescents and youth. As a result of these broad and overlapping age categories, data specific to adolescents are often subsumed in other age-ranges.

Despite limited data, children living with HIV who do not die from AIDS-related illnesses will eventually enter adolescence, and some captured in the 0 – 15 age bracket have already entered adolescence. We also have enough information to know that significant numbers of adolescents are acquiring HIV. Information obtained by APN+ for this report points to serious health and social service gaps in meeting the needs of adolescents living with HIV. While some countries in the region have recently taken commendable steps to make their youth-oriented prevention efforts more attuned with key populations at higher-risk; adolescents living with HIV are a missing component of national and regional treatment, care and support strategies.

A global survey of organizations working with adolescents and young people living with HIV found that reasons for policy disengagement on adolescent issues included: lack of recognition of the specific needs of adolescents, inadequate understanding of the developmental impact of HIV on older children and its ongoing or longer-term impact on adolescents, and insufficient appreciation that existing guidelines and regulations can actually impede access to health services.<sup>11</sup>

Now is the time for policymakers and programmers in the Asia Pacific to ensure adequate investment in programmes and interventions that address the specific needs of adolescents living with HIV, including through designing or scaling-up age-appropriate health and support services for adolescents living with HIV. In addition, existing networks of people living with HIV should strengthen their capacity to reach out and provide support to adolescents.

### ***The focus of our report***

This report is intended to serve as an advocacy tool for organizations and individuals working to improve the health and well-being of HIV-positive adolescents aged 10 - 19 in Asia Pacific. Drawing on strategic information obtained through several processes, it highlights five pressing issues affecting adolescent health:

- 1) Disclosure of their HIV status
- 2) Navigating healthcare systems
- 3) Dealing with life-long treatment
- 4) Sexuality and sexual and reproductive health
- 5) The social environment

Recommendations for how to address these issues draw on published literature but also the suggestions of adolescents, doctors, nurses, social workers and caregivers, who confront these questions every day.

The Asia Pacific region is large and extremely diverse, comprising 56 countries<sup>12</sup> and 3,200 languages.<sup>13</sup> In addition, the countries in the region vary in terms of levels of development, types of government and political conditions, including conflict and post-conflict situations. This report

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<sup>b</sup> While the Convention on the Rights of the Child (CRC) defines children as 0 - 18, unless majority of consent is obtained earlier, many countries in the region report HIV infections in two categories: child 0 - 15 and adults 15 - 49.

is not able to cover each individual country, but attempts to include as many country examples as possible and to highlight regional and sub-regional trends, especially in countries with concentrated and generalized epidemics. Central Asia is the only sub-region in Asia that is excluded in this analysis, as it is not part of the Asia Pacific Network of People Living with HIV (APN+).

### Overview of the report methodology

Information was obtained from APN+ through multiple sources; a desk-based literature review; an in-person youth-led consultation, *My Right to Health*, in 2013 with 14 adolescents and young people; youth-led focus group discussions in Papua New Guinea, Viet Nam, Thailand and the Philippines; and in-person interviews with 45 adolescents, medical practitioners, caregivers and social workers in Cambodia, India, Lao PDR, Nepal and Thailand. The box below illustrates the different questions APN+ set out to address and the sources of information utilized for this report. For additional information, please see Methodology Annex II.

### Different sources of information for this report

#### Gaps to be addressed:

- How do ALHIV experience treatment, care and support in the region, as well as other issues such as stigma and discrimination, leadership development, and so on?
- What do caregivers, medical providers and community-based organizations working with ALHIV see as the main challenges for ALHIV health and well-being?
- What do ALHIV recommend to improve the current situation?
- How are policies and programs in the region responding to the needs of ALHIV, especially in the key areas of disclosure of HIV status, support for transition, dealing with life-long treatment, facilitating uptake of care, sexual reproductive health services and promoting leadership and advocacy?
- What are some case studies or best practices of how community-based organizations are addressing ALHIV health and well-being?

Source(s) of information	Process
<b>Focus group discussions (FGDs)</b> in four countries with ALHIV and YPLHIV (not always possible to identify younger ALHIV to participate): Nepal, Papua New Guinea, Thailand and Viet Nam	Standard FGD guide and methodology; FGDs hosted by community-based organizations working with ALHIV and PLHIV networks
<b>In-depth interviews</b> with ALHIV, caregivers, medical providers and community-based organizations in Cambodia, Lao PDR, Nepal and Thailand	Interview subjects identified by community-based organizations and PLHIV networks, with attention paid to gender, age and socio-economic diversity whenever possible
<b>My Right to Health Consultation</b> , February 2013, Bangkok, Thailand, which brought together 14 adolescents and young people from Cambodia, India, Malaysia, Pakistan, Philippines, Papua New Guinea, Thailand and Viet Nam	Adolescents and young people identified to participate through national networks of PLHIV; youth-led consultation in Bangkok with two days for youth participants only and a third day of dialogue between participants and regional stakeholders
<b>Desk-based literature review</b> of published studies and program and policy guidance, focusing on countries with documented generalized and concentrated epidemics including: Cambodia, China, Fiji, India, Indonesia, Lao PDR, Nepal, Thailand, Pakistan, Papua New Guinea and Viet Nam	Search terms, databases, inclusion and exclusion criteria developed and implemented. <i>Further details in Methodology Annex 2.</i>
<b>Site visits</b> in Cambodia, Lao PDR, Nepal and Thailand to visit programs of community organizations supporting ALHIV	Organizations recommended through APN+ and its partners. Program examples are used throughout the report to demonstrate best practices and lessons learned

While we do make some distinctions in the report between adolescents who are perinatally infected and adolescents who acquire HIV (**see Table I**), it is also important to ensure that programmes and services for adolescents living with HIV are inclusive of these different needs and do not create divisions between the two groups.

Policy and programme frameworks must create enabling environments for all adolescents living with HIV to access essential services regardless of the route of infection. In some cases, adolescents with acquired HIV are lost to healthcare systems; they may not know they are infected, may not return for services after testing positive, and therefore may not be accessing treatment when needed. This difficulty in identifying adolescents with acquired HIV was experienced during site visits and interviews, and one major limitation of this report is that we were not able to reach many adolescents with acquired HIV for in-country interviews. More work is urgently needed to capture their voices and experiences.

Within the broader category of adolescents living with HIV, some groups are more vulnerable to poor health outcomes than others, including adolescents without parents or caregivers; those who live on the street, sell sex, or use drugs; males who have sex with males; transgender adolescents; and in many contexts, young women and girls. They require special programmatic attention in order to ensure their inclusion in care and support programs.

Throughout this report, we share examples of successful, community-based programmes to improve the health of adolescents living with HIV, including youth-led initiatives. We also attempt to capture the perspectives and voices of adolescents as much as possible.<sup>c</sup> This is their reality.

**TABLE I. Predominant characteristics of adolescents living with HIV in Asia Pacific that should inform the development of policies, programmes and approaches to social and clinical service delivery\***

Perinatally infected	Acquired HIV during adolescence
More likely to be in advanced stages of HIV	Earlier stages of HIV
More likely to have opportunistic infections	Fewer opportunistic infections
More likely to not be on first-line drugs and in need of complex ART regimens	Less likely to need ART or more likely to be on first-line regimens
Higher risks of complications during pregnancy	Lower risks of complications during pregnancy
Higher mortality rates	Lower mortality rates
Less likely to know HIV status, although may have been on treatment for longer periods	If accessing HIV-related services, likely to know their status.
More likely to have experienced multiples losses related to HIV (parents, siblings, etc.)	More likely to lack familial, clinical, and social support systems
Higher risk of long-term chronic diseases early in life	Higher risk of long-term chronic diseases later in life
Experience stigma early on in life: in family, at healthcare settings, schools, etc.	Experience stigma later, usually post-diagnosis but exacerbated by social stigma related to drug use, sex work or sex between men and repressive laws/legal environments if they practice any of these behaviours

**\*Chart adapted from USAID & PEPFAR**, Transitioning of care and other services for adolescents living with HIV in Sub Saharan Africa, Technical brief, 2012. Access at: [http://www.aidstar-one.com/sites/default/files/AIDSTAR-One\\_TechnicalBrief\\_ALHIV\\_Transition.pdf](http://www.aidstar-one.com/sites/default/files/AIDSTAR-One_TechnicalBrief_ALHIV_Transition.pdf)

<sup>c</sup> All names have been changed to protect the identity of adolescents interviewed; unless interviewee was over 18 and/or specifically requested we use his/her real name.

# A REGIONAL OVERVIEW

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In 2012, there were an estimated 2.3 million new HIV infections worldwide, and 780,000 of these cases were among adolescents and youth aged 15 - 24.<sup>14</sup> An additional 1,000 new cases of HIV were diagnosed each day in children under 15 years of age; the majority due to vertical transmission. A small percentage was also the result of sexual transmission through sexual abuse or early sex, sometimes coerced.<sup>15</sup>

Asia Pacific is home to an estimated 180,000 children under 15 years of age who live with HIV.<sup>16</sup> Although approximately 90 percent of children in the region were infected through vertical transmission<sup>17</sup>, some children acquired HIV or Hepatitis C through use of contaminated injecting drug equipment. Other children also acquired HIV through unprotected sex. In recent years, a small number of cases of HIV transmission due to unsafe medical practices and procedures were also reported in China, India, Thailand and Viet Nam.<sup>18</sup>

## ***HIV infection is on the rise among adolescents from key populations***

With regard to adolescents and youth aged 15 - 24, 95 percent of new HIV infections in the region occur among those at higher risk of HIV exposure: young people who inject drugs, young men who have sex with other men, and young people who sell sex.<sup>19</sup> The age at which young people start to engage in behaviours that place them at higher risk of HIV is diverse and varies by country and context, but evidence shows some begin high-risk behaviours during adolescence.

For example, among one sample of sex workers in India, 17 percent reported starting to sell sex under the age of 15, and the median age reported among a sample of female sex workers in the Maldives and Papua New Guinea was 17 - 19 years. In Pakistan, a sample of *hijras* (transgender persons) and male sex workers reported entering sex work at a mean age of 16 years. In a survey of people who inject drugs in India, 21 percent reported initiating injecting drug use between 17 - 18 years of age.<sup>20</sup> In Thailand, one study found high levels of HIV risk behaviour reported among young men who have sex with men aged 15 - 24, including inconsistent condom use during receptive anal intercourse, a self-reported history of STIs and a history of sexual coercion.<sup>21</sup>

## ***Repressive legal environments prevent adolescents from accessing health services***

Late diagnosis and poor treatment outcomes among adolescents living with HIV are not uncommon across the region, especially among those who acquired HIV during adolescence.<sup>22</sup> One reason for this is the legal and policy environment. A forthcoming study on laws and policies affecting young people's access to sexual and reproductive health and HIV services in Asia Pacific reveals that related laws and policies in most countries in this region are unclear or ambiguous, and sometimes conflicting about the HIV testing of minors, in particular about who is authorized to give informed consent and under what conditions.<sup>23</sup> In some cases, the age at which a minor may give consent to a HIV test is actually higher than the legal age for which they can consent to sex or marriage, terminate a pregnancy, or vote. Legal and policy restrictions, such as parental consent for minors to access HIV testing (e.g., Cambodia - 18, Fiji - 18, Viet Nam - 16 years) and age restrictions on access to effective harm reduction strategies for adolescents who use drugs, such as access to opioid substitution therapy and needle exchange programmes (e.g., China and Viet Nam), represent major barriers to uptake of HIV prevention, testing and treatment programmes.<sup>24</sup>



## **Not all governments in the Asia Pacific region are meeting their commitments**

Nonetheless, there is strong consensus among governments in the Asia Pacific region to improve the quality, accessibility, availability and scale of health services for adolescents living with HIV. Most countries in the region endorsed a document from the 2011 United Nations General Assembly High Level Meeting on HIV which explicitly committed countries to *“develop and implement strategies to improve infant HIV diagnosis, including through access to diagnostics at point-of-care, significantly increase and improve access to treatment for children and adolescents living with HIV, including access to prophylaxis and treatments for opportunistic infections, as well as increased support to children and adolescents through increased financial, social and moral support for their parents, families and legal guardians, and promote a smooth transition from paediatric to young adult treatment and related support and services.”*<sup>25</sup>

However, clearly more effort is required to translate these commitments into programmatic actions. There are numerous of programmes targeting orphans and vulnerable children in the Asia Pacific region, ranging from the provision of social welfare through Viet Nam’s Continuum of Care sites to China’s educational assistance programme.<sup>26 27</sup> Yet few Asia Pacific countries address the emerging challenges pertaining to paediatric-adolescent-adult transitions in healthcare settings, or the sexual and reproductive health needs of adolescents living with HIV in their national programmes.

Worse, data in many Asia Pacific countries has not been disaggregated to show how many adolescents aged 10 - 19 are accessing HIV treatment. Most treatment indicators for HIV National Strategic Plans (NSPs) report back against two age brackets: children, defined as 0 - 15, and adults, defined as 15 and up. Failure to disaggregate treatment data by age contributes to a lack of understanding as to how adolescents have different needs from children and adults. In addition, adolescents may be diagnosed at a much later stage from when they acquire HIV, and hence not be adequately captured in existing data.<sup>28</sup>

## **HIV treatment coverage among children is still extremely low**

The largest national treatment programme for children under 15 years of age in Asia is in India, where 22,896 of an estimated 97,000 children living with HIV were on ART in 2010 (high estimates).<sup>29</sup> While adults in some states in India had access to ART from April 2004, it was only in December 2006 that ART was made available to children.<sup>30</sup> In the same period, an estimated 13,000 children were living with HIV in Thailand, with 7,800 (low estimate) to 10,920 (high estimate) reported to be receiving ART.<sup>31</sup> Thailand is considered to be the most advanced country in the region with regards to paediatric HIV treatment coverage, introduced in the form of efficacy trials in 1997, and then offered as routine service by 2002.<sup>32</sup>

Combined, both countries constitute about 54 percent of the overall population of children and young adolescents living with HIV in Asia Pacific.<sup>33</sup> Other countries have unacceptably low rates of treatment coverage for children and adolescents, as well as extremely low uptake of prevention of mother-to-child transmission (PMTCT) services. Nepal, for example, had an estimated 3,100 (high estimate) children living with HIV in 2010, with only 279 (9 percent, low estimate) children accessing ART<sup>34</sup> and only 4 percent (low estimate) of HIV-positive pregnant women accessing the national PMTCT programme as of 2011.<sup>35</sup>

## **National strategies, programmes and resources lack focus on adolescents**

The extent to which HIV National Strategic Plans (NSPs) address issues pertaining to adolescents living with HIV varies from country to country, but from a quick assessment of the current NSPs of 10<sup>36</sup> selected countries with both generalized and concentrated epidemics conducted

by the authors of this report (**see Table II**), only Myanmar recognizes the needs in the area of continuum of care for children living with HIV who are transitioning into adulthood. This includes the provision of on-going treatment, care, and support; psychosocial and spiritual support; livelihood and economic empowerment; and food and nutrition. Contrast this with countries such as Bangladesh, Fiji, Indonesia and Lao PDR, which only recognize the needs of adolescents living with HIV within the broader population of PLHIV and children affected by HIV.

