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### THIRTY-NINTH MEETING

**Date:** 6 - 8 December 2016

**Venue:** Executive Board Room, WHO, Geneva

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**Agenda item 11**

**Thematic segment: HIV and Ageing**

**Country submissions**

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## INTRODUCTION

The PCB Thematic Segment which will be held on 8th December 2016 will focus on the state of the epidemic among people living with HIV and at risk of acquiring HIV aged 50 and above, the impact of ageing with HIV, including for key populations and women living with HIV, and identify areas of health and social sector responses.

In order for the session to be as up to date and evidence-based as possible, PCB Members, countries, partner organizations and colleagues were invited to submit case studies that illustrate key aspects of successful HIV interventions in the context of HIV and ageing.

A total of 17 submissions were received: 4 from African States, 3 from Asian States, 1 from Eastern European State, 1 from Latin American and Caribbean State, 6 from Western European and Other States, and 2 from multiple countries.

The submissions reflect the work of governments, civil society, United Nations and international organizations, as well as collaborative efforts. Many offer innovative approaches to HIV programming in a wide variety of services and programmes for people living with HIV aged 50 and older (including sex workers, men who have sex with men, transgender people, prisoners and people who use drugs). Together, they showcase best practices and provide compelling evidence for the need to support programs and health system structures dealing with a growing number of ageing people living with HIV.

## **I. AFRICAN STATES**

### **1. BENIN**

**Title of the Program:** Camp de retraite des jeunes adolescents nés avec le VIH pour le renforcement de l'éducation à la vie

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**Programme is being implemented since:** 2006

**Implemented by:** Gouvernement et Institution académique

#### **Scope of Submissions**

- Age-appropriate (and gender-sensitive) sexual health education
- Health services that support the transition from health services to Adolescents living with HIV who become adults
- Psychosocial programs for children born with HIV

**Has the programme been evaluated / assessed ?** Oui

**Is the program part of the implementation of the National AIDS Strategy?** Non

**Is the program part of the National Plan Broader than the National AIDS Strategy :** Non

#### **Contexte**

L'Unité de Prise en charge de l'enfant exposé ou infecté par le VIH (UPEIV) du Service de Pédiatrie de l'Hôpital d'Instruction des Armées de Cotonou au Bénin a été créée en Février 2000 dans la période où le Bénin s'est résolument engagé dans le programme de Prévention de la Transmission Mère-Enfant et de la mise à l'agenda du PNLN du renforcement de la prise en charge pédiatrique. Cette unité dans ses défis à lancer le projet « vivre, survivre et vieillir » avec le VIH en Mai 2007 après une revue de ses acquis qui montrait que l'introduction des sciences sociales et humaines en accompagnement de la clinique faisait réduire drastiquement la morbidité

et la mortalité, voyant des perspectives meilleures de vie à ces enfants. Ainsi la vision « vieillir » a vu une déclinaison de différentes stratégies dont l'une consistait à faire des camps de retraite en vue d'engager une vie responsable de ces adultes de demain. L'annonce du statut replonge l'enfant au centre de ses préoccupations de santé et de vie. Le partage d'expérience avec les pairs reste un véritable challenge. Pour documenter cette problématique que nous décrivons ici les défis et bénéfices d'un camp de retraite d'adolescents infectés.

## **Description**

Le camp de retraite a consisté au regroupement des adolescents infectés, filles comme garçon dans un milieu retiré et convivial. La pratique de la méthodologie « des boîtes de la mémoire » avec la démarche qualitative selon l'approche de phénoménologie descriptive a été appliquée à un groupe de 20 adolescents à chaque session. Dans une approche participative et interactive, entretiens approfondis, focus group, reconstruction de l'histoire, réalisation du « Memory box », lettres aux parents défunts, rivière de la vie, génogramme, livre du héros entrecoupés d'animations et jeux ont été menés pendant 10 jours. Ils sont hébergés en considérant leurs caractères, sexe et comportements. Les adolescents infectés sélectionnés étaient scolarisés, orphelins ou non d'au moins un parent, informés de leur statut, dont le consentement a été obtenu après celui de leurs chargés de soins. Certains frères et sœurs adolescents participent également selon le cas.

L'encadrement (2 psychologues, 3 assistants sociaux, 1 agent communautaire, 1 membre de l'équipe de soins) a utilisé des questionnaires de résilience, une échelle des sentiments, des enregistrements, et des films pour le recueil des données.

**Les objectifs** de ce camp de retraite sont de mieux connaître du vécu des enfants, de faire partager les expériences, de renforcer leur résilience et de définir leur accompagnement dans la vie.

Chaque camp de retraite est suivi d'une évaluation un an plus tard au cours de laquelle les acquis des adolescents ainsi que les composantes opérationnelles sont appréciés afin de faire des réajustements aussi bien programmatiques que structurelles pour mieux répondre aux besoins des adolescents.

Ce programme est fait et validé par une équipe multidisciplinaire sous la conduite opérationnelle de l'ONG OPTIMA-BENIN, structure mère du volet communautaire de l'Unité de Prise en charge de l'enfant Exposé ou Infecté par le VIH.

## **Résultats du programme**

Au total 4 camps de retraite ont été organisés de 2009 à 2010 et 135 adolescents y ont participé, 78 filles, 13 étaient des frères et sœurs non infectés. Le partage d'expérience des adolescents est

possible et très productif: ils peuvent décrire leur vécu, partager leurs expériences ; sont résilients et capable d'ouvrir les perspectives pour leur vie. Le principal facteur favorisant de leurs capacités ainsi renforcées est l'annonce du statut. Ils ont désormais foi en leur devenir en exprimant leur responsabilité dans leur perception de la maladie et dans l'observance du traitement. Les défis ont été l'obtention du consentement des parents et la gestion des crises psychologiques liées au rappel des souvenirs douloureux.

Par ailleurs, les demandes individuelles en termes d'accompagnement dans leur vie familiale, scolaire, et également dans leur vie sexuelle et reproductive sont connues avec des plans individuels d'accompagnement. Ce qui a conduit à l'organisation des rencontres thématiques au niveau de l'ONG OPTIMA-BENIN.

Une évaluation annuelle de ces rubriques est faite selon la demande de chaque adolescent.

### **Impact du programme**

L'impact a été la bonne rétention dans le programme ; la bonne scolarité des enfants, puisqu'on dénombre plus d'une trentaine de niveau universitaire allant jusqu'au Master 2 et ceux qui ont été mis en apprentissage ont pu s'insérer ; un bon programme d'éducation sexuelle, 6 adolescents ayant des enfants sains(non infectés par le VIH) et ayant une vie de couple stable. Par ailleurs tous les partenaires sont jusqu'à présent non infectés et connaissent le statut de leurs compagnes.

Une réduction drastique de la mortalité dans la cohorte. Les anciens ou les premiers adolescents sont actuellement de véritable cadre de développement des activités socio- communautaires et des encadreurs car nombres d'entre eux ont choisi comme cursus universitaire les études en sciences sociales et humaines ainsi que juridiques pour mieux s'impliquer dans la lutte au côté des cliniciens.

### **Financement et gestion**

Le programme a été exclusivement géré par le volet communautaire avec les autres unités de l'UPEIV, une mobilisation des ressources a été le succès ainsi que le leadership dans le suivi et l'évaluation des résultats et impact attendus.

Les différents partenaires, global health foundation, fondation gsk, caritas bénin et certaines personnes physiques notamment le personnel de l'UPEIV ont joué un rôle clé dans la réussite de cette initiative originale dans l'espace de soins aux enfants infectés par le VIH au Bénin

### **Enseignements tirés et recommandations**

Le fait que ce programme s'inscrive dans une vision d'amélioration de la performance globale du site de prise en charge de l'enfant dans le contexte du VIH a été le facteur important de son succès. A celui-ci s'ajoute le caractère multidisciplinaire de l'équipe qui s'est librement intégré des



activités de renforcement de compétences au travers de la recherche et de la formation. Tout ceci grâce à la participation des enfants et de leurs parents qui ont suivi et apprécié la transformation responsable des enfants qui aujourd'hui sont des cadres de développement et des acteurs de la stabilité financière de leur famille.

## 2. SOUTH AFRICA

**Title of the Program:** Putting the 'Great White Hope' out to pasture

**Contact:**

Name: David Patient Ross

Title: Inspirational Speaker, Trainer, Author and long-term survivor of HIV

### **Putting the 'Great White Hope' out to pasture**

*David Patient Ross, Inspirational Speaker, Trainer, Author and long-term survivor of HIV, 54 years old*

Ever since my health issues have escalated from March 2015, I have been questioning my desire to be 'David Patient- the Great White Hope-AIDS poster boy'... I've been doing it for 30+ years and while I do not underestimate my contribution, I am now asking the question, who is David Patient now and what does he want?'

Physically I am heavily restricted and while I tend to put on a brave 'no problem' face, I am uncomfortable most of the time [in any position, except when on my couch at a 45 degree angle or lying down on my bed]...anything else is very uncomfortable like sitting in a chair or plane seat/car seat] and in the past weeks, the pain in my hips and knees has escalated and is getting worse...I am destined to end up in wheelchair, it's just a matter of time. Not a reality I am looking forward too, but a reality nonetheless. My issues are not fixable and are degenerative. Fact.

Now that the farm has sold and we are moving along to a new future, I have made the call, after long talks with Neil, to retire "The Great White Hope"...I am done. I want to have a simple life with no public profile, no public commentary... nothing...I am done. I literally want to drop off the face of the 'HIV/AIDS/public health' scene.

So what does this mean?

Starting with immediate effect, I will no longer make public appearances. I have to be realistic. I simply cannot handle it. I'm also not a very good poster boy, regardless of how often I let people know that what I am going through is largely unrelated to HIV, they just don't get it. I certainly don't look like a monument to good health and not a good ad for positive living.

Another piece is that I am out of integrity... I tell people that none of this is HIV related

and while there is an element of truth in this, it's not 100% honest...long term use of ARV's have contributed to what I am dealing with - almost 13 years on Chemo have taken their toll on my body. The neuropathy, osteoporosis and osteoarthritis are as a direct result of long term exposure to ARV's. So I am out there advocating for people to get treatment but not telling them the long term effects of both the ARV's as well as the ageing process...the longer you are on ARV'S and the older you get, the more complications you have as you have to add ageing conditions/illnesses to the equations, so it gets complicated.

In addition, being away from my home, which is set up to deal with all my health challenges, is extremely stressful. My colostomy causes all sorts of embarrassing situations and I find my anxiety levels are through the roof as I never know if I am going to have a blow out in the middle of a training/talk/etc. I'm currently in a hotel and they are not set up for my needs despite me having a handicapped room. Cleaning out the bag is a nightmare while away from home and the height of the furniture/bed is not geared to my physical needs, so this adds to the pain and the angst. In this symposium I'm at now, I have had two blowouts and several loud farts [which I have no control over] and while I laugh it off, it is humiliating.

So I am putting The Great White Hope out to pasture and as of today, will be done with him. I have to draw a line in the sand and will now do what is in my best interest and based on my abilities. This symposium will be my last public engagement. As of noon today, I am retiring from The Great White Hope. I will finish my life story, have it published and that will close this chapter of my life. And those of you who know me, know that I never look or go back. I will maintain all agreements I have made but will not make any more. I will resign the various positions I hold and not assume any new ones. And I will pick and choose what and who I offer my experiences to as I am a born social worker and cannot not be involved in helping people. It's just who I am.

A professor asked me yesterday if I am aware of the contribution I have made to HIV, nationally, regionally and internationally and my response was " I will never truly know the answer to that Professor- history will be my witness and record keeper...the final chapter is still to be written!"

I have had an incredible life, no, make that a remarkable life. I have done things, gone places and worked with people I would never have been exposed to had it not been for HIV and for that I will always be grateful. I still say without hesitation that HIV has been my greatest teacher. I have incredible memories and have experienced emotions that cover the full range of human emotions and for all of it, I am filled with humility, joy, sadness and every known emotion in between. I have been extremely fortunate and now want to exit my old life and embark on a new one. What that looks like remains to be seen. It's a new chapter that I will write as it unfolds.

In closing, I want to say thank you to so many of you who have given me support and encouragement; who have taught me; challenged me; fought me; been there for me and

who have given me the drive/passion/tenacity to be who I am. I could not have done it alone.

And now it is time for me to move along... I just want to be plain old David and have to find out who he is and what makes him tick...

May you always have Enough.

Farewell and as Douglas Adams says in the series The Hitchhiker's Guide to the Galaxy series, So Long, and Thanks for All the Fish...

**David Patient Ross**

**28 October 2016**

### **3. UGANDA**

**3. 1 Title of the Program:** Improving the quality of life of older persons and the people under their care, especially orphans and vulnerable children through livelihood support, advocacy and institutional development

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**Programme is being implemented since:** 2008

**Implemented by:** Civil Society

**Scope of Submissions**

- Advocacy
- Prevention programmes for people living with HIV 50+
- Age-sensitive strategic information and monitoring systems

**Has the programme been evaluated / assessed ? Yes**

**Is the program part of the implementation of the National AIDS Strategy? Yes,**

**Is the program part of the National Plan Broader than the National AIDS Strategy : No**

## **Background**

Uganda has over 1.4 million people who are 60 years and above and this is expected to increase by 2030 (National OP Policy). 64% of the older people (OP) are sexually active and 91% have never used a condom during sexual intercourse (URAA and HelpAge, 2009). About 150,100 people aged 50+ are living with HIV and their HIV prevalence is estimated at 6.8% (Negin J and Cumming R, 2010), compared to 6.6% for the 15 – 49 age group (Uganda AIS 2011); Of these only 10% know their HIV status due in part that HIV counselling and testing centres are not age-friendly. 63% of the OPs take care of orphans and vulnerable children including those with HIV (MGLSD SAR, 2009).

The number of People Living with HIV&AIDS graduating into Old Age is increasing due to ARVs that have prolonged people's lives (HelpAge International, 2009). Healthy life expectancy at age 60 in Uganda is 3.7. Given this background, HelpAge International and Uganda Reach the Aged Association (URAA) identified the need to establish HIV Prevention, Care and Treatment advocacy group in 2008 to mitigate the impact of HIV&AIDS among older persons in the country

## **Description**

The advocacy group approach initiated by URRRA with support from SWEDEN SWEDEN and NORAD (Norwegian Agency for Development Cooperation) through HelpAge International was adopted by CSOs to implement a 5 year project titled titled "Strengthening social protection to prevent and mitigate the impact of HIV and AIDS in sub-Saharan Africa". The advocacy groups' drew their membership from Civil Society Organisations (CSOs), Older persons Associations (OPAs) and the government departments that are keen to develop and implement advocacy and policy influencing strategies which address the impact of HIV and AIDS among older persons in Uganda. The HIV advocacy group comprises of; THETA, NACWOLA, TASO, MGLSD-Department of elderly and disability, ADD, AIC and UNASO as the advocacy group coordinator. The objective of the group is to advocate for increased access to HIV prevention, care and treatment information for older persons in Uganda; The advocacy group identifies priority issues generated by evidence with an aim of influencing policy development and implementation

## **Results of the programme**

The advocacy group was able to reach over 200 older persons during evidence gathering and stakeholders meeting at the national level and Iganga district where the programme is also being implemented

### **Impact of the programme**

The advocacy aimed to influence; the inclusion of older persons in National HIV&AIDS policies polices and strategies, HIV messaging for older persons as well as increase number of older persons accessing HCT services and , HIV treatment and care services. At the national level, the programme has achieved inclusion of older persons in the MOH data collection (HIV incidence data tool age group was increased from 45-65), inclusion of older persons in HIV&AIDS policies policies, strategies and plans including the revised HTS policy, National HIV&AIDS strategic plan, policy on information and knowledge management and the HIV&AIDS control and prevention Act 2014. At the district level, there has been notable increase in the number of older persons accessing HCT services in Iganga district since January 2015

### **Financing and Management**

The programme is managed by URRRA who supports the advocacy group both financially and technically. It is coordinated by UNASO and the major partners include; THETA, NACWOLA, TASO, MGLSD-Department of elderly and disability, ADD and AIC

### **Lessons learned and recommendations**

- Team composition

The advocacy group comprises of individuals from institutions that have knowledge and interest in issues affecting older persons and work in the area of HIV&AIDS

- Evidence based advocacy

The advocacy group gathers evidence/information that is used during dialogues with key stakeholders

- Working with older persons

The advocacy group comprises of older persons including those living with HIV who are passionate about championing issues of older persons

### **Challenges**

- Inadequate financial resources that have affected the scope of engagement
- Lack of national data on older persons
- Delayed response from concerned duty bearers to prioritize older persons concerns

### **3.2 Title of the Program: Ugandan Grandmothers Gathering**

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**Programme is being implemented since:** 2015

**Implemented by:** Civil Society

#### **Scope of Submissions**

- Mobilization of grandmothers infected and affected by HIV that are caring for children orphaned by AIDS
- Psychosocial programmes for people living with HIV 50+
- Gender-responsive programmes, in particular for women living with HIV 50+
- Community-based services for people living with HIV 50+
- Old-age pension and supportive social care systems

**Has the programme been evaluated / assessed ?** No

**Is the program part of the implementation of the National AIDS Strategy?** No

**Is the program part of the National Plan Broader than the National AIDS Strategy?** No

#### **Background**

According to the UNAIDS 2013 AIDS by Numbers report, an estimated 3.6 million people living with HIV worldwide are aged 50 or older, and about 2.9 million of them live in low- and middle-income countries, where the percentage of HIV positive adults over 50 is above 10 percent. In Uganda, many of the elderly who are infected or affected by HIV – overwhelmingly the grandmothers – have had to return to parenting duties to care for the 2.1 million children

who have lost one or both parents to AIDS-related causes<sup>1</sup>.