From 2002 - 2010, The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) contributed 2.4 billion USD to HIV programmes in the Asia Pacific region, with an estimated 330,000 orphaned and other children affected by AIDS, including those living with HIV, benefiting from the GFATM-supported programmes for treatment, care and support.<sup>37</sup> Countries such as India have traditionally included paediatric treatment in their HIV grants, including GFATM Rounds 2, 4 (including the Rolling Continuation Channel), 6, 7 and 9. Other countries often focus solely on delivery of ART for women through PMTCT programmes (for example, Myanmar, Round 3), targeted prevention interventions for young people and key populations at higher risk for HIV exposure (for example, Bangladesh, Rounds 2 and 6) or provision of treatment for all PLHIV without differentiating between the needs of children or adolescents living with HIV in their programmatic approaches or monitoring and evaluation indicators (for example, PNG, Round 4).

Under GFATM grants in Cambodia, Lao PDR, Nepal and Thailand, there has been a specific focus on the needs of orphans and vulnerable children (OVC), a term meant to include children living with HIV. Nepal has initiated the development of a more robust social protection policy, highlighting support for children living with and affected by HIV through women-centred programmes to reduce economic and social vulnerability, family support for children affected by AIDS (i.e., CABA, another term meant to include children living with HIV) and the standardization of services at orphanages for CABA, including cash transfers (included in GFATM Round 10) - although many of these have yet to be implemented at the time of writing this report. Cambodia has prioritized impact mitigation with a focus on protecting, caring and supporting OVC through strengthening PLHIV-led groups that provide home-based care (Round 7). Despite being a low-prevalence country, Lao PDR under the OVC component in its GFATM programme (Round 8) focuses on the development and distribution of guidelines on comprehensive care and support for children infected and affected by HIV, including basic psychosocial work, case management and counselling, as well as trainings for medical providers on these guidelines.

More comprehensive GFATM-funded programmes for children and adolescents include the recent grant for Thailand (Round 10), which highlights increased access to essential child-focused services for children and young people living with and affected by HIV through strengthened social protection laws and policies alongside community systems strengthening.<sup>38</sup> The Thai programme recognizes the importance of empowering young people living with HIV to provide psychosocial support to their peers in areas including adherence, disclosure and sexuality, with a specific focus on effective care in the transition period between adolescence and adulthood. It also promotes positive role model programs and the leadership development of young people living with HIV by enabling them to work alongside the national network of PLHIV (e.g., TNP+) to address stigma and discrimination.

Bilateral donors that support OVC, adolescents and young people living with HIV in Asia Pacific include the U.S. Government through its President's Emergency Plan for AIDS Relief (PEPFAR) programmes (for example, in Viet Nam), the U.K. government through DFID (for example, in Nepal) and the Clinton Health Access Initiative (for example, in PNG). Yet despite significant funding from international donors, few programmes appear to be reaching or responding directly to the needs of adolescents living with HIV.

## **Social protection measures for adolescents and children affected by HIV vary from country to country**

In many Asia Pacific countries, while social protection has gained considerable traction as a means of responding to poverty, economic volatility and food insecurity, HIV has not been a primary component of most existing social protection schemes. A recent study commissioned by UNICEF to map social protection measures for children affected by HIV in Asia Pacific draws the following conclusions: first, unconditional cash transfers, though not extensively evaluated, are being used in some countries (particularly in other regions) with success, especially to encourage continued education for at-risk children and gender equality by raising the status of women in households. Second, while programmes are in place to aid chronically ill caregivers, there is little emphasis on enhancing caregiver capacity through training or support to manage the needs of HIV-affected children. Third, social insurance is not always inclusive of HIV-affected children, notably for those who fall out of the scope of the formal workforce, namely migrant workers. Additionally, based on a qualitative assessment of programmes across the region, the study recognizes China as the only country in which social assistance, social insurance and social services are all oriented to offer children affected by HIV some form of support.<sup>39</sup>

A more comprehensive approach is needed across the Asia Pacific region to ensure the needs and rights of adolescents living with HIV are recognized and addressed.

**Table II. An assessment of a selection of HIV National Strategic Plans with regards to priorities for adolescents living with HIV**

NSP	Treatment target for ALHIV	ALHIV adherence	ALHIV disclosure	ALHIV support and care	ALHIV SRH specific program
Bangladesh					
Cambodia					
Fiji					
India					
Indonesia					
Lao PDR					
Mongolia					
Myanmar					
Nepal					
Papua New Guinea					
Philippines					
Thailand					
Viet Nam					

### **Table Key**

No specific mention
Mentioned as part of PLHIV communities more broadly
Mentioned only in the context of children affected by HIV/ paediatric care/ PMTCT
Prioritised (Recognise the evolving needs of adolescents living with HIV)

# I WANT TO KNOW MY STATUS AS YOUNG AS POSSIBLE

Adolescents living with HIV in Asia Pacific learn about their HIV status for the first time at different ages and from a range of sources. How and when adolescents receive information about their status plays an important role in how they understand what living with HIV means for their health and well-being. It impacts their self-esteem, attitudes towards treatment and their caregivers, and may inform how they in turn choose to disclose their status to others.<sup>40</sup>

A recent literature review of available studies around disclosure in developing and developed countries found that many adolescents living with HIV face similar challenges around disclosure. However, it also showed a deficiency of studies focused on developing countries, particularly longitudinal studies that could give insight into best practices for the long-term process of disclosure.<sup>41</sup>

There are varying guidelines internationally for disclosure of HIV status from caregiver to adolescent; many do not mandate disclosure at a certain age, instead suggesting a decision is made on a case-by-case basis depending on indications the child is mature enough to handle the information. There are few child and adolescent disclosure standards in Asia Pacific, although

encouragingly Nepal is currently in the process of developing disclosure guidelines. In 2009, regional HIV experts came together to discuss ongoing challenges with regards to paediatric HIV management and prevention of parent to child transmission, and arrived at a similar conclusion; that the most appropriate time for disclosure is when children start asking questions regarding their condition and reasons for taking medicine. They also recommended that disclosure should be done gradually, through age-sensitive approaches and contents.<sup>42</sup>

**Important resource:** *It's My Right to Tell... and My Right to Know: a guide on HIV disclosure for guardians, caregivers, parents, health workers, field workers, social workers and project staff working with children living with HIV in Cambodia*  
Access at: [https://www.dropbox.com/s/jiwysuggft4zixj/Disclosure Guideline-Cambodia-English-Final-18 Feb 2013.pdf](https://www.dropbox.com/s/jiwysuggft4zixj/Disclosure%20Guideline-Cambodia-English-Final-18%20Feb%202013.pdf)

Yet many adolescents interviewed for this report expressed the desire to know their status as early as possible. At the *My Right to Health* consultation, adolescents and young people said that knowing their status empowered them to take care of their own health. When caregivers did not disclose their status until a later age, adolescents and young people reported feeling angry that it had been kept from them.

## **Disclosure of HIV status from caregiver to adolescent**

For perinatally infected adolescents, their parent or primary caregiver often makes the decision about when to disclose with a health care provider or a counsellor. Depending on the caregiver's comfort level, disclosure may come directly from the caregiver, from a health care provider, or from both.

Some health care settings in Asia - such as the Chiang Mai University Hospital in Chiang Mai, Thailand - have a standard disclosure process that doctors and nurses adhere to, working with

caregivers and parents over the course of six to nine months to assess an adolescent's capacity for understanding the news about their HIV status, actual disclosure and follow-up. "Some may just feel relief," said Dr. Virat Sirisanthana of the Chiang Mai University Hospital. "They know that right now, [after we disclose their status], they can talk frankly with us or their caregivers."

Similarly, in Vientiane, Lao PDR, medical staff work closely with caregivers on the disclosure process. "In terms of disclosing to the child, if the parents agree, the nurse will do the disclosure, but an assessment needs to be taken before the nurse decides to disclose, including considering the age of the kids," said Nurse Linda, who oversees a caseload of adolescents living with HIV at Setthathirath Hospital in Vientiane. "The youngest case we disclosed to was at the age of eight, with parental agreement. It's important to monitor the consequences of disclosure; parents have to commit to following up and [monitor] what's going on at home... [after disclosure] kids feel more mature, and take more responsibility for their health."

Other communities, however, lack a formal process; disclosure may be ad-hoc or at the discretion of the caregivers, and can come late in an adolescent's life. In a Thai study that examined disclosure among 103 children living with HIV, the most common reason from caregivers not to disclose at a young age was fear the news would cause psychological damage to their children; caregivers noted they needed additional assistance with disclosure.<sup>43</sup> In the focus group discussion held in Cambodia for the purpose of this report, one adolescent from Phnom Penh reported learning about his status at health services at the discretion of his parents, but said he did not understand the information and that there was no follow-up of any kind.

"I was disclosed my status by my grandmother at the age of seven, but back then I didn't know what that meant. When I was 12, a volunteer worker better explained what that means to me and to my body. Then I started to understand better about what living with HIV means. It was quite useful to have that information. I already knew since I was very little that I had health problems, so having my grandmother telling me at the age of seven was not too young."

- Adolescent male living with HIV, 15 years, Lao PDR

Adolescents interviewed for this report who had been living with HIV from birth typically learned their status in the range of 7 - 13 years. In some cases, adolescents who learned at younger ages about their status reported higher-levels of self-acceptance and positive self-esteem as older adolescents; it is possible that knowing their status early and understanding its implications for their health allowed them to accept it as part of their life, rather than struggle with acceptance as older individuals. Adolescents also said knowing their status helped them assume responsibility for their health.

One study in Thailand found that when caregivers hide an adolescent's HIV status from them, it creates a "wall of silence" which "was found to have isolated them and increased their psychosocial vulnerability by blocking open communication with family members, peers and teachers, and left them to cope with their problems on their own."<sup>44</sup>

Often adolescents suspect they are living with HIV before formal disclosure happens. "The doctor disclosed my HIV status when I was 12 and still in primary school," said Somsri, a 21-year-old young woman living in Chiang Mai. "I kind of knew before, because I needed to go to the hospital every month and I was receiving counselling before that on what drugs do to my body." Dr. Virat Sirisanthana estimated that 20 per cent of her patients knew they were living with HIV before they were officially told. Some adolescents may suspect they have HIV, but have been told by caregivers they have another illness, such as a heart condition.<sup>45</sup>



### ***"She knows her HIV status but shuts down that part of herself": One family's story from Lao PDR***

Somrudee is a 38-year-old caregiver to her niece, Soupaphone\*, a 14-year-old girl living with HIV since birth. Somrudee, her husband, three children and Soupaphone live in a three-room house on a small piece of land a 45-minute drive outside Vientiane. Nearby, the Mekong River snakes between Lao PDR and Thailand. Behind Somrudee's house squats a chicken coop and small garden; Somrudee sells vegetables and fresh eggs at the market for extra income.

Soupaphone's mother had a long-term relationship with a Thai man who migrated to Lao PDR for short periods to work, living the remainder of the year in Thailand with his wife. Soupaphone was five months old when her mother passed away from AIDS. Soupaphone's other aunt initially raised her, and at the age of four took her to the doctor after noticing recurring health issues, where she was diagnosed with HIV. Shortly after learning of Soupaphone's HIV status, her aunt relocated to France to work as a housekeeper.

After Soupaphone came into Somrudee's custody, Somrudee has endeavored to keep Soupaphone healthy and shield her from the pervasive stigma around HIV in the local community. *"People always had the perception she had a curse, being born in a non-married relationship. People think that when she gets sick, she is being haunted by the spirits,"* said Somrudee.

Despite Somrudee's efforts, Soupaphone has struggled in school, recently repeating the same grade. A few years before, other parents, suspecting Soupaphone is HIV-positive, told their children not to play with her; Somrudee publicly denied her status in an effort to protect her from social isolation. Soupaphone now only plays with younger children.

Somrudee said one positive development in Soupaphone's health was attending a sleepover camp for children and adolescents affected by HIV organized by the community organization Lao PHA; as a result of the camp sessions on ARVs, Soupaphone expressed greater interest in taking her treatment. She also connected with Lao PHA staff who check-up on her when they're in the area, and became friends with other campers.

Despite Somrudee's up-beat demeanor, she is worried about who will care for Soupaphone in the future. *"If I pass away, who's going to take care of the kid? Who will ensure that she's in school and receives care?"* she said.

\*Names changed

Adolescents who acquire HIV through sexual transmission or drug use usually find out about their status from a medical professional or counsellor after they have received a HIV test. These adolescents may experience different emotional reactions to learning their status from their peers who were perinatally infected, including increased feelings of shame, guilt and self-loathing. Often these feelings stem from the perception they are "to blame" for their status. *"When I learned about my status,"* said one participant from the Philippines at the *My Right to Health* consultation, *"I thought it was the end of my life...my dreams destroyed."*

Improper post-test counselling and support may exacerbate these feelings.<sup>46</sup> *"When I came to know about my status I was 18. The doctor took very little time [with me] and I started crying - I felt that I shouldn't think about my dreams. I stopped my guitar classes, and I felt I was going to die soon,"* said a young man from India at the *My Right to Health* consultation. Said another young woman from PNG, *"The counsellor just tested me without "counselling" - it took 10 minutes and then [he] just said: you are HIV-positive."*

#### **Disclosure without consent**

Adolescents living with HIV have the right to decide to whom to reveal their HIV status. Their right to privacy is enshrined in Article 16 of the United Nations Convention on the Rights of the Child (CRC), ratified by all countries in Asia Pacific. The Committee on the Rights of the Child, which monitors implementation and issues interpretations of the human rights provisions of the CRC, stated in its General Comment on HIV/AIDS and the Rights of the Child, *"States parties must protect the confidentiality of HIV test results . . . including within health and social welfare settings, and information on the HIV status of children may not be disclosed to third parties, including parents, without the child's consent."*<sup>47</sup>

Young people living with HIV “have the **right to decide whether or not to disclose their HIV status to others**, including within the context of educational institutions. There is no justification whatsoever for making access to or retention in education conditional upon disclosure of HIV status as this may limit a learner’s right to education. The basic human right to education is further supported by conventions such as the Convention against Discrimination in Education which specifically promote equality and non-discrimination and are the cornerstone of achieving education for all.”

- UNESCO/GNP+ Positive Learning: Meeting the needs of young people living with HIV in the education sector, 2012

This important resource can be accessed at:  
<http://unesdoc.unesco.org/images/0021/002164/216485e.pdf>

Unfortunately, not everyone recognizes that the choice of when and to whom to disclose is an essential right of adolescents. In many countries in the region, adolescents still report that their status has been shared without their consent. For example, in India, there are documented cases where health care facilities and orphanages have disclosed the status of children and adolescents without their consent.<sup>48</sup>

School is also reported to be a common place where non-voluntary disclosure may occur. In some cases, this is due to requirements to disclose one’s HIV status before admission, or for the waiver of tuition fees that children and adolescents living with HIV may be entitled to as part of social welfare programmes. In other cases, it may stem from gossip, often from the perception of other parents. Adolescents

living with HIV in India, Lao PDR and Nepal reported being excluded from school after someone disclosed their status to education officials. “I don’t want to disclose my status to anyone at school now,” said Maina, a 16-year-old young woman living in Kathmandu. “I may get discriminated against if I tell my friends in school.”