After losing their adult children, grandmothers across Uganda and sub-Saharan Africa have stepped in to raise their orphaned grandchildren. They help them through their grief, keep them in school, feed them and keep them safe. They struggle with their own grief, age, sickness and poverty in order to build a future for the next generation filled with hope, health and opportunity. Local community-based organizations support the grandmothers with vital home-based care; income-generation projects; grief counselling and parenting workshops; school fees; nutritional support; housing; psychosocial, anti-stigma and disclosure support etc. In recent years, the number of grandmothers holding families and communities together has become too big to ignore, and some recognition of their commitment, sacrifice and challenges has begun to impress itself upon the international donor and development communities.

Grandmothers are standing up and speaking out. In October 2015 – just after the International Day of Older Persons, celebrated on October 1st – almost 500 grandmothers from across Uganda came together for the first ever National Grandmothers' Gathering, to raise national awareness of the issues they face and advocate for recognised rights and increased support.

## **Description**

Grandmothers began organizing at the community level in sub-Saharan Africa for the purpose of saving their grandchildren, families and neighbours from the worst ravages of the HIV/AIDS pandemic. Many took on leadership roles, and are now moving beyond the immediate struggle for survival and lobbying for systemic change. The National Gathering was planned to enable them and the organizations that support them, to develop agendas for advancing grandmothers' rights in relation to old age pensions and cash transfers; housing, land and inheritance; protection from violence; and improved access to HIV treatment and care.

The Ugandan National Gathering had four clear objectives: increased advocacy for grandmothers' issues countrywide; inclusion of grandmothers' agenda in national policy frameworks; inclusion of grandmothers' agenda in media, business, civil society, religious and bilateral planning; and establishment of a National Consortium to foster the grandmothers' agenda at national level. The Gathering took place over three days: two days of workshops run by and for grandmothers and, on the final day, a march through the streets of Entebbe, which culminated in the issuance of the Ugandan Grandmothers' Statement: a call to action and for increased rights and support.

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<sup>1</sup>Uganda National Household Survey 2009/10 UNHS 2005/06

Eleven workshops were held in three main thematic areas: economic empowerment (savings schemes; financial management; agriculture; wealth creation), HIV and AIDS (living with HIV; raising HIV positive children; disclosure) and social protection (land and housing; social security; inheritance; child support). The Gathering was organized by a dedicated organizing committee, made up of six key Ugandan community-based organizations working with grandmothers infected and affected by HIV and AIDS.

### **Results of the programme**

473 grandmothers from every region in Uganda attended the Gathering. News of the Gathering and the issues it raised reached the country and the world via news stories in every major Ugandan outlet as well as the BBC, Observer and Daily Monitor. The event was addressed by Theo Sowa, the CEO of the African Women's Development Fund; the First Lady of Uganda Hon. Janet Kataaha Museveni; Sulaiman Madada, Minister of State for Disability and the Elderly, and a representative of the President of Uganda.

### **Financing and Management**

The Ugandan Grandmothers Gathering was organized by members of an organizing committee, made up of leadership and programmatic staff from six key Ugandan community-based organizations. They coordinated the workshops and liaised with the grandmothers who ran them; organized the march; oversaw the budget; managed all the event logistics and administration; and produced the final report.

The Gathering was funded by the Stephen Lewis Foundation (SLF), which works out of Toronto, Canada to support community-level organizations that are turning the tide of HIV & AIDS in Africa by providing care and support to women, orphaned children, grandmothers and people living with HIV & AIDS. SLF's work is supported by a grant from the Slaight Family Foundation, which enables the SLF to host ongoing national grandmothers gatherings in countries across sub-Saharan Africa.

### **Lessons learned and recommendations**

The Gathering owes much of its immediate success and ongoing impact to the pivotal place in Ugandan communities of the grassroots organizations represented on the organizing committee. These groups are founded and staffed by community members themselves, who know the immediate and long-term needs and priorities of their families, neighbours and colleagues. The organizing committee members were founders and executive directors of



these community-based organizations, most of which have been supporting their communities for over fifteen years. They brought to the event a sense of urgency, a deep knowledge of the issues and challenges, an intimate connection with local grandmothers, communities, and leaders, and an expertise on Ugandan laws and available services surrounding the rights and support of grandmothers, orphans and people living with HIV and AIDS. They were able to mobilize logistical and financial support, organize a huge event quickly and efficiently, and confidently represent – through constant conversation and a dedicated granny representative – the needs and concerns of the grandmothers themselves. The Gathering would not have happened without them.

In order for the Gathering to be successful it needed to provide financial and emotional support to the grandmothers so they could arrange childcare, meals, school attendance for their grandchildren, and then travel long distances in order to attend. Many of the grandmothers were sick or weak themselves, and many had never before left their communities. The logistics, costs and strain of leaving their families and communities presented numerous challenges and required significant added input from the grassroots organizations that support them.

### **Key lessons included**

- Grandmothers themselves must be represented on the organizing committee
- The workshop agenda must be guided by input from grandmothers on what topics they most want to see and what information they most want to share
- Whenever a government official addressed the grandmothers in plenary, they had to agree to a Q&A portion where the floor would be open for all grannies to ask questions and engage directly
- Translation into local languages had to be organized in order to be inclusive of all grandmothers
- A marketplace was a valuable part of the gathering, where grandmothers could share their work and generate income
- There should be a platform for each grandmother group to share a performance from their region
- Workshops should be set up in circles so the grandmothers are comfortable and the time is interactive and conversational
- Counselling support and quiet space must be available to help grandmothers cope with the emotions brought up during sessions
- Health staff (with ambulatory care) must be on site at all times

- Healthy and familiar food must be serve

\*More Information on 'Ugandan Grandmothers Gathering' can be found at -  
<http://www.stephenlewisfoundation.org/news-resources/grassroots-newsletter/fall-2015/2>

## **II. ASIAN STATES**

### **4. INDIA**

**Title of the Program:** Vihaan Care and Support Programme for People Living with HIV and AIDS

**Contact:**

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**Programme is being implemented since:** April 2013

**Implemented by:** Civil Society

### **Scope of Submissions**

- Health-centre initiatives for people living with HIV 50+
- Community-based services for people living with HIV 50+
- Psychosocial programmes for people living with HIV 50+
- Gender-responsive programmes, in particular for women living with HIV 50+
- Services and programmes for key populations living with HIV 50+ (including sex workers, men who have sex with men, transgender people, prisoners and people who use drugs)
- Care services for people living with HIV to deal with long-term effects of living with HIV and taking ARVs

- Health and social services for children born with HIV and young people living with HIV
- Psychosocial programmes for children born with HIV
- HIV-sensitive education programmes for children born with HIV and young people living with HIV
- Health services that support the transition for adolescents with HIV to adult health services
- Age-appropriate (and gender-responsive) sexual health education

**Has the programme been evaluated / assessed ? No**

**Is the program part of the implementation of the National AIDS Strategy? Yes**

**Is the program part of the National Plan Broader than the National AIDS Strategy? No**

## **Background**

Alliance India's Vihaan (meaning dawn) care and support program was established under the fourth phase of India's National AIDS Control Programme (NACP), complementing the National ART programme. Vihaan established Care & Support Centres (CSCs), which were linked to the government's ART centres across India, serve as a comprehensive unit for treatment support for retention, adherence, positive living, referral and linkages to services. Vihaan CSCs also foster an enabling environment for PLHIV by working closely with stakeholders to ensure stigma-free and holistic services for PLHIV, especially those from high risk groups, and women and children infected and affected by HIV. Care and support services are provided through institutional and community based counselling, outreach activities and linkages with service providers to ensure that no PLHIV are left out of the care continuum.

## **Description**

The overall goal of Vihaan is to improve the quality of life of PLHIV. The program is implemented through 359 CSCS across India, and specific objectives of the program include:

- Early linkages of PLHIV to care, support and treatment services.
- Improved treatment adherence and education for PLHIV.
- Expanded positive prevention activities and early testing and diagnosis encouraged through appropriate counselling and peer support. All those who are tested positive will be supported to engage their sexual partners, family members and children for testing.
- Improved social protection and wellbeing of PLHIV.

- Strengthened community systems and reduced stigma and discrimination.

### **Results of the Programme**

Implemented in 32 states and 3 Union Territories of the Indian Union, the Vihaan program has enrolled 988,359 PLHIV in active HIV care with the ART centres of NACO till 30th June 2016, Enrolment in Vihaan is done by providing at least one service as per the program guidelines.

### **Impact of the Programme**

Out of 988,359 PLHIV enrolled under Vihaan, 114,260 (12%) belong to below 50 age-group. This includes 71,635 male, 42,461 female and 164 transgender population. The program provides the following services:

- Home-based care services to enhance management of treatment side effects, drug resistance, treatment failure and switching the regimen of ARV.
- Screening, testing and ensuring treatment initiation for those who are co-infected with TB.
- Rehabilitation of aged sex workers who are not getting any support from their family.
- Linkages with different government schemes like old age-pension and housing facility.
- Linkages with various government and non-government institutions for palliative care
- Aging PLHIV are engaged in positive prevention and positive living activities. They are treated as role-models and healthy lifestyle icons.