“My grannie told me [I was HIV-positive] when I was eight years old,” said Alpana, now a 20-year-old young woman living independently also in Kathmandu. “My parents passed away at the age of seven (dad) and eight (mom). At first I felt very bad. I was taken out of school by the principal. After I was kicked out, I moved to Kathmandu and went to another school.”

### **Disclosure from adolescents living with HIV to family, friends and sexual partners**

Adolescents with acquired HIV have difficulties disclosing their status to their families. Adolescents often report feeling ashamed to tell their parents about their status. “One huge difference is that when you are born with HIV, your family or guardian knows, but the [ones with] acquired [infection] have to deal with disclosure to families, and lack of family support makes them lonelier,” said one young person from Viet Nam at the *My Right to Health* consultation. Adolescents may not tell their families for fear their families will express judgement, experience shame or in worse case scenarios force them to leave home. In addition, adolescents from key populations may not want to share how they contracted HIV.

In India, one study examined health centre data for 84 people who tested positive during adolescence. According to counsellors at the health centre, 48 percent of the young people shared the outcome of their HIV test with their father followed by 25 percent with their mother. Five percent of the adolescents refused to divulge the result of their test to anyone.<sup>49</sup>

In many countries in Asia Pacific, high levels of stigma and discrimination towards PLHIV make it difficult for adolescents to feel comfortable being open with their HIV status. One study documented the stigma and discrimination faced by adolescents living with HIV in India. “Since HIV is generally associated with unsafe sex practices and premarital sex in the Indian society; it is considered a taboo and thus the HIV-positive adolescents face discrimination at different levels: medically, professionally, academically, and even socially,” wrote the authors.<sup>50</sup>

As a result, adolescents have little incentive to disclose their status. A study of 54 perinatally infected adolescents in Northern Thailand found that nearly half – 48 percent – had never disclosed their status to anyone.<sup>51</sup>

In some contexts, young women face added stigma due to their gender after the process of disclosure occurs. *“Some people blame and discriminate against me [because] I had sex with multiple partners; [they said] only a “whore” like you deserves this. Even my husband’s family scolds me often, and they always [said] that my husband got HIV due to me,”* said Srijana, a 19-year-old young woman in Kathmandu, Nepal who acquired HIV during adolescence.

In PNG, where extreme stigma and discrimination continue to exist towards PLHIV and especially women living with HIV, none of the three young women who participated in an APN+ focus group discussion were comfortable disclosing their status to anyone outside of their immediate family.<sup>52</sup>

To avoid having to deal with disclosure and its consequences, some adolescents decide not to engage in intimate relationships. *“I know I have the right to tell and my partner has the right to know. But the situation is confusing, and so I’d rather not be in a relationship,”* said Somchai, a young adolescent male in Northern Thailand.

### **The power of peers: Inside the Raks Thai Power Teen Support Group**

The Raks Thai office is nestled in a small suburb of Chiang Mai, on a leafy street where the long branches of trees shelter houses from the sun. Raks Thai is a registered non-governmental organization in Thailand working on a range of issues, including health and the environment. As one of the first organizations working on supporting children living with HIV in Thailand’s North, Raks Thai also came to incubate the Power Teen Support Group.

The Power Teen Support Group consists of 15 regular members, all of whom are living with HIV and between the ages of 14 – 22. This youth-led initiative provides a critical service for other YPLHIV in Chiang Mai. Group members visit the Chiang Mai University Hospital on days when other young people are picking up their ARVs, making themselves available to answer questions about treatment, adherence and sexual and reproductive health.

With initial support from the Asia & Pacific Alliance for Sexual and Reproductive Health and Rights (APA) and then a two-year grant from HIV Young Leaders Fund, the Support Group expanded its activities to include a sexual and reproductive health manual for YPLHIV in Thai, as well as sexual health workshops. They are also advocating for the removal of mandatory HIV testing protocols for Thai students applying to university. Lately, the Support Group has also begun outreach to migrants in the rural Phayo district, where increasing numbers of Burmese workers often lack access to basic health services, including HIV prevention, treatment and care. While the Support Group is youth-led, Raks Thai staff provide mentoring, counseling and support for fundraising.

*“What contributes to the success of Raks Thai Power Teen has a lot to do with the ownership and participation – the ideas are generated by the teen leaders themselves,”* said Tom Suwannasopit, a social worker at Raks Thai. *“The frequency of their meetings is significant as well, because the more the adolescents get the opportunity to meet, the more it builds the connection and network; they know how to keep in touch and know their strengths and weaknesses.”* Tom estimates that the Support Group has reached over 500 adolescents and young people aged 12 – 24 with HIV-related information and activities.

*“I like participating in the peer support group and organizing activities with other adolescents,”* said Somsri, one of the Support Group’s older members at age 22. *“I like taking responsibility and I like to challenge myself to look at how well I help other people; I feel like I’ve made a contribution towards a better life for other people and that makes me quite happy.”*

Caregivers of adolescents living with HIV also mentioned noticing a difference in their child’s attitudes after attending Support Group meetings. *“I think it’s really useful that he engages in the activities by Raks Thai,”* said Noppamas, a 47-year old shop owner and mother to a 19-year-old son who was born with HIV. *“Being part of the peer group really helps him calm down, and answers some of the questions he has about school, sex and health, being in a relationship, even how to talk to his parents.”*

Noppamas’s son, Somchai, agreed. *“I was exposed to several problems that ALHIV face [at Raks Thai] and some of the problems helped improve my skills in problem solving – I apply this knowledge to dealing with my own situation. I’m told by the psychiatrist that before you can help others you need to deal with your problems first.”*

One of the factors contributing to Raks Thai’s success appears to be the relationship between the adult staff and the Support Group’s young members. All ideas and activities are generated and led by the young members, but staff help actualize the ideas. In addition, they provide psychosocial support as needed. Said Somchai about his relationship with Tom, the social worker, *“I learned a lot about friendship, how to maintain a relationship, public speaking skills, and a lot of knowledge, especially around sexual and reproductive health – she always helps me to improve my understanding.”* Another factor is the strong relationship between the Chiang Mai University Hospital and the Support Group; the two coordinate their activities to mutually support each other.

Some adolescents living with HIV in urban areas of Thailand appear to have more ease with disclosure than their peers elsewhere, which may be due to peer support they received. *"I disclosed my status to my immediate family members, my social workers, my peer and my boyfriend. With my boyfriend I disclosed my status after one month, and the reaction was quite positive because his family is also affected by HIV...I'm really at ease about my HIV status, so if asked I'll tell, because there seems to be a lot more acceptance in society, excluding a group of people that still lack knowledge and [therefore] have prejudice,"* said Somsri, who received peer support services from the Raks Thai and has been a part of the Raks Thai Power Teen support network for several years.

Caregivers of adolescents often lack access to training to understand how to support adolescents with disclosure to others. Caregivers may fear the consequences of disclosure due to HIV-related stigma and discrimination and as a result influence an adolescent's attitude about disclosure. Said Shammi, a 14-year old boy in India, *"My mother strictly informed me not to disclose about this disease to anyone. My mother said if I tell them, then all my friends will leave me alone."* One Thai study concluded that caregivers needed guidance and support from health-care providers to assist with disclosure-related issues for their children.<sup>53</sup> In addition, caregivers living with HIV may also need support for their own disclosure process to their family and others.

After over thirty years of the HIV epidemic, it is unacceptable that proper services are not in place to help adolescents and their families deal with disclosure in the Asia Pacific region. Adolescents need programs to help them understand when and how they might disclose, how to deal with the consequences of intended and unintended disclosure and support for legal redress.

# I GET LOST IN THE HEALTHCARE SYSTEM

## Young people living with HIV said health services should be:

- a. Confidential
- b. Flexible (with school/ university timings)
- c. Involve some component of peer support
- d. Involve some component of psychosocial support. For example, opportunistic infection (OI) management could include counseling on adherence to OI meds.

*My Right to Health Consultation, Bangkok, Thailand February 2013*

How healthcare systems respond to adolescents living with HIV varies among Asia Pacific countries. Adolescents by definition often fall somewhere between services, policies and guidelines designed for children and adults.

Countries in the region typically fall into one of two distinct models of HIV healthcare service delivery for adolescents. In Thailand, Malaysia, Philippines, Indonesia, Nepal and PNG, the ART clinic or doctor is the first point of contact for adolescent and young people's primary health care and/or OI-related issues. However, in Cambodia, Viet Nam, and India, the first point of contact is the general hospital, closest clinic or general practitioner. Only if the symptoms are very severe do adolescents living with HIV in these countries see an HIV specialist first.<sup>54</sup>

### **The challenging change from paediatric to adult care**

In some Asia Pacific countries, adolescents living with HIV receive healthcare services under a paediatric department until age 15 or 18, when they are then considered an adult and can switch to adult services. But in some contexts, adolescents living with HIV since birth have had the same doctor for their whole lives, and are afraid to change doctors or hospital settings. *"An adult HIV doctor does not have time for me, and I felt uncomfortable sharing what I feel with someone I do not know very well,"* said Somsri, a 21 year-old woman in Thailand, who continues to receive medical services at a paediatric department.

In Thailand, HIV guidelines stipulate that by age 18, children should have transferred to adult medical services. But for Dr. Virat Sirisanthana of Chiang Mai University Hospital, such a transition is not feasible. Dr. Virat tried to transition about 20 adolescents living with HIV to the adult HIV wing; they all came back and requested to remain in her care. *"They do not want to go see adult doctors,"* said Dr. Virat. Some of the reasons adolescents do not want to change doctors include not trusting a new doctor with their personal story or medical history, and worrying that the quality of care will not be as strong in the adult system.



Countries with an age-related healthcare transition need programmes that support healthcare professionals to communicate and inform patients and their caregivers about the transition as early as possible, so that they have time to mentally prepare.<sup>55</sup> Osmana Krishnan, a nurse in New Delhi, said NGOs can play a critical role in supporting adolescents through the transition period. *"It can be very important to arrange home visits from NGO counsellors,"* Krishnan said. *"The counsellors can inform them who is taking responsibility for the child, and also link them with additional resources for people living with HIV."*

Promising results also occurred when the Chiangrai Prachanukroh Hospital strengthened a rural paediatric HIV care network by training community hospital (CH) care teams to receive referrals of children for community follow-up. One study found that this decentralized approach resulted in excellent health outcomes,<sup>56</sup> and further research should be conducted to determine whether such a network could also support the transition from paediatric to adult services.

**Important resource for healthcare workers and policy makers:**

Transitioning HIV-infected Youth Into Adult Health Care  
 – policy recommendations

Access at: <http://pediatrics.aappublications.org/content/early/2013/06/19/peds.2013-1073.full.pdf+html>

**Barriers to accessing healthcare services for adolescents living with HIV\***

- a. Long queues;
- b. No flexibility for picking up ARVs (interferes with school/ university/job);
- c. Judgmental healthcare provider;
- d. No treatment education – e.g., No information about how to manage ARV side effects; fear of starting treatment;
- e. Lack of transport to healthcare centre;
- f. Lack of money to pay for OI medicines;
- g. Religious and cultural beliefs, especially around SRH and condoms;
- h. Lack of linkages between ARV and other needed services;
- i. Lack of confidential services (service centres are publically known as HIV clinic; fear of disclosure if seen at centre).

*\*as identified at the My Right To Health Consultation, February 2013*

Cambodia is currently in the process of developing clinical paediatric transition guidelines; other countries in the region should follow suit to ensure a smooth transition. In addition, existing models of essential transition services are now available for some countries outside of the region, especially in Africa, but also in Eastern Europe and South America; these models could be studied and adapted for

suitability in Asia Pacific. (See Annex I for examples of promising programs in other regions).

**Lack of a consistent doctor during adolescence**

In other countries, adolescents living with HIV have not had the same doctors over the course of their teenage years, and may lack access to medical professionals with paediatric knowledge. This is especially the case in impoverished settings, where doctors rotate frequently. *"Now there are more and more doctors – but still not enough,"* said Dr. Susheil at the Bir Government Hospital in Kathmandu, Nepal. In addition, staff at Nava Kiran Plus, a home for children and adolescents living with and affected by HIV in Kathmandu, reported a poor quality of paediatric care for children living with HIV.

This lack of specialized knowledge and frequent changes in doctors create anxiety in adolescents, who are wary of disclosing their status to new faces. Failing to have a relationship with a doctor may compromise their quality of care; without trusting their doctor, adolescents are less likely to feel comfortable asking questions about their health.

*"I feel so sad when I change doctors all the time, because each time I have to tell them the story of my life. I wish I had the same doctor, but I don't have that option,"* said Maina, a young woman living with HIV in Nepal. In addition, some adolescents reported new doctors were often keen to switch their treatment regimen, and they were unclear why their regimen was changed, raising concerns about the communication process between doctor and patient.<sup>57</sup>

NGOs and CBOs can play critical roles in helping adolescents manage their health needs. In two cities in Northern Thailand, the NGO Raks Thai supports a social worker and adolescent peer leaders to be present at the hospital or ART centres when adolescents arrive for services. Raks Thai can then support linkages for other health services, and help answer questions from the adolescents. *"Sometimes I help orientate other young people living with HIV to various departments in the hospital, to make sure they do not feel lost,"* said Namtan, a 19-year-old young woman peer leader from the Raks Thai Power Teen Support Group.

Since 1998, Cambodia has implemented a programme called the Home Based Care Team, which was expanded nationally in 2000. Dr. Sos Mary, the HIV doctor at a NGO clinic in Phnom Penh, said the Home Based Care Teams are able to support adolescents living with HIV more effectively than their caregivers. Through the home visits, adolescents can receive information and support with adherence, OIs and other issues.<sup>58</sup>

### **Shaming and blaming of adolescents living with HIV**

Adolescents, particularly those who have recently acquired HIV, may experience discrimination from healthcare providers, especially if they are seeking care outside of an ARV centre or

specialized HIV medical service, and have to disclose their status to medical staff who are not sensitized about HIV issues.<sup>59</sup>

*"In India, counsellors judge us after giving an HIV diagnosis. They are only doing counselling for the sake of it."*

-Young man living with HIV, at the *My Right to Health* consultation

In too many contexts, healthcare providers express judgmental attitudes about adolescents' HIV status, especially if they are adolescents with acquired HIV. Health care providers may infer the adolescent has done something wrong to contract

HIV at a young age.<sup>60</sup> Such attitudes 'shame and blame' adolescents living with HIV. Some young people at the *My Right to Health* consultation reported they preferred receiving medical services from NGOs, as they felt government healthcare providers were often stigmatizing.

Misinformation about how HIV is transmitted also continues to be an issue in health care settings. In Nepal, one adolescent reported doctors inappropriately used surgical gloves when they touched him for a check-up, causing him to feel angry and ashamed. Such unfortunate actions by healthcare providers can contribute to an adolescent's internal self-stigma and on-going fear of discrimination in healthcare settings.

Recent research among young men who have sex with men and transgender women living with HIV also found that they were afraid to access health services, for fear of stigma as well as whether healthcare workers would disclose their status without their consent.<sup>61</sup>

In some countries in the Asia Pacific region, including Indonesia, girls and women living with HIV have reported forced sterilization or coercion from medical professionals to abort their pregnancy.<sup>62</sup> This is confirmed by an APN+ study in 2012 which assessed the experience of pregnant HIV-positive women 16 years of age and up in accessing reproductive and maternal health services. The study revealed that among 757 women living with HIV from five countries (Cambodia, India, Indonesia, Nepal and Viet Nam), 30 percent were encouraged to consider sterilisation and more than half (61 percent) indicated these recommendations came from gynaecologists and HIV clinicians on the basis of the women's HIV-positive status.<sup>63</sup>

Adolescents living with HIV may also face stigma when giving birth. One adolescent reported in the FGD discussion in the Philippines that she felt doctors and nurses were stigmatizing towards her during the birthing process.<sup>64</sup>

### **Co-infection prevention, diagnosis and management**

When adolescents living with HIV contract other illnesses, the combined effect with HIV greatly weakens their immune system. Young people living with HIV at the *My Right to Health* consultation reported lacking information on how to prevent co-infections, as well as lacking knowledge on how to manage co-infection treatment and ARV drug interactions.

One co-infection that is particularly damaging to adolescents living with HIV is Hepatitis B (HBV). One study found that the prevalence of HBV/HIV co-infection was 3.3 percent in a sample of 521 perinatally infected Thai adolescents receiving ART. The study found that HBV is more prevalent in HIV-positive Thai children than those without HIV, and that in addition children living with HIV were more likely to be susceptible to HBV and may need to be re-vaccinated.<sup>65</sup> Countries in the region should ensure HBV vaccination is included in standard childhood vaccination programs, as well as ensure adolescents living with HIV can receive a second vaccination. Adolescents living with a co-infection of HIV and HBV need access to proper HBV treatment, which can be expensive to obtain in many countries in the region.

# I STRUGGLE TO COPE WITH THE IMPACT OF LIFE-LONG TREATMENT

There is currently no disaggregated data that show how many adolescents living with HIV aged 10 - 19 are on treatment in Asia Pacific. Children born with HIV who have survived into adolescence are likely to be on treatment already if their HIV status is identified early in their lives, unless they are lost to follow-up or are a 'slow progressor' and did not receive an HIV diagnosis.

Some of the reasons children are lost to follow-up include lack of caregiver contact information, stigma and counselling challenges, the burden on patients to return for results, and weak follow-up systems within clinics.<sup>66</sup> Research shows that HIV-positive mothers are more likely to return to health facilities for a child's diagnosis and treatment if they have accessed the 'four prongs' of PMTCT programmes, including peer counselling, which is often provided by PLHIV organizations and networks.<sup>67</sup>

If their status is not identified early in their lives, these children may be lost to healthcare systems until the appearance of poor health results in their caregiver bringing them to a doctor. In the worst case scenario, their status is not diagnosed and they die of AIDS-related complications. Although progress has been made to increase paediatric coverage for children who need treatment (rising from 19 percent in 2005 to 43 percent in 2012 in South and South East Asia)<sup>68</sup> the gap for paediatric treatment coverage remains high.

Adolescents who acquire HIV may or may not be on treatment, depending on their health, their national treatment guidelines, affordability, accessibility and their willingness to start treatment. Late diagnosis and poor treatment outcomes among adolescents living with HIV are not uncommon across the region, especially among those who acquired HIV during adolescence.<sup>69</sup> In addition, there is little information available about the adolescent "treatment cascade" - when adolescents test positive but then do not return for follow-up HIV services.

Paediatric HIV researchers are extremely concerned about the long-term toxicities of ART, the side effects of which impact a child into adolescence and during the transition to adulthood. The TREAT Asia Paediatric HIV Observational Database, which monitors a cohort of children living with HIV in several Asian countries, observed metabolic complications, as well as behaviour and neurocognitive outcomes, in children linked to long-term ARV use.<sup>70</sup>

Some ARVs also have harsher long-term side effects for children living with HIV than others. For example, long-term use of the ART stavudine (d4T) can result in lipodystrophy, where fat is re-distributed on a person's body. The 2010 WHO HIV guidelines<sup>d</sup> recommended reducing the use of d4T<sup>71</sup>, but a 2010 WHO survey found that in Cambodia, among 3,236 children who were on the first line ARV regimens in 2009, 3,058 (94.5 percent) were on regimens including d4T; and in Viet Nam, 1,324 children in a sample of 1,817 (72.9 percent) were on regimens including d4T.<sup>72</sup>

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d The WHO released new treatment guidelines in 2013; however at the time of the report there was not information about their implementation in Asia Pacific.

In compliance with the same 2010 WHO guidelines, the Thai national paediatric HIV treatment guidelines were revised in 2010 to recommend the short-term use of d4T only in cases of pre-ART anaemia.<sup>73</sup> Yet other countries have failed to follow Thailand's lead. Reasons for this may include lack of political will, poor national paediatric guidelines, drug procurement and supply management issues and in some cases, the fact that countries have procured large amounts of d4T under programs such as the Clinton Health Access Initiative (CHAI) and are now reluctant to let these go to waste.

Across the region, many children and adolescents living with HIV may be on sub-optimal treatment regimens, such as those that include use of d4T, which contribute to a poorer quality of life, result in undesirable side effects (including those which have physical manifestations associated with HIV), and can contribute to treatment resistance and failure.

### **Complicated paediatric treatment regimens affect adolescents**

Unfortunately, today in Asia Pacific many adolescents do not have simple treatment regimens, in part due to their experience with paediatric treatment as children as well as what treatment is currently available in Asia Pacific.

Paediatric dosage regimens are usually based on either age, weight or body surface. Most of the currently available paediatric ARV formulations are ill-suited to resource-poor settings, requiring children to take frequent doses of powders or bitter-tasting syrups, many of which need to be refrigerated or mixed with clean water before taking. Such conditions are a barrier for poor families who may lack electricity or clean water. Paediatric formulations typically also have a limited shelf life after opening and are very costly.

Once children reach 10 or more kilograms in weight large volumes of syrups are typically recommended, but many children are instead likely to be on adult capsules or tablets due to the lack of proper paediatric fixed-dose combinations. These tablets are broken or mixed by caregivers, and if not guided properly, caregivers could be under-dosing or over-dosing children.

One young Thai female participant attending the *My Right to Health* consultation emphasized the importance of having access to more simplified ART regimens. *"I need simpler and better regimens: ones that do not need to be kept in a cool place all the time, as I do not carry a refrigerator with me everywhere."*

### **Current paediatric formulations**

Today over 45 paediatric formulations are used by country programmes supported by UNITAID or the GFATM with 48.8 percent of all children living with HIV in low and middle-income countries on a first-line regimen of zidovudine+lamivudine and nevirapine, followed by stavudine+lamivudine and nevirapine (23.8 percent).

Creating better paediatric treatment depends on simple fixed-dose combinations and child-friendly adapted formulations, such as dispersible and Orally Disintegrating Tablets (ODTs), improved palatability and heat-stable formulations for storage in tropical climates. Examples include the need for ritonavir-boosted atazanavir and heat-stable ritonavir-boosted lopinavir in palatable paediatric formulations. Several paediatric formulations that meet these requirements are still in the pipeline; for example, Atazanavir powder, Cobicistat dispersible tablets, Granules 40/10 mg lopinavir-ritonavir (equivalent to 0.5 ml liquid) or LPV/rtv/ABC or AZT/3TC (4-in-1) in granules FDC, among others.

**Sources:** Implementing 2013 WHO Guidelines for Children: Ensuring scale up of effective interventions; and The changing epidemiology of the global paediatric HIV epidemic: keeping track of perinatally HIV-infected adolescents: Annette H Sohn, Rohan Hazra; and <http://www.pipelinereport.org/2013/pediatric-ARV>



## The New WHO consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection

The 2013 WHO Consolidated Guidelines recommend a LPV/r-based regimen for all children under 3 years, combined with either AZT/3TC or ABC/3TC, and a number of new formulations that respond to these recommendations are in the pipeline. For those older than 3 years old, it is suggested that efaviranz be used instead of LPV/r and that treatment for adolescents is harmonized with that for adults (TDF-based regimens). Generic versions of adult treatment regimens are already available in fixed dose combinations.

Many countries in Asia Pacific put children on a different first-line regimen; guidance is urgently needed to help countries understand the new WHO guidelines and the benefits of implementing them in the region.

Source: <http://www.who.int/hiv/pub/guidelines/arv2013/download/en/>

## Adolescents perinatally infected with HIV are at risk of running out of affordable treatment options

According to 2010 WHO guidelines, which are still widely implemented across countries in Asia Pacific, the preferred option when choosing a first-line regimen for infants and children is two nucleoside reverse transcriptase inhibitors (NRTIs) plus one non-nucleoside reverse transcriptase inhibitor (NNRTI). These regimens are effective, inexpensive, available from many national ART roll out programmes and do not require cold storage. In addition, the potent class of protease inhibitors (PIs) are then saved for a potential second line regimen.<sup>76</sup>

Many adolescents living with HIV since birth begin to show signs of resistance to their treatment regimen during adolescence or even before. Some infants and children also have developed resistance to nevirapine and/or other NNRTIs due to previous exposure to single-dose nevirapine (SdNVP), which was commonly used for preventing parent-to-child transmission several years ago but is now being phased out across the region. While countries like Indonesia and Malaysia have stopped using single dose nevirapine, use is still reported in countries like Mongolia and PNG as of 2011.<sup>77</sup> As a result, some adolescents need to be put on a different treatment regimen that is more costly.

Second-line switches are defined as a change in two or more ARVs, including a class switch (i.e., from NNRTIs to protease inhibitors [PIs] or vice versa), or if a single-drug class switch is made on the basis of reported treatment failure.

One survey of 17 ARV and health centres in Asia reported that of 3,600 children living with HIV in their care, 20 percent were already past their first-line ART regimens.<sup>78</sup> Data from Cambodia, India, Indonesia, Malaysia and Thailand showed that second-line regimens in use varied widely, and the WHO recommended combination at the time of the study - abacavir (ABC) and didanosine - was used in less than five percent of children.

Unfortunately, paediatric second-line regimens (or alternative first-line) are expensive in Asia Pacific. For example, Lopinavir/ritonavir 80/20mg/ml oral solution produced by the generic pharmaceutical, Cipla, costs \$292 per person per year, while the generic abacavir costs \$122 per person per year. By contrast, commonly used first-line fixed-dose paediatric regimens (Zidovudine, Lamivudine and Nevirapine) cost an average of \$97 or less per person per year.<sup>79</sup> Clinical sites in Asia have reported difficulty in accessing abacavir and other second-line regimens.<sup>80 81 82</sup>

Other existing second-line formulations are inconvenient to dose, administer and store, especially if they are only available in liquid form or with a high pill burden (in cases where fixed-dose combinations are not available).

Not only are the treatment options for children and adolescents on second-line therapy limited and expensive, but there have also been limited investments in research for new formulations. In addition, should children and adolescents experience treatment failure while on a second-line regimen, there are almost no affordable options for a suitable third-line regimen in the region. Adolescents in developed countries have access to third-line paediatric ARVs, such as ritonavir-boosted darunavir. But these drugs have not been made widely available in developing countries due to patent laws prohibiting the production of generics. The monthly cost of darunavir is prohibitively expensive in the developing world - for an adult in Thailand, darunavir is 400 USD<sup>83</sup> per month or 4,800 USD a year.

It is therefore critical that children start HIV treatment early and be provided with optimal paediatric regimens - ones that are easy to adhere to and administer. Non-adherence to the recommended paediatric treatment regimens will eventually result in less treatment options as they enter adolescence. It is also important to quickly speed up access to affordable second and third-line treatment regimens.

#### Newer, better paediatric formulations in the pipeline?

"Today, the only formulation of LPV/r available is a 42 percent alcohol-based solution that is foul tasting. In 2012, the Drugs for Neglected Diseases initiative (DNDi) and Indian drug manufacturer Cipla announced a collaboration to develop two protease inhibitor-based fixed-dose combinations for children, AZT/3TC/LPV/r and ABC/3TC/LPV/r.

These formulations will take the form of heat-stable solid granules, will taste better, and will be easily given with food, milk, breast milk or water. They will also allow easy dosing across weight bands. These products are expected to be available by 2015. In addition, DNDi is developing ritonavir heat-stable granules for children co-infected with TB who need additional boosting while on LPV/r treatment. Cipla is also developing a LPV/r -only sprinkle/ minitab formulation, registration of which is expected by early 2014."

Source: MSF, *Untangling the web of antiretroviral price reductions*, July 2013

#### Difficult side effects impact adolescent mental and physical health

Many adolescents who commenced treatment in early childhood have experienced side effects from the medications, including lipodystrophy, anaemia, nausea, dizziness, memory loss, inability to sleep, rashes, weakness and other symptoms.

Such physical side effects create a complicated relationship between an adolescent and their body. They can result in lower self-esteem, as adolescents struggle to understand why they might look different from their peers or try to hide physical side effects like rashes that could prompt questions from other children. *"These side effects are the biggest barriers between adolescents living with HIV and other children,"* said Omama Krishnan, a nurse in New Delhi, India at the Lott Carey Care Home. *"It is because of the side effects that the adolescents living with HIV develop internalized stigma, and then it becomes difficult to address their issues."*

Lipodystrophy, or even the perception that there is a risk of appearance change, can lead adolescents to discontinue their medication, and a swift reaction from a doctor can help prevent a treatment gap.<sup>84</sup> *"I had lipodystrophy - it was really prominent - you could see in my face,"* said Somsri in Chiang Mai. *"The doctor noticed it and suggested I change my regimen. It was good for me because I want to look good and feel confident, so I agreed with the decision."*

Adolescents with acquired HIV who start treatment for the first time also experience difficult side effects. If the side effects are severe, adolescents may miss school or work to try and cope with severe side effects. If schools and work settings are not supportive, these adolescents may be fired or have to switch schools, further setting them back from acquiring the skills and resources needed for their lives.

### ARV drug toxicities in children & adolescents

The most common toxicities include the following:

**Haematological:** with AZT (anaemia, neutropenia and, thrombocytopenia).

**Mitochondrial dysfunction:** with other NRTI drugs: include lactic acidosis, hepatic toxicity, pancreatitis and peripheral neuropathy.

**Lipodystrophy and other metabolic abnormalities:** more common with stavudine (d4T) and protease inhibitors, and to a lesser degree with other NRTI drugs. Abnormalities include fat maldistribution and body habitus changes, hyperlipidaemia, hyperglycaemia, insulin resistance, diabetes mellitus, osteopenia, osteoporosis and osteonecrosis.

**Allergic reactions:** including skin rashes and hypersensitivity reactions. These are more common with the NNRTI drugs, but also seen with certain NRTI drugs, such as abacavir (ABC).

**Hepatic dysfunction:** in children with hepatic dysfunction of any aetiology NVP requires careful consideration because of its potential life threatening hepatotoxicity.

*Source: Manual on paediatric HIV care and treatment for district hospitals. Geneva: World Health Organisation, Department of Child and Adolescent Health and Development (CAH) and HIV/AIDS; 2011. WHO.*

In addition, adolescents who are living with HIV and use drugs may need careful treatment monitoring to address any side effects arising from drug interactions. The WHO notes it is important for medical providers to be watching for any interactions between ARVs and methadone or buprenorphine, and to adjust regimens accordingly. Adolescents living with HIV who use drugs may need additional pain relief drugs, which should also be monitored for any potential interactions.