### **Financing and management**

India HIV/AIDS Alliance, being a Principal Recipient (PR) of the Global Fund, implements Vihaan programme through 17 Sub-Recipient (SR) and 361 Sub Sub-Recipient (SSR) organisations. These organisations include State and District Level Networks of PLHIV (SLN/DLN) and non- government organizations (NGOs). Nearly 70% of the implementing partners are SLN/DLNs. There is a three-tier structure for the programme implementation—PR at national level, SR at Regional/State level, and SSR at the district level. The PR is responsible for overall coordination with the National AIDS Control Organisation (NACO), State AIDS Control Societies (SACS), SRs, SSRs, and other key stakeholders involved in the programme implementation.

## Lessons learned and recommendations

Identifying the unique issues faced by PLHIV above 50 years and addressing them individual has been Vihaan's greatest success

- Strengthening outreach and LFU tracking through eMpower - Vihaan's data on Lost of Follow-up (LFU) clients, indicate that PLHIV above 50 years, are more prone to discontinue ART. The late diagnosis and ART initiation among them, often result in increased levels of side-effects and co-infections may prove to be critical, at times resulting in higher mortality rates. Vihaan addressed this by tracking every LFU client through an active outreach team. The outreach has been digitized through a tablet based application called 'eMpower'. This application enables outreach workers to keep track of the clients through live updates, indicating those who have not been regular or have fallen out of ART for high-priority follow-up.
- Reducing stigma through Vihaan's CSCs - Stigma against PLHIV is both societal and internalized as self-stigma, forcing PLHIV to live either undiagnosed or in denial out of fear of abandonment by family members or loss of employment and related benefits. Vihaan teams have adopted the policy of Greater Involvement of Positive People (GIPA), with many team members being PLHIV leaders. This enables the team to reach the PLHIV client base and provide effective support and empathetic counselling to them. They serve as role models by helping other clients to understand and challenge the stigma faced by them. They also regularly advocate on PLHIV issues and take action against stigma and discrimination cases.
- Community led initiatives - Vihaan supports community based organizations and PLHIV networks through capacity building initiatives, meetings and events to engage new members and develop new leaders. The biggest challenge faced here is of second-line leadership as many community leaders are above 50 years and face several health issues making them less active, yet they are unprepared to handover their responsibilities and have not developed a second line leadership to take over. Vihaan works intensively to overcome this challenge.
- Community friendly policies and laws - There are several programs and policies for the benefit of PLHIV above 50 but their implementation remains poor. Particularly, for the social protection schemes available for PLHIV, preferences are given to orphans and widows. While, PLHIV above 50 years may have increasing health issues, equally vulnerable and urgently need to be linked with these schemes. Recently, after years of advocacy the HIV Bill was passed by the Indian Parliament but it is yet to be enforced at the ground level. However, the bill brings the hope that strong legal measures will be developed to protect the rights, prevent and mitigate issues such as, stigma, against PLHIV and create an enabling environment for them.

## 5. THAILAND

### 5. 1 Title of the Programme: Living Longer with HIV in Asia Pacific

#### Contact:

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**Programme is being implemented since:** This was a research programme conducted between 2012 and 2014.

**Implemented by:** Civil Society

#### Scope of Submissions

- This was a research project by PLHIV about PLHIV living longer with HIV. It addresses the issues and needs identified for many of the above categories and indicates which ones are particularly important and provides some insight into what such services need to deliver.

**Has the programme been evaluated / assessed ?** The research was conducted against all the requirements of valid research and was approved by the Ethics Committee of the University of Malaya.

**Is the program part of the implementation of the National AIDS Strategy?** No

**Is the program part of the National Plan Broader than the National AIDS Strategy?** No

#### Background

APN+ is the regional peak body for Asia and the Pacific representing the voices of the PLHIV community. Its members are the in country PLHIV groups and networks in thirty countries of the region. This research was undertaken to identify the issues facing PLHIV who are living longer with HIV and primarily those growing older. The intention was to identify the key issues to inform policy and programmes to address the aging PLHIV population in Asia and the Pacific. This is

the ONLY research of its kind undertaken to date, with the research conducted by PLHIV with PLHIV, and under the auspices of the University of Malaya, thus ensuring the validity of the research for a technical, procedural and ethical point of view. It is the only research that examines aging other than in developed countries where the issues can be quite different because of the resource context.

## **Description**

The objectives of the research were:

- To raise awareness and encourage discussion among positive people in the Asia Pacific region about living longer with HIV;
- To create a body of knowledge about living longer with HIV that is culturally and/or norms specific to the Asia Pacific region;
- To inform advocacy on appropriate, effective and sustainable responses to living longer with HIV;
- To lead a positive community-centred response of living longer with HIV in the Asia Pacific region.

It was conducted by PLHIV on behalf of APN+, led by Martin Choo of Malaysia, under the guidance of an APN+ Working Group. It was designed after wide community consultation and it was conducted using an online platform. It looked at living longer with HIV and the consequences for economic, social, physical and mental well being. The project was funded by the Australian Government and had financial oversight by John Rock of APN+.

Most importantly the proposed presentation to the PCB on the conclusions from that research includes a post research update from John Rock on further insights into aging with HIV. At 72 and living with HIV for 36 years John Rock has a unique perspective on the subject. His own experience combined with that of a small cohort of long term survivors in developed countries (30 years and more), is extrapolated to the consequences for developing countries where he has done most of his HIV work.

He served on the NGO Delegation to the PCB as Asia Pacific Delegate, is on the Global Board of ITPC, a member of the Communities Delegation of UNITAID and has worked for APN+ regionally since 2004, and understands the different contexts in developed and developing countries. He will explain how the long term consequences of living with HIV are only now just beginning to be understood and has suggestions as to how Member States can minimise the future impact on individuals and their health systems by action now.

## **Results of the programme**

There were 360 respondents from 21 countries in the region. The research showed some very specific concerns, trends and issues together with recommendations for action.

Key issues included

- Only 60% were on treatment
- Many had difficulty accessing treatment
- Less than half of those on treatment had undetectable VL
- 43% of people suffered depression
- There was a high incidence of high blood pressure, non depressive mental illness, sexually transmitted infections and moderate levels of kidney disease and cancers
- A majority had economic difficulties. A third had not been able to afford food during the prior three months. Higher education and job security were indicators of better outcomes overall
- Almost half had had unprotected sex the last time they had sex

Whilst this was unique and groundbreaking research it also demonstrated the need for more research to be undertaken.

## **Impact of the programme**

The intention of the research was that it should be used in advocacy by in-country PLHIV groups to advocate with their governments and other institutions for action to address the issues highlighted. However since 2014 the ability of in-country PLHIV networks to undertake such advocacy has been hampered by lack of funding. The outlook for funding is even more dismal now. For there to be impact from any evidence based information generated by (or even about) the communities involved, there must be both funding and a willingness by governments to engage with such community groups.

## **Financing and management**

The research was funded as part of an Australian Government HIV Regional Capacity Building initiative. The funding ceased in July 2015. It was managed by APN+ staff (Project Officer) and a project working group, with financial oversight from an APN+ Advisor. It was implemented by a PLHIV consultant associated with APN+ and in consultation with the University of Malaya. The project would have been further strengthened by (i) Follow up research and (ii) The ability of the member PLHIV in-country networks to be able to conduct advocacy on the findings. There is no funding for either of these.



### **Lessons learned and recommendations**

APN+ has conducted several groundbreaking peer based research projects on issues such as stigma and discrimination, and treatment access, as well as aging with HIV. The value of such peer based research in informing the HIV response is huge. This research was a first step and could be usefully followed up with some further specific more in depth research on older demographics.

The research showed that there are significant concerns as PLHIV live longer with HIV, around economic, social, sexual, and physical and mental well being. These are largely ignored in Asia Pacific (and most probably in all the rest of the world, even in developed countries). Furthermore it is now more recently becoming obvious that many of the problems with the older cohorts and people who have lived longest with HIV are the consequences of HIV as an inflammatory disease. These require specialist medical attention and costly drugs, pathology and other interventions to address them.

It is not all about side effects of treatment itself, but many of the serious problems and premature aging we see are due to the inflammatory nature of the disease and the effect that has on the whole body. This is seen through premature onset of a range of NCDs and symptoms such as heart disease, severe arthritis, diabetes, organ failure, poor mobility, cataracts, frailty, etc. The potential costs to the individual and the health care systems (especially in developing countries), as well as loss of productivity, are huge.

**5. 2 Title of the programme:** Seniors fulfill their dream while knowing their rights Building capacity for promoting older people's rights and income security in Thailand.