### Taking medications regularly becomes difficult during adolescence

Adolescents born with HIV often experience difficulties regularly taking their treatment once they become teenagers. *“Adolescent adherence is particularly complex because of the socio-economic pressures related to orphan-hood, neurocognitive deficits associated with chronic and severe HIV infection, and stigma and discrimination,”* wrote Sohn and Raza in an article published in the Journal of the International AIDS Society in June 2013. Adherence typically gradually decreases as children become adolescents, and accordingly assume more responsibility for their medication.<sup>86</sup>

Several interviewees noted one factor that may influence adherence is whether adolescents are being taken care of by their own parents or caregivers from older generations. Thanks to stable access to effective ARV regimens, some adolescents living with HIV have parents who are alive today. But other adolescents have lost either one or both of their parents and are cared for by their grandparents or other family members. *“Those adolescents under their own parents’ custody adhere much better - they will take drugs together and remind each other when to take them,”* said Nongyao, a paediatric HIV nurse at the Chiang Mai University Hospital in Thailand. Of course the quality of care and attentiveness varies from family to family - one Thai study found that children who were cared for by caregivers aged 45 years or above had a better quality of life than those whose caregivers were 20-45 years old.<sup>87</sup>

For adolescents whose caregivers normally administer treatment, refusing to take the pills may be an act of rebellion, or a way to express their autonomy. It can also be a response to feeling depressed or frustrated with taking pills every day.<sup>88</sup>

Said a 79-year-old caregiver in Lao PDR about her 15-year old grandson, *"I still support him in taking medicines now, I put the meds on the table and I monitor how he takes it and whether he took three of the meds or just two of them, which normally is the case. When it comes to taking meds, he's not really disciplined but I always keep an eye on him and he knows as well that if he doesn't take medicines then people will further discriminate against him because he will have skin rashes, and he's really scared of that. But still, sometimes he lies and says he takes the medicines when he didn't."*

Some adolescents reported it was difficult to take their treatment in a public place – instead they had to remove themselves from social situations, making it more likely they might also miss a dose. *"I face problems when I have to take medicine when my friends are around or when I go to a party,"* said Shammi in India. *"I generally go to a secluded place and take it there."*

Others may have negative feelings when they take the medicines. *"I feel very bad while taking my medicine,"* said Amar in India. *"Maybe when I grow up I won't have to take this medicine every day."*

For adolescents with acquired HIV, some have a different attitude towards treatment, perhaps because they have not been on it as long. Adolescents with acquired HIV consulted for this report said they viewed their treatment as a positive step for protecting their health. *"It's my life, so I take it,"* said one young person attending the *My Right to Health* consultation. More research is needed to understand how adolescents with acquired HIV feel about their treatment and adherence. Adolescents with acquired HIV may face difficulties in adherence, including not having the support of parents or caregivers and having to assume sole responsibility of their own health.

### Thawatchai's Story, Lao PDR

"I am 15, my name is Thawatchai and I live with my grandmother.

I like football and watching TV from time to time. I study – I'm in the 9th grade. There's no problem at school; I do well, and I'm able to follow the studies.

I am taking medicines. I am currently taking blue medicines – 6 tablets per day, 3 per time.

Since the age of 10 I started to hang out around the house, playing with other friends, and that's when I sometimes forget to take medicines because I'm not home at 7 [when I normally take them].

I don't disclose my status to anyone, even my close friends.

With regards to my health, I only discuss it with my doctor and my grandmother, so they always know my health record and my needs. I changed doctors twice and there was no problem, but I wish I didn't have to go very often to get medicines.

I was put on the more toxic regimens before and then I got a severe allergy; my grandmother had to take me back to the hospital to have them put me on another regimen.

What helps me to take the medicines more easily are water and the programme on the television – the second part of the news – which reminds me to take the medicine.

In primary school, my teachers knew my HIV status and it was easier for me to be allowed to miss classes to go to the hospital. But in high school it's a little more difficult; I didn't tell my teachers about my HIV status.

I don't think much about being HIV positive, I forget it sometimes. The only advice I would like to give is to allow people like myself to get a stock of medicines for more than a month because the distance from here to the hospital is really far. It takes time to go, it takes a lot of reasons to explain to the teachers, so if I could get a stock of more than one month it would be much easier.

My hope is that I finish my school and I am recruited by the LAO PHA to be one of their staff."

There is almost no published research in Asia Pacific on how to support adolescents with treatment adherence. One study which examined Thai young people living with HIV found that a common adherence model in the U.S., the information-motivation-behavioural skills model, could be applicable in Thai settings but with modification to account for the collective nature of a Buddhist society.<sup>89</sup> The study suggested that how adolescents perceive their responsibilities to their family and community impacts on treatment adherence. A UNICEF case study of a treatment programme in Northern Thailand found that the following methods could improve children's adherence: direct observation, pill counting, pill boxes and adherence diaries.<sup>90</sup>

Another possibility is that ARV fixed dose formulations that are easier to take could improve adolescent adherence, especially one pill a day. However, at this point one pill a day is not widely available for adolescents and adults in Asia Pacific. *"Adherence is a problem I cannot solve,"* said Dr. Virat. *"One tablet a day would help with my kids...in the future if they can have a drug that's only once a week, that would be best."*

#### **Important emerging resource:**

Adolescents living with HIV toolkit  
Accessed at: <http://www.k4health.org/toolkits/alhiv>

The experiences of adolescents participating in the *My Right to Health* consultation also emphasized the importance of peer support groups to assist with treatment education and adherence. The effectiveness of peer support is underscored by a WHO review of psychosocial support to adolescents, which found that it is, *"highly effective in helping young people*

*adhere to treatment, as is a communication style that is open, straightforward and trusting."* In addition, mobile phone alarms and watches help adolescents as they assume responsibility for their treatment.

#### **The necessity of treatment education**

People living with HIV who understand what anti-retroviral drugs they are on, how the drugs work, and common side effects are in a better position to take care of their health.<sup>91</sup> Yet while adolescents in Asia Pacific understand how treatment affects them on a daily basis, many are lacking critical knowledge about ARVs and ART regimens. Many adolescents with acquired HIV reported not receiving adequate treatment education. *"Medicine is given without explanation,"* said one participant from PNG at the *My Right to Health* consultation. *"This affects our adherence."*

Many adolescents interviewed for this report did not know the name of their treatment regimen. However, some understood how ARVs affect their body thanks to training they received at the ART centre, hospital or through peer support groups.

*"The main factors for adherence are really the knowledge that has been built about the drugs they are taking and the regimens - the drugs themselves - if they're easy to take, it's more likely they'll adhere to treatment,"* said Dr. Saykham at the ARV centre in Vientiane.

Adolescents who are empowered to discuss their treatment from a medical perspective, for example understanding when and why a doctor changed their treatment regimen, and to manage their own HIV care through monitoring for opportunistic infections and treatment side effects, are better prepared to live a healthy life.<sup>92</sup>



### **Lao Positive Health Association Camp for Adolescents Helps with Treatment Education**

LaoPHA is a community-based organization in Vientiane, Lao PDR.

The organization runs an annual sleepover camp for adolescents living with HIV to help them understand their status and how to take care of their health. Through the camp, LaoPHA reaches up to 40 adolescents from seven different provinces in Lao PDR.

The three-day camp covers topics such as ARVS, cooking and nutrition, sexual and reproductive health, Buddhist life skills, leadership skills, and more. To ensure the camp is fun for adolescents, staff use a variety of techniques for different age levels, including games and art projects. Each participant also gets a watch with an alarm, and LaoPHA staff demonstrate how to use the alarm as a reminder to take ARVs.

The four step leadership development model the camp uses for adolescents is:

- 1 - Understand what HIV is and how medicines treat the disease
- 2 - Understand how to take care of yourself and be healthy
- 3 - Once you are strong and healthy, help others around you
- 4 - Collectively, you have a voice and can work for broader changes

The camp provides an important source of information, education and social connection for adolescents living with HIV in Lao PDR. After the camp, participants can join a support group run by LaoPHA, and many stay in touch with the new friends they made.

One of the challenges seen by the camp staff is the major need for adolescents to have access to mental health services; monks are often the only people providing any form of counselling. Another challenge is continued funding and sustainability of the camp; LaoPHA is uncertain of their future funding beyond 2013.

*“Two years ago I changed to this regimen [efavirenz/emtricitabine/tenofovir disoproxil fumarate] because I find it’s really difficult to wake up at 7 and take medicine twice a day. So I discussed with my doctor, and my doctor allowed me to take this one pill a day and this really helped me. I also further negotiated with the doctor the time of taking my medicines to be before going to bed; otherwise I wouldn’t be productive enough to do other things during the day because of the side effects, and the doctor agreed,”* said Somchai, a 19 year-old adolescent male in Chiang Mai.

Some adolescents also expressed the desire for fun and engaging treatment literacy games, and when asked agreed age seven was an appropriate time to begin improving their knowledge about treatment.

### **The hidden costs of ARVs & related health issues**

Various interviews with adolescents living with HIV, caregivers and social workers for this study pointed out a common concern: from time to time, they bear the burden of out-of-pocket spending on ARVs and other health needs, including transportation costs to health facilities, treatment of opportunistic infections, and costs associated with primary care.

Some of these costs are covered by Global Fund grants supporting orphans and vulnerable children (such as in Thailand and Lao PDR), and others by governments under social welfare or social security schemes, but many fall on caregivers and adolescents themselves.

One NGO worker in Lao PDR mentioned that he is particularly worried about the costs for treatment of OIs, potentially as a result of poor procurement and delayed disbursement of Lao PDR’s Global Fund grant. *“CD4 and viral load test is normally free, as well as some OI drugs.*

*However, at times there were problems with procurement and deficits of the OI drugs. Parents needed to pay out-of-pocket from private hospitals. Right now, it's been four and five months already that we have problems with the OIs drugs [not being available], such as Bactrim - the medicine to treat Pneumocystic Pneumonia (PCP)."*

Certain groups of adolescents living with HIV, such as undocumented migrants and their children, are also left out of national ART programmes which cover many adolescents at no cost.

In recognition of this, Thailand recently amended its national health policy to extend the provision of health services to migrants. This policy is now being implemented, allowing migrant workers and their families to access ARVs under broader health insurance schemes that can be purchased at affordable prices (for 7 years old children and under - 12 USD yearly).<sup>94</sup>

A healthcare worker in Chiang Mai described the problem she and her peers faced, "As we receive an exact dose for the number of patients registered through a national programme, it is difficult to re-distribute the medications (mainly Efavirenz) to those who are excluded from the national programmes. Many non-Thai patients are left out and I always have to take a quota from other programmes to ensure they get their medications. I feel slightly uncomfortable about it."

In addition, adolescents with acquired HIV may not be able to ask their families for support. A young MSM participant from Indonesia at the *My Right to Health* consultation said that despite being close with his parents, he does not want to disclose his HIV status - as a result, he lacks money to pay for needed medicines and services. Another participant from Pakistan at the consultation said that despite the free provision of ARVs, he could not afford the related tests and services.

# I'M HARDER TO REACH BECAUSE I ACQUIRED HIV DURING ADOLESCENCE

While there are gaps in what we know about how to best support adolescents who are perinatally infected, there is even less information available about addressing the needs of adolescents who acquire HIV. Adolescents who acquire HIV in many parts of Asia Pacific are likely to also be considered part of a “key population”, which includes adolescents who sell sex, men who have sex with men, transgender adolescents and adolescents who use drugs. In certain contexts, such as in PNG, adolescents who acquire HIV are likely to be young women and girls.

## **Missing data**

There is very limited robust data available from most countries in Asia-Pacific to enumerate and describe adolescents with acquired HIV, especially those from key populations. Many of these adolescents live on the fringes of society, hiding their sexuality, gender or occupation from their families and sometimes peers. Legal restrictions, including the criminalisation of drug use, sex work, and consenting sex between males, make it even more difficult to reach these adolescents, who fear arrest and abuse if their behaviours are discovered. Barriers to engaging these adolescents in research include legal and ethical concerns for studies involving adolescents younger than 18 years, weak collaboration and coordination efforts among HIV and child protection systems, and lack of political and social supports, among others.<sup>95</sup>

Nonetheless, in recent years some surveillance data among key populations re-affirm that explosive epidemics are occurring among men who have sex with men (MSM), people who inject drugs, sex workers and transgender people with high prevalence observed among the younger cohort of these populations.<sup>96</sup> For example, several studies in Bangkok indicate HIV incidence among adolescents and young MSM (between the ages of 15 and 22) has nearly doubled in recent years, from 4.1 percent in 2003 to 7.7 percent in 2007<sup>97</sup>, and 25 percent in 2012<sup>98</sup> - a faster increase than among older MSM in Thailand. In 2008, Pakistan had an HIV prevalence of 23 percent among young people who inject drugs aged 15 - 24 years old.<sup>99</sup> An Indonesian survey from 2007 -2009 showed an HIV prevalence of 5.4 percent among 15 - 19 years old waria (transgender) adolescents who sell sex, and 14.2 percent prevalence among their 20 - 24 year old counterparts.<sup>100</sup>

The lack of population size estimates and the collection and publication of age-disaggregated information on younger groups of key populations on commonly collected indicators, such as use of sterile injecting equipment and HIV treatment coverage, among others, hinders effective planning and provision of services as well as monitoring and evaluation of programmes and policies. In addition, more programmatic research is urgently needed to better understand how to support adolescents living with HIV from key populations in managing their different, intersecting needs.

## **Falling through the gap of health and peer services**

Adolescents perinatally infected may already be in the healthcare system and as a result may be part of a peer support group of some kind. However, adolescents who acquire HIV may not be receiving healthcare services of any kind. In addition, a majority of them may not even know they live with HIV – pointing to the critical importance of increasing testing uptake for adolescents across the region.

Even when adolescents know their status, those from key populations face additional difficulties accessing healthcare. For instance, transgender adolescents may not have access to medical providers sensitized to their issues, and as a result may not seek health services.<sup>101</sup> In some countries, adolescents who sell sex may be extremely difficult to reach with information about HIV-related services.<sup>102</sup>

Adolescents living with HIV who are not part of a health care system may lack access to information about peer support groups, which frequently use hospitals and ARV centers to recruit new members. Many are not linked to further care and support services after they are diagnosed as HIV-positive. During in-country visits to CBOs that hosted peer support groups, few had adolescents with acquired HIV as members. In addition, older networks of key populations often do not have adolescent engagement strategies.

## **Hostile law enforcement and legal environments**

Repressive laws and punitive legal environments drive adolescents from key populations away from services they need, including HIV testing, treatment, care and support.<sup>103</sup> Across Asia Pacific, laws that criminalise consenting sex between males, sex work and drug use are being enforced

against adolescents from key populations. Punishment is often severe and may carry the death penalty or harsh sanctions including imprisonment (such as for illegal drug use). Adolescents from key populations also report cases of police misconduct, such as confiscation of condoms and syringes, extortion, harassment, sexual and physical abuse, and arbitrary detention of adolescents.

### **Important resource:**

Godwin, J. *Young people and the law in Asia and the Pacific: A review of laws and policies affecting young people's access to sexual and reproductive health and HIV services.* Bangkok: UNESCO

*(Report forthcoming, late 2013)*

For those adolescents who inject drugs, certain countries like China and Viet Nam have laws and policies that restrict access to opioid substitution

therapy (OST) and/or needles and syringes to people over a prescribed age.<sup>104</sup> These policies clearly violate adolescents right to health as enshrined in the CRC.

Like other young people, adolescents from key populations are also subject to the enforcement of laws and implementation of policies that require parental consent for minors to access HIV and STI testing, medical treatment and other SRH services including contraceptives. For example, parental consent to HIV testing is required for minors under 18 in Cambodia. Such policies create barriers to testing and early diagnosis of HIV. One young person in the APN+ Philippines focus group discussion reported that young people would rather self-medicate than disclose their HIV status to their parents in order to access medical services.<sup>105</sup>

A few countries in the region do have laws that recognize the evolving capacity of adolescents to make independent decisions regarding their health, such as the “mature minor” principle that consent of a parent or guardian to a medical procedure is not required if an adolescent under 18 is considered to be sufficiently mature. Countries with some variation on this principle include Fiji, Lao PDR, Marshall Islands, Pohnpei State of Micronesia and Papua New Guinea (PNG).<sup>106</sup>

Participants of the *My Right to Health* consultation from Cambodia and Viet Nam also raised concerns with respect to their peers living with HIV and using drugs who are in detention centres and/or prisons. In such settings, access to SRH commodities, such as condoms, and other essential harm reduction services, such as needle exchange, overdose prevention services and opioid substitution therapy, is limited, while rampant sexual harassment and violence against young people who use drugs is common. In addition, law enforcement authorities do not pay specific attention to their health needs, including ensuring uninterrupted access to ARVs.

It is also in these settings that young people who use drugs and are living with HIV may be engaged in transactional sex in exchange for cigarettes or other drugs. Some of them are also influenced by older people in prison to switch to harder drugs. Without access to condoms, harm reduction, and other sexual and reproductive health services, these behaviours may increase their vulnerability of contracting HIV or passing HIV to others in that setting.<sup>107</sup>

### **Srijana's Story**

“My name is Srijana\*. I'm 19 years old and am three to four months pregnant.

Currently, I'm living with my husband in a small room we rent at Sinamangal near the Tribhuvan Airport in Kathmandu, Nepal. My husband is also from a drug use background; he's currently on opioid substitution therapy (buprenorphine) and staying at a residential [rehabilitation] program.

I got married at the age of 18. My husband is 26 years old, and works in the Pashupatinath temple area, where people from Hindu backgrounds do funeral ceremonies. He collects the discarded property of the dead individuals, such as clothes, ornaments, etc, and sells it to others - that's how he feeds us.

Due to a family problem, I used to live on the streets. My father left when I was small, and my mother is an alcoholic. There were always quarrels and domestic violence in my home, and that's why I left.

I studied till the 5<sup>th</sup> standard. I like to learn, and I wanted some skills so that I could earn some money and feed myself and my family.

I tried several drugs when I was living on the streets; at first I used to sniff dendrite. I used to be high a lot during my street days; I was sexually harassed from the street boys and sometimes even by the police. It's been six to seven months since I quit using drugs and dendrite; I only smoke cigarettes these days.

I came to know my [HIV] status three to four months ago from a sister of Dristi Nepal. And then my husband was also tested, he also got the same [positive] result.

I haven't told anyone except you, my husband, and a few sisters of Dristi Nepal as well as the doctor who is looking after my pregnancy. I got [HIV] because I was forced to live on the streets at a young age; I used to beg on the streets.

I do not know any networks or organizations [for YPLHIV]. In the health centers and hospitals in my area, they don't treat me nicely. Whenever I go to hospitals, the staff stare at me in a surprised way and ask me, “How did you get the virus at such a young age?” I feel so uncomfortable that I never go to the health centers.

I have lots of hope in my life, but still; let's see about the future.”

*\*Name changed to protect identity*



# I DO NOT WANT TO DATE; I'M SCARED TO BE IN A ROMANTIC RELATIONSHIP

Sex and relationships were identified as one of the four most frequent problems faced by young people living with HIV in a WHO global literature review.<sup>180</sup> Many young people begin thinking about sex and relationships during adolescence, and adolescents living with HIV may become or already be sexually active.

Access to sexual and reproductive health care is a right enshrined in the Programme of Action of the 1994 International Conference on Population and Development. *"Information and services should be made available to adolescents that can help them understand their sexuality and protect them from unwanted pregnancies, sexually transmitted diseases and subsequent risk of infertility. This should be combined with the education of young men to respect women's self-determination and to share responsibility with women in matters of sexuality and reproduction."*<sup>109</sup> Yet adolescents living with HIV across Asia often lack appropriate information, education, skills and tailored services to experience satisfying romantic and sexual relationships.

## **Sexuality, shame and self-esteem**

*"I've never had a romantic relationship. I have not thought about it, because I think it is not related to me. I don't think I'll be in a romantic relationship one day. Not all of us can be happy."*

- Noi Alpana, a 20-year-old young woman living with HIV in Kathmandu.

Shame about their HIV status and fear about the possible steps to have a healthy relationship – including potential disclosure of their status, safe sex techniques, and so on – are major barriers to the sexual health of adolescents living with HIV. *"Because I feel ashamed, I do not want to discuss these things with anyone,"* said 14-year-old Shammi in India. A young participant at the *My Right to Health* consultation noted that after his diagnosis, *"I turned to sex. I felt bad on the inside so*

*I tried to feel good on the outside."*

In some cases, adolescents noted they were afraid to express their sexuality for fear of rejection or possible transmission of HIV to a negative partner.

Overall, adolescents living with HIV in Asia Pacific reached for this report indicated they thought that preventing onward HIV transmission was solely their responsibility.

In some contexts, older adolescents interviewed did not feel worthy of experiencing a romantic relationship, and expressed no desire for a sexual relationship of any kind. *"Because of my HIV status I don't want to date,"* said Sudin, a 19-year-old young man in Kathmandu.

**Important resource:** Healthy, happy and hot: a young person's guide to their rights, sexuality, and living with HIV

International Planned Parenthood Federation, Accessed at: <http://ippf.org/resource/Healthy-Happy-and-Hot-young-peoples-guide-rights>

Strong views about not being able to have a fulfilling romantic relationship or not desiring sex were expressed by many adolescent women living with HIV, including those born with HIV and those who contracted HIV during adolescence through unprotected sex with a partner.

These adolescents' perceptions of relationships appeared connected to feelings of shame, low self-esteem and concerns about whether anyone would love them due to their HIV-positive status. There was also a lack of understanding about how to practice safe and pleasurable sex, about the positive benefits of HIV treatment on transmission rates and about the effectiveness of prevention of parent to child transmission.

Yet shockingly, few to none of the adolescents interviewed were receiving any services, such as counselling or peer support groups from national programmes, CBOs or NGOs to address these issues. Instead, adolescents were left to grapple with sexuality and relationships entirely on their own, leaving them isolated and fearful of sex and sexuality.

### **Sexuality and reproductive health education - a missing link**

Sexual and reproductive health education that is specifically catered to the unique needs of adolescents living with HIV is missing from school and healthcare settings in the region. For example, some adolescents interviewed in Lao PDR mentioned receiving some information about sexuality education in school. However, the sexuality education they received did not mention how to have safe sex as a person living with HIV, or how to deal with disclosure to a sexual partner.

A review of policies and strategies to implement and scale up sexuality education in Asia and the Pacific carried out by UNESCO in 2012 shows that across 28 surveyed countries, there are considerable differences in the approach and content of HIV and SRH curricula across countries and across levels of education. The approaches range from a focus on imparting selected areas of knowledge through one or more (often non-compulsory or extra-curricular) subjects to comprehensive approaches focusing on knowledge and skills building, as well as addressing underlying issues such as gender equality and poverty. Other challenges raised in the review include resistance within education systems to sexuality education, as well as more general barriers to acceptance around the HIV and SRH content of curricula, and lack of teachers' capacity and training to cover sensitive content in classroom settings.<sup>110</sup>

*"In school only one chapter of the health curriculum touches on HIV, and it doesn't answer the questions I had then about how HIV is harmful to my health and about [how to handle] HIV in relationships,"* said a 15-year old boy living with HIV in Lao PDR. Other adolescents still do not receive any sexuality education in schools.

At the Chiang Mai University Hospital, Dr. Virat and her team have supported over 200 children living with HIV as they navigate adolescence. Dr. Virat and her nurses typically speak to adolescents living with HIV once they turn 12 or 13 about puberty and its accompanying physical changes, and link to family planning services on an as-needed basis. But Dr. Virat reflected that this was an area where the hospital staff could use further training and where additional services should be provided. *"Retrospectively, this may be our weak point,"* said Dr. Virat. *"We need additional support - it's very difficult for Thai caregivers [to discuss sexual health]. They still think that their kids are kids - it's not time yet, they say when we bring it up."*

### **Inside the home of Nava Kiran Plus in Kathmandu, Nepal**

Nava Kiran Plus is a group home for adults and children living with HIV. To reach Nava Kiran, you must first navigate a series of hair-pin turns up one of Kathmandu's mountains.

The grounds of Nava Kiran are perched on a cliff overlooking the rambling capital city, which continues to grow each year. In the morning and evening, mist blankets the valley below. Nava Kiran has separate living quarters for adults and children, a cafeteria, offices for the staff and a small water bottling plant, recently launched as a way to eventually raise additional revenue for the organization.

There are currently 25 children and adolescents living at Nava Kiran. Many lost their parents to HIV or were abandoned by their communities; the most recent arrival, a 2-year old girl, was found buried alive in a sandpit after her caretakers discovered her HIV status. Many but not all of the children and adolescents are living with HIV. Nava Kiran used to have over 50 children in its care, but due to recent funding cuts has had to limit the number of spots.

At Nava Kiran, all children and adolescents receive free shelter and food, as well as treatment and care. They typically sleep four to a room on bunk beds; stickers and magazine clippings adorn the bedroom walls. They attend a nearby school, walking together each morning and afternoon on the twisting cobblestone road. In the evenings, they eat together, study and play jump rope or football outside. Often the older children take care of the younger ones, guiding them carefully from building to building, comforting them when they're upset, pulling their hair into a tidy ponytail.

Many of the older adolescents transition to living on their own around age 18, and attend college or pursue technical training. These young people are committed to Nava Kiran's future; many are now working to raise additional funds so that other children can have the same opportunities they did.

*"I'm 19 years old," said Sudin, one of Nava Kiran's residents, when asked to describe himself. "I like to walk, and discover new things. I study sociology in university. I've been at Nava Kiran since I was 2 years old. I don't know where I was before. I have a support group at Nava Kiran; I talk to staff at Nava Kiran if I have some concerns. That makes me feel better. In 10 years, I want to work at Nava Kiran and support other children."*

One of the major challenges staff face is providing high-quality care for all of the children with a limited budget. *"Nutrition is a major challenge," said Nava Kiran's medical officer. "The children are on a high carbohydrate diet - it's difficult to get them enough protein, and I worry it's affecting their memory."* Basic necessities, such as t-shirts, socks and underwear, are limited - the majority of the children own just one item or pair of each. Many of the children's school fees, which are approximately 1000 rupees a month (10 usd) are covered by staff who donate part of their salary.

In the coming year, the staff hopes to raise additional funds to address some of these basic needs. Donors in Nepal are reportedly moving away from funding "orphanages" and group homes like Nava Kiran for children, claiming they are unsustainable. Yet for the children without anywhere to go, they remain an essential component of a humane HIV response.

Many of the adolescents reported not wanting to have children; despite knowledge about prevention of parent to child transmission they remained fearful they would pass on the virus. *"I think it is not 100 percent that your children will not be born HIV positive. There is still a 1 percent chance that they are born positive. Even if it's 100 percent certain - I still don't want [to do it]. I don't want my child [to be born positive] and to experience difficulties,"* said Maina in Nepal.

### **Access to condoms and other SRH commodities**

While current surveillance in Asia Pacific countries may look at reported condom use among adolescents, it does not capture condom use among ALHIV specifically. The only study identified during this review specifically examining condom use among adolescents living with HIV in Asia Pacific took place in Thailand and with a relatively small sample.<sup>111</sup> Across the region, in the general adolescent population, condom use continues to be low, due to issues concerning availability, social stigma, gender dynamics, and lack of education, all of which also affect adolescents living with HIV.

The study conducted in Bangkok, Thailand, involved 70 HIV-positive young people between 16 and 25 years of age, and showed that almost half of the participants practiced inconsistent condom use.<sup>112</sup>

Young women living with HIV in Papua New Guinea reported that it is difficult to access condoms and water-based lubricant.<sup>113</sup> Some of the only service-providers in PNG are religiously affiliated and do not always encourage condom use, promoting abstinence instead.

Recent community-based research by Youth Voices Count also found that in many country contexts, including Cambodia, China, Indonesia, Nepal and Sri Lanka, adolescent and young males who have sex with males reported difficulties using condoms due to the desire to feel loved and accepted by their partner.<sup>114</sup> More research is needed to better understand if this is also the case for male adolescents living with HIV who have sex with other males.

In addition, young female adolescents living with HIV in the region need access to additional family planning commodities if they desire them, such as hormonal contraception and intrauterine devices (IUDs). Yet there is currently a lack of information as to the most appropriate contraception methods for female adolescents living with HIV and especially those on ART in both developed and developing countries.

Hormonal contraception, delivered in the form of a pill, implant or injectable, needs further study among adolescents to determine its effect on HIV disease progression, as well as possible interactions between hormones and ARVs. The WHO currently recommends that women living with HIV can use existing hormonal contraceptive (HC) methods without restriction<sup>115</sup>, but they are in the process of revisiting their recommendations regarding the use of HC for people living with HIV in light of the development of new WHO guidelines on reproductive health which are scheduled to launch in December 2014.<sup>116</sup> To date, no clinically significant interactions have been reported between contraceptive hormones and nucleoside reverse transcriptase inhibitors (NRTIs) in adult populations,<sup>117</sup> but some of the interactions between contraceptives and ARVs in adult cohorts have led to increased ARV toxicity, and some ARVs such as ritonavir-boosted protease inhibitors decrease contraceptive steroid level in the blood.<sup>118</sup>

Emergency contraception, in the form of a hormonal pill taken 72 hours after unprotected sex or the insertion of an IUD up to five days after, is also potentially an important commodity to have available for adolescent girls living with HIV. Yet more study is also needed, as the effectiveness of a standard dose of emergency contraception for an adolescent on ARVs has not been confirmed.<sup>119</sup> In addition, while IUDs are highly effective in preventing unwanted pregnancy, more information is needed as to the IUD's side effects for adolescents living with HIV.<sup>120</sup>

For female adolescents living with HIV who are sexually active, prevention and diagnosis of the human papillomaviruses (HPV) also deserves attention. HPV is linked with genital infections which can cause cervical cancer. Screening for cervical abnormalities (cytology, HPV DNA testing, and visual methods) to detect pre-cancerous changes in cervical tissues is recommended<sup>121</sup> as one study found that women living with HIV were eight times more likely to develop invasive cervical cancers than HIV-negative women.<sup>122</sup>

Without supportive services and commodities, comprehensive sexuality education and support to address the mental health aspects of sexuality, adolescents living with HIV will be unable to fulfil an important aspect of their lives and one to which they are entitled.

# MY FUTURE IS UNCERTAIN

Adolescents living with HIV in Asia Pacific have hopes and fears for the future like many other young people growing up around the world. Sometimes their HIV status complicates these hopes and fears; other times conditions like gender inequality, poverty and conflict affect them more than their HIV status.