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**Programme is being implemented since:** n/a

**Implemented by:** Civil Society

### **Scope of Submissions**

- Community-based services for people living with HIV 50+
- Prevention programmes for people living with HIV 50+
- Care services for people living with HIV to deal with long-term effects of living with HIV and taking ARVs
- Integrated services (non-communicable diseases, mental health, sexual reproductive health,
- Old-age pension and supportive social care system

**Has the programme been evaluated / assessed ?** Yes

**Is the program part of the implementation of the National AIDS Strategy?** Yes

**Is the program part of the National Plan Broader than the National AIDS Strategy?** n/a

### **Background**

Fulfilling the dreams of older people requires preparation from society, especially the economic and health sectors. Fulfilling the dreams also requires knowledge about older people's rights, which provides them with encouragement. The project Building capacity for promoting older people's rights and income security in Thailand, in cooperation with the Older People's Group (OPA) in Banthi District, Lamphun Province, organized a volunteer team named "Older People's Rights Promotion Volunteer Team of Banthi".

The team's purpose is to promote knowledge about older people's rights and to encourage, monitor, and protect those rights. The volunteer team also works with relevant government agencies in the 10 pilot villages to raise their awareness about the rights to older people. The project area of Ban Thi comprises 10 out of 20 villages with 1,191 families. The total population of the 10 villages is 4,838 people where the number of older people is 870 (M = 393; F = 477) which is 17.98 per cent. There is an older people's club in each village. Most of the older people, but those who are frail, are included to be members of the club. One hundred and fifty (150) out of 870 older people are engaged in the driving the club activities to address problems and needs of older people who are affected by HIV/AIDS

### **Description**

Gathering a strong group of older people brought us the power of negotiation with key organizations such as municipal offices. It is obvious that the HIV/AIDS is one of the causes of

poverty due to the lack of knowledge of the disease. The families were willing to spend resources for caring for the adult children who are infected. In reducing poverty, workshop style meetings were used in various villages to educate older people about 13 critical rights and entitlements for older people in accordance with Thailand's Older Persons Act 2003. The workshops also brought strength to OPAs. In the past, older people lacked useful knowledge and information for their daily living, especially knowledge of older people's rights, access to health services, and access to the Elderly fund provided by the government and so on. The Older Persons Act is in place but there is a gap between the Act and its implementation.

Since the volunteer team was organized a few years ago, Banthi OPA team have been handing out information such as on older people's rights in monthly meetings. That also strengthened the OPA itself. She also provided information to older people through word-of-mouth during special occasions such as Buddhist holidays.

Realising and accessing their rights brings an important change for older people, such as access to health services. For example, now they are keen to ask for a shorter queue for seniors. They also negotiate with government organizations for funding to support their OPA. The relevant organizations to be aware of older people's rights to access to their benefits and make them visible in society, the working group of the volunteer team who has worked hard on older people's issues for several years, to relevant organizations on behalf of older people.

### **Results of the programme**

The group of older people work has been recognised by local authority and provincial government departments. Significantly, the OPA of Ban Thi is the laboratory of community based aged care for other NGOs, CSOs and others. This group has been financial supported by the Ban Thai Local Authority. Society at large perceived better understanding of the families of people living with HIV/AIDS. In some areas the older people whose family members passed away with AIDS hesitate to participate in community cultural activities which leads to isolation. The project did bring back them to community events as usual by providing opportunity to engage in income generating activities to support their families.

### **Impact of the programme**

HIV/AIDS stigma has been gradually reduced and the older people living with people with HIV/AIDS are no longer isolate themselves. By and large, the fear of AIDS seems to be disappeared. This has brought the active older people who live with people with HIV/AIDS to engage in community activities, especially income generating activities (IGAs) to boost up the community economics.

### **Financing and management**

FOPDEV provided seed corn money for the OPC members to start their IGAs as the results of participatory needs assessment. The club members were trained on project management which include participatory monitoring and evaluation, proposal formulation, narrative report writing as well as basic financial management and reporting.

### **Lessons learned and recommendations**

In promoting older people themselves to run the activities of the project confront with some extent of physical capability. The lesson learned suggested that integration of activities and resources with local authority, community hospital and other related government department.

## **III. EASTERN EUROPEAN STATES**

### **6. POLAND**

**Title of the programme:** "My short Story" Wojciech J.Tomczyński Chairman of Polish Network of PLWHA "Sieć Plus

**Contact:**

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**Programme is being implemented since:** n/a

**Implemented by:** Civil Society

### **Scope of Submission & Description**

- Personal Story of a 70 year old man - living 30 years with HIV
- Helping in the sphere of psychological, social, spiritual and moral people living with HIV / AIDS and their relatives
- Taking measures to self-acceptance and acceptance of people living with HIV and their loved ones
- Formation of rational social behavior against the risk of spreading HIV
- Defending the rights of people living with HIV / AIDS

**Background:****My story**

“I was infected in 1986 at the age of 40. This year I turned 70; I have lived 30 years with HIV. When I found out, after confirming the Western blot, that I am infected with HIV-1, I felt like my life was coming to an end and thought I only had 2-3 years more to live. In those years, my knowledge about the infection and AIDS was very modest, hence why I thought I was soon going to die and so slowly began to prepare for that impending moment.

I quit my job, broke contact with immediate family and because I wanted to forget everything, I started drinking and taking sleeping pills. I decided not to return to Poland and was at the time living in one of the countries of Latin America, my life was a slippery slope lasted until December 1988 - 31 Grudnia. I then decided to return to Poland because I missed my children. On the 2nd of January because there were no flight tickets available to the capital, I went to go get the night bus. During the night-time drive, I was knocked unconscious and completely robbed! Thanks to the Polish Embassy, with the dressing on my head, was flown to Warsaw. From the airport, I was then immediately taken to a hospital for infectious diseases where I stayed for a month.

After the hospital, I lived with my mother, but as soon as I learned that the late Marek Kotański was organizing a meeting for people who know they are infected, without hesitation, I took part in this meeting, where I met my buddies later. During that meeting, we decided on the appointment of the first Polish organization whose task was to provide assistance to people who are HIV-positive and be involved in activities to prevent the spread of HIV.

This then was the first home for HIV-positive people in Rembertów near Warsaw.

Unfortunately, this functioned only one month, as local residents were protesting and then gave an ultimatum: either residents (4 persons) leave by January 31, or the house will be burned along with the house residents.

Immediately I came to my colleagues to sympathize with them and possibly stand up in their defense. Apart from me, it riled up a lot of people, Members of the Parliament, activists of other organizations, doctors, television and other media and the then Deputy Minister of Health, Ms Krystyna Sienkiewicz, who saw aggression of the residents and proposed to shift all the inhabitants to the cinema hall in the building of the Ministry of Health.

It was then when I decided that my place was among people living with HIV and so I joined four of them and lived with them in the Ministry of Health. We slept on mattresses on the floor, the meals were brought to us in vessels, which no one wanted to have back afterwards, they provided us with a separate bathroom; we spent two weeks there. Both Polish and foreign journalists came to visit us as well as important personalities of political life. On February 15 Father Arkadiusz Nowak of the Camillians, assisted by the spokesperson of the Ministry, took us away and moved into a beautiful house in Konstancin near Warsaw. It was a villa that

belonged to the Bureau of Government Close Protection, that was given in our possession by the Deputy Prime Minister and the Minister of Internal Affairs.

That's when Poles really learned more about HIV and AIDS because it was a "hot topic". During the 8 years existence of the house, it helped a number of infected people.. At the time, they succumbed to the infection mainly among injecting drug users. And sometimes the house served us, in some cases for detox. After the trauma and experiences abroad I lived in the so-called internal emigration until 1993, when he visited our house AIDES delegation from France, who came to scout for Polish and with a mission to help organize the environment of HIV positive people. Among the delegation was the oldest living man with HIV. When I heard about his story, I become aware that you can live with HIV and do something useful with your life.

Even while I was in France there had been a breakthrough in me and I decided I had had enough of this inertia and told myself "you should start doing something useful and help others so they in turn can help themselves". In 1990, my wife and I divorced but through all that and despite the limitations, I still had contact with three of my children; two boys and a girl. When I got to the infectious disease hospital for the first time, I asked Ms. head how many years I had to live. She replied that I have fairly high levels CD4 count and a promising 10 something years. After a month, I asked again and this time the response was 8 years. I was sure that life my life was going to end by 2000 and I was not going to live to see the new century.

However, fortunately, that was possible for me. I started taking drugs in May 1995 when pneumonia CD4 dropped me to 198 cells. I started taking AZT and in the summer from a nurse in Geneva, I got 1 package of saquinavir. Unfortunately, it was just this one that I had. Luckily for me, even from the beginning I was in the hands of excellent doctors who did a lot for me.

During those 30 years I had pneumonia twice and bronchitis many times. I came close to tuberculosis, infected HCV type 3A, but got rid of it after 48 weeks of treatment with interferon, operated on me cataracts on both eyes. In 2000, I was diagnosed with chronic obstructive pulmonary disease (COPD) and recently bronchiectasis. In addition, I have degeneration of the spine. Despite these small problems all the time, I am on ARV therapy but for various reasons I changed combinations of drug and 18 months and I'm on treatment one-tablet Stribild. My Cd4 increased to 1009 copies of the viral load has been undetectable for years.