Adolescents living with HIV benefit from supportive government policies that seek to ensure their basic needs are met, including housing, healthcare, nutrition and education. Yet many countries in the region do not have systems in place to ensure proper care for adolescents living with HIV, or have different programs that are not well integrated to address the needs of adolescents living with HIV. In Pakistan, for example, despite the country's leadership in issuing paediatric guidelines and social protection for CABA, there is no information or available research about how existing child protection systems include or assist children and adolescents living with HIV.<sup>123</sup>

## Safe housing

Some adolescents living with HIV in Asia Pacific are raised by loving caregivers, including parents, extended family members and grandparents. But others do not grow up in supportive households. Adolescents born with HIV who lose both their parents to AIDS may not have family members to take them in and may be forced to live on the street or to stay at an institution. Adolescents who lose one or more parents may also struggle with consistent housing, while adolescents who acquire HIV may be kicked out of their homes by their caregiver, due to the continued stigma surrounding the disease or other behaviours such as consenting sex between men, drug use or sex work.

A regional analysis commissioned by UNDP in 2011 on the social-economic impact of HIV at the household level in Asia confirmed that children in HIV-affected households in countries like China, India, Indonesia and Viet Nam were less likely to attend school, have a higher rate of school drop-out, and were more likely to have entered the workforce earlier than those in non-affected households.<sup>124</sup> In addition, one study in Cambodia also established the impact of HIV on household vulnerability, concluding that, *"HIV-affected households were more likely to sell off assets, borrow from family members, take out loans, and ration medical care and food for*

*children. Children in HIV-affected households reported eating fewer meals in a day, increased frequency of hunger, and increased household and employment responsibilities compared to other children."*<sup>125</sup>

### Important resource:

Better Care Network - library of resources related to children who lack adequate family care

<http://www.crin.org/bcn/>

Adolescents without caregivers may assume the added burden of needing to identify safe housing at a young age. It is important to reunite adolescents with extended family members if possible. However, if extended family members cannot offer a safe housing environment for adolescents living with HIV, or refuse to provide housing, then shelter homes may be these adolescents' only option - if they exist and have the space.



Without a safe place to stay, as well as without money for other daily living expenses, adolescents may work on the street to survive, through shoe shining, selling candy, begging or selling sex.

### **Mental health**

As discussed earlier, many factors influence the mental health of adolescents living with HIV, including their views about ARV treatment, their health, sexuality and stigma from the community. In addition, adolescents living with HIV may also experience internal or self-stigma.

For example, adolescents may experience negative feelings from not being able to be open about their HIV status for fear of adverse repercussions. These feelings include anxiety, fear and shame. *"I am tired of living two lives,"* said Shammi in New Delhi. *"With my friends I cannot be free and open about my status because then they will stop being my friend. I am open about my status in meetings I go to with my mother, but I do not have friends there."*

In addition, adolescents living with HIV may experience other mental health problems. One social worker in Thailand said diagnosed mental health disorders among the adolescents she worked with were rare, but she had come across at least two cases of female adolescents who showed signs of serious mental health conditions. *"One of them is suffering from a severe bipolar disorder, while the other could maybe be suffering from a serious form of attention-seeking personality [histrionic] disorder,"* she said.

A WHO review of psychosocial support interventions for young people living with HIV found that little research exists on effective psychosocial interventions for those aged 10 - 24.<sup>126</sup> Yet in their review, they concluded that adolescents and young people living with HIV benefit from multidisciplinary forms of support - such as counselling and participation in youth-led support groups. Youth-led approaches, including youth-led organizing around HIV or other issues, were found to be extremely relevant interventions, helping to give adolescents a sense of community and purpose.

The WHO review also suggested service providers draw from other available literature on broader mental health and adolescent studies. For instance, the same WHO analysis noted that a separate literature review found that cognitive behavioural therapy and interpersonal psychotherapy were the most promising interventions in reducing depressive symptoms in both children and adolescents.

### **Access to education and job training**

Almost all of the adolescents living with HIV interviewed for this report recognized the vital role of education in shaping their future. Yet many adolescents living with HIV in the region face obstacles to completing their education.

Adolescents living with HIV may be more likely to drop out of school than other young people due to economic pressure to provide for their families, a change in caregivers or living situation, and discrimination from schools.<sup>127</sup> In addition, schools without supportive policies for children and adolescents living with HIV may fail to meet their needs and hinder their ability to remain in school.

School fees and related costs are also a barrier to education for adolescents living with HIV, who may be more economically disadvantaged than other young people due to losing a parent or caregiver, or living independently, as well as the costs of their medical care (such as transportation to and from ARV centres, treatment for opportunistic infections, and so on). Even if school fees are waived under HIV or social protection related programs, costs such as uniforms, books, transportation to school and extra-curriculum activities are usually not covered.

In Nepal, for example, several NGO workers at Nava Kiran, a child shelter for HIV-positive children and adolescents, end up donating part of their salary to support monthly school fees.

Countries in Asia Pacific like China, India, Thailand and Sri Lanka, among others, provide free high school education as part of compulsory education<sup>128</sup>, but university education is normally excluded. Admission for tuition-waiver programmes for universities is highly competitive; for example, in Sri Lanka only ten percent of young people qualified. In Thailand, one paediatric doctor has been supporting adolescents to attend higher education out of her own pocket. *"If the tuition fee is 13,000 baht (about 420 USD), the doctor will support 10,000 baht - believing that we should provide an incentive for these youth to meet the additional needs - to work and pay for themselves. But the doctor cannot pay [out of pocket] for the full amount,"* said Nongyao, a nurse in Chiang Mai, about the doctor she worked for at a Chiang Mai hospital.

In addition, some schools have discriminatory policies. For example, some higher education institutions in Thailand, such as medical universities and military academies, require a HIV test with an application for admission. This requirement discourages adolescents living with HIV from applying, out of fear that their status will be involuntarily disclosed.

Access to education can be increased through reducing monetary barriers via cash transfers or scholarships for school fees, uniforms and school supplies. For example, Urmila, the mother to a young boy living with HIV in New Delhi, said he receives a free uniform from the school, and she also receives a small monthly stipend from a local NGO to support his tuition. In China, children orphaned by AIDS are entitled to receive free schooling.<sup>129</sup>

In addition to support to complete their education to the desired level, adolescents who need to provide for themselves at earlier ages need skills-based training so that they can obtain decent work. *"It's not just the education but also vocational training for young positive people,"* said Vieng Dang of LaoPHA. *"They want to be self-sufficient, they want a job to earn money."*

### **Social protection for adolescents living with HIV**

Adolescents living with HIV may benefit from broader social protection schemes that seek to ensure the rights of marginalized children and support households living in poverty, of which ensuring access to education is usually one of several components.

However, existing social protection measures for orphans and vulnerable children have not been thoroughly studied in Asia as to whether they also meet the needs of adolescents living with HIV.<sup>130</sup> Promising social protection policies that support marginalized children include cash transfers to households to support nutrition and other basic needs, programmes to ensure access to health, education and other social services, and non-discrimination policies.<sup>131</sup>

*"Social support is like protection,"* said Vieng Dang of LaoPHA. *"Children cannot access social welfare without it."*

In addition, households with adolescents living with HIV may need specific care and support services, such as nutrition and legal services. *"With the cost of fruits and vegetables and other basic food items skyrocketing over the last few years,"* said Urmila in New Delhi, *"additional nutrition support would be helpful."*

Caregivers are also worried that their adolescents will not receive proper support if they pass away. This concern was expressed by at least two caregivers interviewed for this report. *"I am worried that when I pass away, who's going to take care of her? How do I ensure that she's in school and receiving care?"* said Somrudee, aunt of a 14-year old female girl living with HIV in Lao PDR.

## **Leadership opportunities**

For many of the adolescents interviewed for this report, peer groups that foster leadership skills and NGOs or positive networks that give adolescents living with HIV a role to play can have a significant positive impact on their health and future. Such opportunities build key skills for future employment, and allow adolescents to make new friends and feel less isolated. This is clearly evident with the Raks Thai Power Teen Support Group, which has helped adolescents living with HIV cope with multiple transitions as they become adults.

Some NGOs also hire or provide paid internships to older adolescents living with HIV. For example, in Kathmandu, two adolescents reported part-time work at local CBOs that provided them with a small stipend. Both adolescents said they treasured their time working at the CBO, and that they hope more adolescents living with HIV could access paid opportunities as they had. Across the region, some adolescents living with HIV reached for this report said their dream was to work at a CBO or PLHIV network so they could provide support to other children and adolescents experiencing similar issues.

Unfortunately, the majority of these adolescents had not experienced a peer support group or involvement with a CBO or PLHIV chapter. Adolescents at the *My Right to Health* consultation suggested PLHIV networks should have a specific adolescent and youth engagement strategy. They also said networks could utilize social media and mobile phone technology to reach out to adolescents living with HIV confidentially. In addition, many adolescents living with HIV reported not being reached by national or local youth organizations, even organizations with a focus on SRH and HIV. These organizations could also develop engagement strategies for adolescents living with HIV.

# A BETTER WAY FORWARD FOR US: OUR CALL TO ACTION

Across Asia Pacific, many doctors, nurses, social workers, parents and caregivers are providing tremendous support and care to adolescents living with HIV. There are inspiring examples of doctors and social workers covering their patients' school fees out of their own salaries, of grandmothers raising their grandchildren as their own, and of local organizations using participatory approaches to empower adolescents to deal with disclosure, treatment and other issues. Some adolescents living with HIV in the region are also forming peer networks and assuming responsibility for their health, even as they grapple with understanding how their status affects their future.

Yet despite the incredible strength of adolescents and many of their supporters, the majority of adolescents do not have access to proper treatment and care. Most of the above support depends on ad-hoc, voluntary, unsustainable and project-based structures, without resources or guidance from official government policies or programmes. Adolescents with acquired HIV in many countries are especially lacking in support, and deal with their status in relative isolation.

The current response to HIV in Asia Pacific is failing adolescents living with HIV. The gaps in addressing their needs are unmistakable – countries can do more to ensure a better present and future. The below recommendations are not exhaustive, but offer concrete suggestions for how to improve the health and rights of adolescents living with HIV.

## **BETTER DATA, BETTER ANALYSIS OF EXISTING DATA AND MORE RESEARCH ARE URGENTLY NEEDED**

**Countries and regional partners need to support data systems which track perinatally infected children through their lifespan, as well as disaggregate national programme data on reported cases to show accurate numbers of adolescents living with HIV.** *“Unless national HIV programmes and UNAIDS create mechanisms to count and keep track of the perinatally infected, we will not know how many of these children are and are not surviving into adulthood. Every year that goes by without dedicated global PHIVA surveillance means that tens of thousands of children could be lost in the crowd...In addition, without longitudinal cohort studies, we would have few opportunities to characterize the consequences of HIV disease and treatment in order to find ways to prevent them. There are now multiple paediatric and adolescent cohorts scattered around the world. Although they vary with regards to both size and depth of data collection, global cohort collaborations could potentially generate the “big data” needed to answer common research questions,”* wrote Sohn and Reza in the Journal of the International AIDS Society in June 2013.

Without knowing how many adolescents are living with HIV in each country, or how many are accessing treatment, it is difficult to design effective policies and programs to address their needs. In addition, governments, donors and multi-lateral funding mechanisms such as GFATM and PEPFAR should disaggregate their impact data based on age and invest in research that helps us to understand the following questions:

- How to encourage the health-seeking behaviour among adolescents living with HIV;
- What are the rights-based and adolescent-sensitive approaches to encourage HIV testing uptake among adolescents who have a higher risk of acquiring HIV;
- What are the best methods to address adolescents' emotional and mental health needs, including around sexuality and relationships;
- What are the best methods to link people who test positive during adolescence to care and to increase retention in care for both adolescents perinatally infected and acquired, as well as maintain adherence;
- How many adolescents are accessing ARV treatment, as well as treatment for OIs, co-infections, and harm reduction;
- Whether children living with HIV experience cognitive delays as a result of the virus or the use of ARVs at a young age. One study in Thailand and Cambodia showed that children born with HIV were more likely to experience cognitive delays and do poorly in school than children not living with HIV,<sup>16</sup> but more research is needed.

### HOLISTIC HEALTH SERVICES FOR ADOLESCENTS LIVING WITH HIV

**Adolescents aged 10 - 19 need a package of services, including health, care and other support services to transition toward HIV self-management and into adulthood.** All adolescents living with HIV should receive healthcare services in a confidential and non-judgemental manner. For adolescents with acquired HIV through unprotected sex or use of contaminated injecting drug equipment, the following are considered essential services: pre- and post-test/on-going counselling and linkages to HIV care; sexual and reproductive health (SRH) services and commodities, including contraception, condoms and lubricants; harm reduction for adolescents who use drugs; mental health services and possibly referrals to legal services and child protection services if desired.

For perinatally infected adolescents, the following are considered essential services: strong linkages with primary healthcare; opportunistic infections management; mental health services; sexual and reproductive health (SRH) services and commodities, including conception advice and contraceptives; condoms and lubricants.

**A proper transition for adolescents from paediatric to adult care in health settings is essential.** Transition must involve the early engagement and participation of the adolescent and his/her family and/or caregivers, with the paediatric and adult health care teams in; a) assessing the readiness of the adolescent to assume responsibility for his/her own care before initiating the transfer; b) developing a formal plan for transition as well as a way to track, document and assess health outcomes; c) ensuring on-going communication among all health providers; d) building the relationship between the adolescent and the new doctor.

**Peer support services providing treatment education, opportunities to boost self-esteem, mentoring, healthcare transitions and more are critical for adolescents living with HIV but currently neglected.** Treatment literacy, support for adherence, sexual and reproductive health counselling, and support for dealing with HIV-related stigma are often best delivered through peer support groups, with the support of knowledgeable social workers and medical professionals. Unfortunately, peer support programs remain under resourced in the Asia Pacific region.

Where they do exist, organizers of peer support groups should ensure both adolescents perinatally infected and adolescents with acquired HIV have access to their services. In cases where adolescents with acquired HIV are more difficult for peer groups to reach, positive networks and community-based organizations should develop careful outreach strategies to include these adolescents. While in some contexts it may make sense to have different support groups for adolescents perinatally infected and adolescents with acquired HIV, in other contexts it could be divisive to create separate structures and one entity may be able to cater to the needs of both groups.

## GIVE ADOLESCENTS LIVING WITH HIV THE BEST POSSIBLE TREATMENT

**Better paediatric formulations:** Children need better regimens from birth in order to mitigate potential problems, such as treatment complications, in adolescence. Same as adults, adolescents living with HIV need improved treatment regimens, including one-pill-a-day formulations. This would make it easier to adhere, and prevent the embarrassment they face when they must leave class or other social situations to take their medication. The pharmaceutical sector should be pressured and incentivized to invest in developing better formulations – children’s rights must come before profits.

In addition, second and third line ARVs must be made accessible and affordable given possible drug resistance due to non-adherence and to the length of time on medication. Countries in the region should utilize all TRIPS-related flexibilities to obtain optimal, generic ARVs for children.

**Reduce unnecessary side effects through diagnostics, monitoring and optimal treatment regimens.** Adolescents living with HIV need regular HIV-related diagnostics and monitoring. Access to CD4 and viral load testing is limited in most settings. Sub-optimal treatment regimens, such as d4T, are still being used in certain countries and must be phased out immediately. D4T in particular can result in lipodystrophy and other side effects that impact appearance, which impact adolescents’ self-esteem and create treatment complacency.

**Improve treatment education programs.** There is an urgent need for better, age-appropriate treatment education. Adolescents living with HIV need fun and engaging treatment literacy games as early as possible. Adolescents need to be empowered to discuss their treatment with their medical teams, to understand when and why for example, a doctor changed their treatment regimen, and to manage their own HIV care through helping to monitor OIs and treatment side effects. Medical staff also need training on how to provide age-appropriate treatment knowledge to adolescents as part of the standard delivery of care.

**Include adherence support as part of treatment services.** Adherence is often more complicated for children born with HIV, who have been on ARVs longer than adolescents who acquire HIV at older ages. Yet there are few programs in Asia Pacific devoted to supporting adolescents with adherence. Hospitals, ARV treatment centres, mental health workers, doctors and CBOs should work together to create adherence support programmes. Peer support groups could be particularly helpful in supporting adolescents to take their medication properly. New technology or social media should also be explored as a potential platform for providing peer-to-peer support and counselling.



## SEXUALITY & REPRODUCTIVE HEALTH EDUCATION AND SERVICES MUST BE EXPANDED

**Adolescents urgently need 'ALHIV specific' sexuality education and confidential access to SRH services, including safe and affordable family planning methods.** Regular sexuality curricula even where they are currently implemented in Asia Pacific countries do not address their particular needs or specify their safe sex options. SRH commodities, including condoms and different types of birth control, must be made available and accessible to adolescents living with HIV when desired. In addition, adolescents living with HIV could benefit from the support of older YPLHIV who have navigated sexuality, relationships and having children through mentoring or trainings.

**SRH programs must develop ways to address the mental health issues which affect adolescent sexuality.** Adolescents who fear intimate relationships or do not think they are entitled to relationships urgently need programs to help them discuss their fears and improve their self-esteem. Guidance on how to address this aspect of ALHIV sexuality is needed from the international community. Role models of healthy romantic partnerships - including between discordant couples - could be beneficial.

## FOSTERING A SUPPORTIVE ENVIRONMENT

**Disclosure from parents to children must happen at younger ages.** Children born with HIV unanimously suggested that disclosure should happen as early as possible, with seven as a recommended age to begin the disclosure process, or even earlier if children begin asking questions related to their health. If children and adolescents know their status earlier, they can be more empowered to take care of their health. Learning they are HIV positive during middle adolescence (14 - 16) has negative mental health effects and could potentially affect relationships between adolescents living with HIV and their caregivers, resulting in self-destructive behaviours (for example, refusal to take medicines as a way to rebel).

Children need programs that work with parents and guardians to help them understand the benefits of early disclosure. Hearing from young people living with HIV who are comfortable with their status could be a powerful way to help parents understand the evolving capacities of their child and convince them to disclose to the extent possible.

**More systematic support is needed to assist adolescents living with HIV in developing their skills for disclosure and help them understand how to deal with its consequences.** Fear of unintended disclosure and lack of skills in how to disclose complicate not only self-management of HIV, but also adolescents' ability and willingness to start relationships or make new friends. Civil society organisations and positive networks can play an important role in creating systematic support for parents, caregivers and adolescents living with HIV around disclosure-related issues.

**There should be more age appropriate livelihood opportunities for older adolescents living with HIV.** Adolescents who have lost one or both of their parents, and adolescents who have been shunned from their families due to their sexuality, drug use, sex work or other situations, are often economically disadvantaged to peers who have consistent family support. Civil society organisations can play an important role in hiring older adolescents living with HIV as compensated peer educators or for other work, but larger-scale opportunities must be created.

**Schools and education settings need to become safe and accessible spaces for children, adolescents and young people living with HIV.** All children have a right to education, but this right is threatened when schools do not have supportive policies, or have policies (or practices even where policies exist) that are discriminatory.

For example, requiring applicants to disclose their HIV-status in college and university applications serves no purpose except to violate an adolescent's right to confidentiality, and open the door to discrimination. Such requirements should be eliminated immediately.

Schools that have policies in place to ensure the principle of non-discrimination must fully enforce and monitor them. Education staff who discriminate against children and adolescents living with HIV should face professional consequences. Schools that do not yet have such policies must be supported to understand the forms that stigma and discrimination can take, and to empower them with the knowledge and tools to adopt measures to address stigma and discrimination.

Schools should also have policies that allow adolescents living with HIV to miss class to access health services, and as much as possible have counselors or be able to refer to mental health services when needed. In addition, scholarships to universities should be expanded for adolescents living with HIV.

**While OVC and CABA programs centred around social support and safety have the potential to help adolescents living with HIV, more evaluation is needed to see whether they actually support the needs of adolescents living with HIV.** In addition, OVC and CABA programs should have specific strategies to support the unique needs of children and adolescents living with HIV, such as around sexuality education, disclosure and adherence. Promising approaches include unconditional cash transfer programmes with a strong monitoring component that support children from HIV-affected households staying in school.

**Governments should remove age restrictions and parental consent requirements that impede adolescent access to medical services, including HIV and SRH services and commodities,** such as testing for HIV and STIs, access to contraception and harm reduction. The law should recognize the evolving capacity of adolescents to make independent decisions regarding their health, and an adolescent should be able to consent independently to medical services/procedures if capable of understanding the nature and consequences of the procedure, as well as being able to assess what is in their own best interest. The WHO recently recommended that young people could *"consent autonomously to HIV testing if he or she is 12 years of age and above, or under 12 years of age, and if he or she is of sufficient maturity to understand the benefits, risks, and social implications of a HIV test."*<sup>133</sup>

## ENABLING ADOLESCENT LEADERSHIP & PARTICIPATION

**Safe spaces must be provided within PLHIV networks, peer groups and support groups at hospitals for adolescents to participate and organize around their issues.** Adolescents living with HIV are hesitant to participate in national networks of people living with HIV or other organizations for fear of the consequences of public disclosure. Safe spaces must be provided for adolescents and young people to participate without disclosing their status publicly or in a limited way.

**Peer education and peer support groups** are a powerful way to encourage leadership and build the self-esteem of adolescents living with HIV - they should be funded and scaled-up to reach more adolescents. The Raks Thai Power Teen Support group in Thailand could serve as a model for other groups in the region.

**Country networks of PLHIV in Asia Pacific should immediately convene in-country discussions with members to review their current response on these issues,** and take steps to put in place a strategy for supporting adolescents living with HIV. Such a strategy should include supporting the leadership of adolescents and young people, such as through involvement in programme design and governance.

# ANNEX 1- Examples of good programmes outside Asia Pacific that support the health and well-being of adolescents living with HIV

Issues addressed	Implementer, Country	Methodology	Programme description highlighting key factors that contribute to the success
Linking testing with care for adolescents newly diagnosed with HIV	Hlanganani Programme, The Bronx Adolescent Health Clinic and CDC, <i>South Africa</i>	Organizing a group programme for newly diagnosed ALHIV using community counsellors	Interactive modular (3 - 6 modules) group programme supports newly diagnosed adolescents to link to care. Community counsellors facilitate group sessions and train adolescents with fun, interactive training modules on HIV. The evaluation study suggests that adolescents participating in this group counselling were more likely to commence ART if eligible than adolescents who did not participate.
Strengthening the continuum of care for children and adolescents with HIV	<i>Africaid, Zimbabwe</i>	Providing community-based treatment, care, support and prevention using trained HIV-positive adolescents as service providers	The “Zvandiri” (meaning “As I am”) model provides community-based treatment, care, support and prevention services for HIV positive children and adolescents. Zvandiri is led by HIV positive adolescents who are trained and mentored as service providers. HIV positive adolescents identify children for HIV testing, link children living with HIV to treatment and care, provide sustained counselling for children, adolescents and their families, provide adherence monitoring and support in clinics and homes, trace treatment defaulters and provide life skills training for their peers. These services are integrated within the clinical care provided by government and private clinics, creating a robust continuum of care for adolescents living with HIV and their families.

Issues addressed	Implementer, Country	Methodology	Programme description highlighting key factors that contribute to the success
Supporting adherence and disclosure for adolescent mothers	The Eve for Life, <i>Jamaica</i>	Using a comprehensive approach to support and care for adolescent mothers living with HIV.	The programme's comprehensive approach includes conducting a needs assessment, engaging older HIV positive women as "mentor moms" to build relationships with adolescent mothers, a monthly support group, support for adherence, and training of health care workers to improve their skills in service delivery for ALHIV. Girls are walked through a process of disclosure and role-play discussions with their loved ones. The process involves discussions regarding the selection of the partner(s), family member(s) or friend(s) to whom the clients will disclose, how and whether or not they require the assistance of a life coach, mentor mom or trained counsellor. It is required that each coach must have disclosed to their partner or a family member so they can be of optimal assistance to the girls in this area.
Strengthening advocacy for and by adolescents living with HIV	East European and Central Asian Union of PLHIV (ECUO) <i>EECA region</i>	Ensuring the needs and concerns of ALHIV are better articulated and communicated by meaningfully engaging ALHIV and strengthening their advocacy capacity.	The project aimed at cultivating advocacy skills of ALHIV with support from adult positive networks. This included the development and monitoring of social networking platforms, organisation of advocacy events where adolescents discussed their needs with policy makers with regard to adherence, education and other social services. The project also included mapping of organisations that provide health and social services to ALHIV in Ukraine, Russia, Kazakhstan, Uzbekistan, Kyrgyzstan and Belarus and beyond.
Linking adolescent-friendly sexual and reproductive health services with other services for adolescents living with HIV	Pathfinder International and the Mozambique government, <i>Mozambique</i>	Integrating support groups for ALHIV into adolescent-friendly health centers that provide HIV counselling and testing, ART and PMTCT	HIV counselling and testing, ART, and PMTCT were integrated into the Youth Friendly Services (YFS) service delivery package for the first time. Young people testing positive were provided immediate support and counselling, given a CD4 test, and linked to treatment if needed. Pregnant adolescents who tested positive were linked to PMTCT services. In addition, a trained psychologist spent several hours a day at the YFS offering counselling and support for disclosure as well as positive and healthy living. Finally, all youth clients testing positive for HIV were urged to join a weekly support group at the YFS facility led by peer educators with support from providers and the psychologist. Recognizing the success of this programme, the Ministry of Health issued guidelines in 2011 that all YFS facilities should have support groups for young people living with HIV.

**\*Adapted from UNICEF, "Lessons Learned: Strengthening health services and outcomes for adolescents living with HIV", 2013.**

# ANNEX 2 – METHODOLOGY

**Focus group discussions:** The goal of the community-based focus groups conducted by APN+ was to allow adolescents and young people (aged 12- 24) who are living with HIV to share their thoughts and ideas around access to health and other services. Four focus groups were held in four different countries: Nepal, Papua New Guinea, Philippines, and Thailand prior to the *My Right to Health* consultation. Each FGD was organized by a CBO affiliated with APN+. All FGDs were conducted in local languages and participants' identities were confidential. All participants signed informed consent forms. Several of the participants from the FGDs attended the *My Right to Health* consultation, and were able to share the results with their peers. For additional information about the FGDs, please contact APN+.

**Youth-led consultation:** '*My Right to Health*,' was a consultation for young people living with HIV in Asia Pacific in February 2013. The consultation brought together 14 adolescents and young people aged 16 -22 living with HIV from countries across the region. Countries represented were: Cambodia, India, Malaysia, Pakistan, Philippines, Papua New Guinea, Thailand, and Viet Nam. The consultation aimed to identify priority issues affecting health and well-being of adolescents and young people living with HIV, and to better understand the extent to which current policies, programs or services meet the needs of adolescents living with HIV. For a full meeting report, please contact APN+.

**Literature review:** A preliminary desk review was undertaken to understand laws and national policies as related to children and adolescents living with HIV in Asia Pacific, as well as relevant programs and interventions targeting or/and led by children and adolescents living with HIV as they relate to disclosure of HIV status, support for transition, dealing with life-long treatment, facilitating uptake of care, sexual reproductive health services and promoting leadership and advocacy, focusing on countries with documented generalized and concentrated epidemics including: Cambodia, China, Fiji, India, Indonesia, Lao PDR, Nepal, Thailand, Pakistan, Papua New Guinea, and Viet Nam.

Searches were conducted on PubMed, the Lancet, and International AIDS Society (IAS) and International Conference on AIDS and Asia (ICAAP) databases. In addition, due to the limited literature obtained through broad key word searches, specific sources were sought-out for relevant information including the AIDS Data Hub, UN agency publication databases, and so on, as well as pulling from the reference section of published articles of interest.

**Search terms:** Adolescents living with HIV and Asia; adolescents living with HIV and Pacific; adolescents and "perinatally infected" and Asia; Children and "perinatally infected" and Asia and HIV; Thailand and adolescent and HIV; adolescent and HIV and India; adolescent and HIV and Papua New Guinea; adolescent and HIV and Fiji; adolescent and HIV and Nepal; adolescent and HIV and Cambodia; adolescent and HIV and Myanmar; adolescent and HIV and China; adolescent and HIV and Lao PDR; adolescent and HIV and Viet Nam; adolescent and HIV and Pakistan; paediatric AND adolescent AND transition AND HIV AND asia; young people AND living with HIV AND asia

In general, while a few search terms returned a large number of results (such as Adolescents living with HIV AND Asia), few studies or reports actually focused on adolescents living with HIV in Asia, and much less with the priority topics identified.

Whether the study dealt with adolescents living with HIV in Asia, based on the abstract, title and key words; was enough to narrow down the results to a handful of sources. In total, 60 resources were identified as addressing some aspect of adolescents living with HIV's life and the key focus areas for the report and were reviewed. In addition, ten HIV National Strategic Plans and several GFATM reports were reviewed. The full list of reviewed literature is available in the Bibliography section of the report.

*Literature that was included in the review:* Full-text articles, brief reports, or abstracts that discussed topic of interest (below) in adolescents living with HIV in Asia Pacific. Due to the limited amount of available literature, some global literature that synthesized findings across regions was also included, as well as global guidance documents on key topics for adolescents living with HIV.

*Literature that was excluded from the review:* Programmatic guidance for countries/regions outside Asia as well as reviews, perspectives, editorials and studies that did not discuss any of the topics of interest in adolescents in Asia.

*Restrictions:* Review was only conducted of materials in English, and was limited to literature from 2002 onwards. In addition, due to limited resources, literature that could not be obtained for free was not reviewed, although often the abstract was reviewed. Finally, a possible restriction is that due to data for adolescents being subsumed in other age ranges, it's possible some articles were missed due to not being classified under our search terms.

***In-person interviews and site visits:*** For this report, 45 interviews were conducted by APN+ with adolescents living with HIV, caregivers, HIV doctors and NGO workers. Interviews were conducted in the preferred language of the participant in Cambodia, India, Lao PDR, Thailand, and Nepal. Forty-four interviews were conducted in person and one on the phone.

Participants were identified through local community based organizations and associations of people living with HIV. Adolescents living with HIV were selected with attention to gender, age and socio-economic diversity whenever possible. Interviews followed a standard question guide developed by APN+ to ensure coherency across the interviews. All participants received information about the report and signed APN+ consent forms.



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