I try to be active all the time, so in 1994. Stowarzyszenie established the Volunteers Against AIDS "Be with Us" in which I was vice-president for 10 years and in 2004 stood at the head Association of National Network of People Living with HIV / AIDS "Network Plus" and the third time this year, was elected as its Chairman.

I try to be active on the international scene as well. I am a member of ECUO, AAE, EATG, ECAB, EHLP and I was also a member of the Polish delegation to the PCB, UNGASS. From 1996 to 2012, I attended the international AIDS conferences IAS and EACS. However, the most important thing for me is my family, three children and their spouses, and my four grandchildren and an additional two on the way and of course all HIV 50+! I think I still have a lot to do here on earth, that is why I "scoffed" at God telling him I will live to be a 100."

#### **IV. LATIN AMERICAN AND CARIBBEAN STATES:**

##### **7. BRAZIL**

**Title of the programme:** Elderly people living with HIV programme in the Treatment and Training Reference Centre (CRT) of São Paulo state, Brazil

**Contact:**

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**Programme is being implemented since:** 2011

**Implemented by:** Government

**Scope of Submission:**

- Health-centre initiatives for people living with HIV 50+
- Prevention programmes for people living with HIV 50+
- Psychosocial programmes for people living with HIV 50+
- Ageing and health management programmes

**Has the programme been evaluated / assessed ?** No

**Is the program part of the implementation of the National AIDS Strategy?** Yes

## **Is the program part of the National Plan Broader than the National AIDS Strategy? No**

### **Background**

The 2009 Brazilian Census estimated circa of 4.5 million the number of elderly people in São Paulo state, which represents 10.7% of its overall population. It must reach about 7 million by 2020. This perspective has already provoked a national debate about a new approach of public health policy to this population, to assure the human right to dignity and quality of life. Those figures are based on notified AIDS cases, which means that is not possible to define the exact number of elderly people living with HIV (unaware of their serologic status). In São Paulo state, from early 1980's to 2015, were notified circa of 26,600 AIDS cases among people aged 50 and older, which represent 10% of all AIDS cases identified in the state of São Paulo during the same period. The incidence rate in 2014 was 14.3 per 100,000 inhabitants against 17.8 verified in Brazil. The average number of new cases has remained at around 1,300 cases per year in the last decade<sup>2</sup>.

The main transmission route among individuals aged 50 and over is sexual intercourse, both among males and females. In 2014, this category accounted for 90% of cases among males and 98% among females. Among males, the predominant exposure category was heterosexual (76%). When observing the proportional distribution of AIDS cases by race/colour in this age group, in 2014, 52% were among people with black race/skin colour, 47% among white, 0.4% yellow and 0.3% indigenous race/skin colour.

The HIV infected elderly people have a higher mortality risk and AIDS related death risk. In São Paulo state were registered 9,370 deaths per AIDS from 2000 to 2014, which represent 28% of the national AIDS deaths in the same period. Although the data indicates that AIDS diagnoses were made at older ages, probably by increasing the HIV incubation period, due to the introduction of highly active antiretroviral therapy, by improving both clinical and laboratory features used in patient follow-up and preventive measures taken by the AIDS control programme in the state<sup>3</sup>.

It is possible that the observed changes in incidence rate reflect behaviour changes such as an increasing of sexual activities in older people and, as a consequence, an increasing exposure of sexually transmissible infections (STIs). This issue could be clarified through specific studies focused on that age group, deepening of serologic information analysis and behaviour of people living with HIV recently diagnosed, such as performed at VCT clinics, and those just linked to the health facilities and services network focused on people aged 50 and over.

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<sup>2</sup> Ministry of Health of Brazil, 2015

<sup>3</sup> São Paulo, 2009



A survey conducted in 2008 by the Ministry of Health of Brazil about sexual knowledge and practices among the Brazilian population showed that 66% of the population aged 50 to 64 years declared to be sexually active in the last year prior the survey. Regarding sexual partners, the survey showed that 4% of people from this age group reported to have had more than five sexual partners and 16% had casual sexual partners in the last year months prior the study.

## **Description**

Earlier in the HIV/AIDS history, people were susceptible to develop opportunistic diseases, such as Tuberculosis and Neurotoxoplasmosis. The introduction of highly active antiretroviral therapy has increased survival and improved quality of life of people living with HIV/AIDS, leading in an ageing HIV-infected population. As a consequence, there was a decline in the morbidity and mortality owing to AIDS-related diseases and simultaneous rise in the proportion of non-AIDS-related diseases, such as cardiovascular diseases, renal disease, diabetes and bone disease. In spite of advances in antiretroviral treatment, adverse events and toxicities play a role with regard to dyslipidemia, insulin resistance, demineralization and renal impairment.<sup>4</sup>

In this context, the elderly people living with HIV programme was created in 2011 as part of the Treatment and Training Reference Centre (CRT) in São Paulo state, located in São Paulo city. CRT is an internationally recognized HIV centre.

The CRT prioritizes the participation of elderly people living with HIV over 50 years old, not yet enrolled in ARV treatment. It integrates two strategic areas of CRT: Infectious Diseases Clinics and Psychology, enhancing the comprehensive care of older people living with HIV. The team has one infectious diseases practitioner, one psychologist and other professionals from related areas such as a geriatrician, a nutritionist, a clinical pharmacist amongst others following a clinical protocol and registering data on medical records. The health facility where the patients are seen is adapted accordingly to this age group. The CRT blueprint accounts with a laboratory and imaging procedures. However, it is important to highlight that the personnel involved in the elderly programme are not exclusive to the medical care for this age group. Thus, the small team limits the public attendance capacity of to two new patients and two follow-up visits every week.

## **Results of the programme**

Since its inception, the elderly HIV programme of CRT have reached about 350 people (65% male and 35% female). The current patient is a man aged 93. This experience provides a better understanding of needs and particularities of the elderly people living with HIV, in a comprehensive care. It also helps to understand better the aging process itself, promoting earlier interventions in pathologies related to people over 50 years old.

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<sup>4</sup> Warriner et al, *Infect Dis Clin N Am* 28 (2014) 457–476

### **Impact of the programme**

The impact of the programme could be observed in qualitative terms, since it provides a personal approach to each patient, focusing on its healthcare needs, ensuring better quality of life to elderly people enrolled in the programme.

It also promotes professional integration and knowledge exchange within the ambulatory. In addition, it creates opportunities to develop partnerships with civil society organizations, aiming to increase HIV testing, counselling, peer education this age group.

### **Financing and management**

There is no private support to implement the elderly HIV programme of CRT. The initiative and its sources are all from the HIV, STI and Viral Hepatitis Programme of the São Paulo state.

### **Lessons learned and recommendations**

We have learned from this programme that lack and shortage of qualified human resources, unawareness of healthcare professionals about HIV and ageing and a comprehensive medical care approach are challenges that still need to be tackled.

## **V. WESTERN EUROPEAN AND OTHER STATES**

### **8. CANADA**

**8.1 Title of the programme:** National Coordinating Committee on HIV and Aging (NCC)

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**Programme is being implemented since:** 2010

**Implemented by:** Civil society

**Scope of Submission:**

- Health system structures dealing with a growing number of ageing people living with HIV
- Age-sensitive strategic information and monitoring systems
- Stakeholder mobilization

**Has the programme been evaluated / assessed ? Yes**

**Is the program part of the implementation of the National AIDS Strategy? Yes**

**Is the program part of the National Plan Broader than the National AIDS Strategy? No**

**Background**

In 2014, there were about 75,500 people living with HIV in Canada (PHAC, 2015). Though no prevalence data disaggregated by age is available for Canada, the UN approximates that 30% of people living with HIV here are age 50 or older (UNAIDS, 2013), and 37% of the CANOC cohort, a group of 10,239 individuals engaged in HIV care from three Canadian provinces, were 50+ as of 2014. This equates to an estimated 22,650-27,935 older adults living with HIV across the country. And since new HIV cases among this age group represent an increasing proportion of all diagnoses, 22% in 2014 (PHAC, 2015), and people with access to treatment are increasingly living into old age with HIV, this cohort will continue to grow.

Despite the fact that people living with HIV in Canada who have access to treatment are now living long lives and reaching old age, a disconnect remains between the HIV response, and organizations historically providing care for older adults and/or people living with chronic health conditions (long-term care facilities, home care providers, seniors' services, rehabilitation providers). The NCC attempts to identify common ground and improve access to services that meet the needs of older adults living with and vulnerable to HIV by bringing together stakeholders from different sectors and professional backgrounds, and older adults living with HIV.

**Description**

The purpose of the National Coordinating Committee on HIV and Aging (NCC) is to foster and strengthen connections between stakeholders who are working to address issues affecting older adults living with or vulnerable to HIV by:

- Supporting a collaborative approach to planning, implementing and evaluating new initiatives;
- Creating opportunities for cross-disciplinary, cross-sectoral, pan-Canadian information

exchange which enhance the ability of participants to respond in a coordinated way to improve quality of life for people aging with HIV and other chronic illnesses; and

- Identifying and securing the resources necessary to initiate and maintain collaborative work;
- Raising awareness of the assets, needs and experiences of older adults living with HIV among policy makers, researchers, service providers, educators, and the general public.

The mandate of the NCC is awareness-raising and policy change, but there are also two active working groups, one focused on programs and services, and the other on research. The NCC and its working groups comprise representatives from: national, regional and local HIV organizations; organizations and/or institutions serving older adults; communities living with HIV and other chronic illnesses, and other organizations/institutions that reflect the collective interests of people living and aging with HIV. Members from across Canada meet quarterly by teleconference and/or web conferencing.

### **Results of the programme**

There are approximately 50 active members of the NCC and its working groups. They are physically located across Canada and are positioned to influence decision-makers at the national, provincial, regional, local, organizational and community levels.

### **Impact of the programme**

Awareness Raising: NCC members published and circulated media talking points on HIV and older adults, and led a social media campaign, in the lead up to World AIDS Day 2015. The goal of this campaign was awareness-raising and both HIV prevention among older adults and the experience of growing older with HIV were addressed. Messaging from these two communications efforts reached more than 250,000 people.<sup>5,6</sup>

Gathering evidence: The NCC Research Working Group is collecting input on research priorities in HIV and aging from stakeholders across Canada and working to identify gaps in our collective knowledge about the needs and experiences of people aging with HIV in Canada. They are also advocating for disaggregation of the 50+ age category in epidemiological data on HIV incidence and prevalence analysed by federal and provincial monitoring agencies.<sup>7</sup>

Sharing promising practices: At each quarterly meeting, one member of the NCC Programs and Services Working Group describes an existing HIV and aging program, or discusses barriers to planning/implementing such programming within their organization.

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<sup>5</sup> National Coordinating Committee on HIV and Aging HIV & Older Adults – Nov 2015

<sup>6</sup> National Coordinating Committee on HIV and Aging World AIDS Day 2015 Social Media Campaign Evaluation Report

<sup>7</sup> EUpdate Article on HIV and Aging Research Priorities - May 2016

Collaboration: On an annual survey of NCC members, over 70% report having been introduced to at least one organization they have not worked with before as a result of being part of the committee. 76% report a moderate to large increase in the number of conversations they've had with colleagues about HIV and aging issues.

### **Financing and management**

Secretariat support for the NCC is provided by the Health Program Specialist at realize and this activity is funded by the Public Health Agency of Canada's National HIV/AIDS Voluntary Sector Response Fund (NHVSRF) through March 2017. Major partners include other national HIV sector organizations, community-based HIV service providers, government representatives, researchers and older adults living with HIV.

### **Lessons learned and recommendations**

- Engaging in joint projects, in addition to networking and sharing promising practices by teleconference, helps 'build a sense of common purpose and strengthen relationships and collaborations'
- Develop, and regularly update, committee terms of reference.
- Members of the NCC are surveyed annually to see if they are satisfied with group process (i.e. use of a consensus decision-making model, facilitation) and outcomes (i.e. whether participation has increased their ability to engage in cross-sectoral collaboration or increased their awareness of policies affecting people aging with HIV)
- Older adults living with HIV are valued members of all NCC working groups

### **8.2 Title of the Programme: HIV & Older Adults: Working Together Across Canada**

#### **Contact:**

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**Programme is being implemented since:** 2013

**Implemented by:** Civil society

**Scope of Submission**

- Training for health care providers about HIV in ageing populations (clinical diagnosis etc)
- Gerontological training for health care providers that includes HIV

**Has the programme been evaluated / assessed ?** Yes

**Is the program part of the implementation of the National AIDS Strategy?** No

**Is the program part of the National Plan Broader than the National AIDS Strategy?** No

**Background**

In 2014, there were about 75,500 people living with HIV in Canada (PHAC, 2015) and at least 30% of these individuals are estimated to be age 50 or older (UNAIDS, 2013). Since new HIV cases among this age group represent an increasing proportion of all diagnoses in Canada, 22% in 2014 (PHAC, 2015), and people with access to treatment are increasingly living into old age with HIV, this cohort will continue to grow.

People living with HIV may experience a greater burden of disease than their HIV-negative peers and thus may require more rehabilitative services and supports, sometimes at earlier ages (Kendall et al., 2014; Justice & Falutz, 2014). A recent study found that over 1600 people living with HIV were accessing home care, long-term care and complex continuing care in Canada, and among those in home care, people living with HIV tended to be younger, more socially isolated and more likely to have chronic psychiatric conditions (Foebel et al., 2016).

According to a needs assessment conducted by realize, only 22% of service providers indicated that their organizations offered sexual health education for older adults and only 14% said their settings offered support programming designed to meet the specific needs of people living with HIV who are age 50+. Less than half of survey participants (43.5%) said that they had personally cared for someone living with HIV and 70% of respondents had never received any training on HIV and aging.

**Description**

This project involved design, delivery and evaluation of an educational intervention for service providers working in HIV organizations, public health departments, long-term care facilities, home care agencies, seniors' services and other settings. The content introduces learners to

the care and support needs and lived experiences of older adults living with and vulnerable to HIV using a blended learning approach. Participants complete: 1) one interactive workshop co-facilitated by a national trainer and a local service provider and/or an older adult living with HIV; and 2) four online self-study modules.

The short-term objectives of the proposed intervention are threefold:

- To increase service providers' knowledge of the needs of older adults living with or vulnerable to
- To reduce HIV- and aging-related stigma among service providers; and
- To increase capacity among service providers to deliver high quality care for older adults living with or vulnerable to HIV.

This educational intervention is underpinned by social determinants of health and applies an intersectional lens to HIV and aging. It aims to increase knowledge, change attitudes and introduce new skills amongst care providers to foster seniors' services that are safe and responsive to the needs of people aging with HIV.

### **Results of the programme**

In 2014, 37 learners took part in a pilot version of the course. In 2016, 90 participants from three cities were engaged in a revised version which utilized a blended learning approach. At least a dozen stakeholders contributed to program development through advisory committees.

### **Impact of the programme**

#### Knowledge

- 79% of participants increased their self-reported knowledge by at least 20%.
- 43% of participants increased their knowledge by at least 10% based on an objective scale.

#### HIV or Age-related Stigma

- 61% of participants' scores increased by at least 20% on a subjective measure of stigma
- There was no change in age-related stigma based on a validated scale for ageism (Relating to Older People Evaluation scale; Cherry & Palmore, 2008)
- Average scores for HIV-related prejudice, stereotyping and discrimination all decreased based on the Health Care Provider HIV/AIDS Stigma Scale (Wagner et al, 2014)

- A number of participants self-reported feeling more comfortable and confident providing care and services for clients with HIV following the course.

#### Capacity to deliver high quality care for older adults living with or vulnerable to HIV

- There was an 18% average increase in confidence in participants' ability to help older adults living with HIV navigate the health and social service systems.
- 21% average increase in confidence in one's ability to recognize the signs of poor mental health among older adults living with HIV.
- 21% average increase in ability to identify at least one person to turn to with a question about supporting older adults living with HIV.

#### **Financing and management**

This project was led by realize, formerly the Canadian Working Group on HIV and Rehabilitation, and funded by the MAC AIDS Fund. It was modelled after a successful HIV and aging capacity-building and technical assistance program delivered by ACRIA in New York. Partnerships included: Canadian Home Care Association, Closing the Gap Healthcare Group, Nine Circles Community Health Centre and AIDS Coalition of Nova Scotia. Two proposals to continue this training program are currently pending - one to bring Working Together to front-line service providers in five new regions across Canada, and the other to train students in health professional disciplines using the blended learning curriculum.

#### **Lessons learned and recommendations**

- Allocate adequate staff time and resources for evidence-based course development and technical support when implementing a blended learning course.
- Identify strategies for increasing participant engagement and retention during the course.
- Amplify the voices of older adults living with HIV throughout the curriculum.
- Diversify learning modalities (embedded text, links to web resources, videos, quizzes and group discussion boards). A web-based format introduces flexibility and allows learners to study at their own pace and to schedule learning around other responsibilities.
- Engage an advisory committee throughout the course to review materials, monitor implementation, interpret evaluation findings, and recommend changes based on their lived experience with HIV and aging.



**8.3 Title of the programme:** Planning for the Long Term: A Psychoeducational Workshop Series for People Aging with HIV

**Contact:**

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**Programme is being implemented since:** 2011

**Implemented by:** Civil society

**Scope of Submission:**

- Community-based services for people living with HIV 50+
- Psychosocial programmes for people living with HIV 50+
- Gender-responsive programmes, in particular for women living with HIV 50+
- Services and programmes for key populations living with HIV 50+ (including sex workers, men who have sex with men, transgender people, prisoners and people who use drugs)
- Care services for people living with HIV to deal with long-term effects of living with HIV and taking ARVs
- Age-appropriate (and gender-responsive) sexual health education

**Has the programme been evaluated / assessed ?** Yes

**Is the program part of the implementation of the National AIDS Strategy?** No

**Is the program part of the National Plan Broader than the National AIDS Strategy?** No

**Background**

HIV prevalence data in Ontario shows that increasing numbers of HIV-positive people in the region are over age 50 (OCHART, 2015). In 2010 and 2011, aging service users of ACT – the AIDS Committee of Toronto (including long-term survivors) requested a group-based

intervention where people aging with HIV could access updated information while forming connections with their peers<sup>8</sup>. Planning for the Long Term (PLT) was created in response to the increasing numbers of people aging with HIV and the concerns these service users were raising with ACT. PLT seeks to achieve the following: (a) decreased social isolation among people aging with HIV, including long-term survivors, through group support that connects people to one another; and (b) increased knowledge about topics related to HIV and aging across physical, emotional, and financial health categories.<sup>9 10</sup>

## Description

PLT is offered twice a year: from April-June focused on physical health and from October-December focused on emotional wellness. Both program offerings are comprised of ten weekly 3-hour sessions. ACT's Group Programming Coordinator trains and supervises two volunteers that facilitate the group and coordinates participant recruitment. The first and last sessions of each series have no guest speaker – the volunteer facilitators work with the group through their anxieties, wishes, and goals for PLT and aging with HIV. The remaining eight sessions are all evenly split between a 90-minute guest speaker presentation and group discussion facilitated by the volunteers. Guest speakers include subject matter experts including people living with HIV, doctors, researchers, and other allied health professionals. The topics covered each year vary somewhat according to need and relevance, but here are the most common topics from year to year:

- **Physical Health:** HIV Treatment (drug interactions, side effects, etc.); Nutrition; Smoking Cessation; Physical Activity; Impact of an Undetectable Viral Load; Sexual Health; Comorbidities; and Substance Use and Harm Reduction.
- **Emotional Wellness:** Cognitive Health and Strategies to Enhance Memory; Rehabilitation; Benefits of School, Work, and Volunteering; Mental Health (managing stress, anxiety, and depression); Communicating with your Doctor and other Service Providers; Managing Disclosure; Healthy Relationships and Social Networks; and Resilience.

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<sup>8</sup> Cattaneo, J., Carusone, S., Makaroka, L., Karapita, S., King, K., Murzin, K., & Husbands, W. (2014). Living with HIV over the long term: Community report. AIDS Committee of Toronto. [https://issuu.com/actoronto/docs/cafe\\_scientifique\\_april\\_9\\_final\\_v7](https://issuu.com/actoronto/docs/cafe_scientifique_april_9_final_v7)

<sup>9</sup> Cattaneo, J., & Murzin, K. (2012). Community report: Planning for the long-term. AIDS Committee of Toronto. <http://www.actoronto.org/research.nsf/pages/act.research.0382>

<sup>10</sup> Ontario Community HIV and AIDS Reporting Tool (OCHART). View from the Front Lines, (2015): Annual summary & analysis of data provided by community-based HIV/AIDS services in Ontario. Toronto, ON: AIDS and Hepatitis C Programs, Ontario Ministry of Health and Long-Term Care and the Public Health Agency of Canada, Ontario Region. [https://www.ochart.ca/documents/2016/VFFL\\_EN.pdf](https://www.ochart.ca/documents/2016/VFFL_EN.pdf)

The objectives of PLT are as follows:

- Provide a thorough understanding of physical and emotional health issues that affect people living with HIV/AIDS through guest speakers and resource distribution.
- Counter fear-based reactions by normalizing emotions caused by discussing these issues. Develop coping strategies to use in day-to-day life.
- Hold a facilitated discussion regarding the topics being presented in a safe, non-judgemental space.
- Uphold a positive outlook throughout the series, reinforcing that you can have a healthy life, strong physical and emotional health, and an active sex life regardless of an HIV diagnosis.
- Link participants to programs, services, and resources available to them.

### **Results of the programme**

PLT is accessible based at ACT in Toronto, ON – an organization with over 1000 HIV-positive service users in a city of approximately 16,000 people living with HIV (City of Toronto, 2014). Over 100 people have accessed PLT since it was first offered in 2011.

### **Impact of the programme**

Impact is measured by likert scale pretest and posttest data in the following categories: Physical Health, Sexual Health, Mental Health, Cognitive Health, and Social Engagement. All participants that complete PLT report positive change in these categories. Impact is also measured through uptake of referred services as many participants choose to access cognitive screening, exercise programs, employment services, and other supports following presentations on these topics. Many participants also form informal support networks with one another and continue to meet and support each other following completion of PLT.

### **Financing and management**

The program is financed by federal and municipal government grants and has proven sustainable through multiple grant cycles.

### **Lessons learned and recommendations**

Building this program from the results of an ACT-led research project meant that research participants could see their contributions having immediate impact. The biggest challenge for the program was encouraging women aging with HIV to participate, as most of the people that informed the program's pilot identified as male. The program coordinator made multiple

presentations to groups of women living with HIV to encourage their participation and currently each series of PLT has an even balance between men and women.

## 9. FINLAND

**Title of the programme:** A video submission “Yhdenvertainen vanhuus- Haluaisin pystyä kertomaan - Risto” (Equal Age)

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**Scope of Submission:**

- HIV and Ageing
- HIV Infected people and their families
- Peer support
- Advocacy

### Transcription of Video

Yhdenvertainen vanhuus- Haluaisin pystyä kertomaan - Risto

“I have lived a really happy childhood. Our mother told us as children that none of us was an unwanted child - we were all hoped for and expected. In 1950s' I first time woke up with the feeling that something was not right, and I was somehow broken. I had the first love affair at school, but it was very secret. At some stage I read from books that it is normal. From SETA (“Sexual equality” -an national human rights NGO) I have received support and learned that we are many, and we can all be different, yet we are all accepted. I'd like to be able to one day tell everyone what I am, and what is the “real Risto”.

My homosexuality alone is one thing I am afraid to tell to anyone, because not everyone would understand it. If they also knew that I was HIV positive, it would be even a greater risk to increase the stigma. HIV medication is a strong part of my life, and I have to take them every day. The day I am unable to control my own medication I need help. I hope someone is there to help me. I have lived the time when in the hospital I was totally isolated due to my HIV positivity. When I recently was in a car accident I was surprised how I was not isolated, I was in a room where there were others, just normal patients. When I was recovering among “normal people” I felt wonderful, being treated as anyone else.

Stigma no longer forced people to protect themselves unnecessarily from HIV. Let's see how it is when I will be put into a home for the elderly, and perhaps people around me will not have the same knowledge and understanding. I regret nothing. I have found in myself the wonderful side of being a homosexual, and I have fully accepted it. It is wonderful. The issue of growing old is a fact. We no longer die of AIDS, but because of growing old and ageing normally. With my friends

we have talked that it would be wonderful if we had a safe haven, and elderly home, where they could treat us accordingly, even at a stage when we have lesser understanding of things. I wish there was an elderly home that could take into consideration homosexuality and understand it is not an illness, it just is.”

## 10. FRANCE

**Title of the Programme:** VIH et VIEILLISSEMENT

### **§.I. Etat des lieux**

Les dernières enquêtes démontrent, la nette amélioration de l'état de santé des personnes âgées de plus de 50 ans vivant avec le VIH.

**Actions traitements, « Vivre avec le VIH après 50 ans, préserver sa santé », brochure en ligne.**

« Entre 2003 et 2011, la proportion des plus de 50 ans parmi les personnes atteintes de VIH a augmenté, passant de 25% en 2008 à 35% en 2011. Nombre d'articles évoquent souvent un vieillissement accéléré ou prématuré qui pourrait être du au VIH et/ou aux traitements contre le virus. Mais les choses ne sont pas si simples. Les études les plus récentes permettent de nuancer certains de ces éléments. L'apparition d'un ou plusieurs troubles associés au VIH (les comorbidités) serait moins liée à l'âge qu'à l'histoire médicale de l'individu, mais aussi à ses habitudes (tabagisme, consommation d'alcool ou de drogues, sédentarité, etc). Ainsi, une personne de plus de 50 ans, sous trithérapie depuis la découverte de sa séropositivité, en rémission immuno-virologique », ayant une charge virale indétectable depuis au moins 5 à 6 ans, un taux de CD4 supérieur à 500 et une bonne hygiène de vie, ne vieillirait pas plus vite qu'un cinquantenaire séronégatif. En 2012, une étude menée sur 80 000 patients en Europe a mis en évidence une espérance de vie quasi équivalente à celle de la population générale. Cette étude a même montré un risque de mortalité inférieur à celui des personnes séronégatives chez les homosexuels masculins atteints par le VIH. Ce résultat s'explique probablement par l'impact positif d'un suivi médical régulier sur la prévention et le dépistage d'autres maladies ».

**Rapport Morlat, « Prise en charge médicale des personnes vivant avec le VIH - Recommandations du groupe d'experts », 2013**

Le rapport Morlat pondère quelque peu ce bilan, mais va globalement dans le même sens que l'article du TRT5, il précise ainsi : « Les PVVIH présentent, avec une prévalence augmentée par rapport à la population générale, un certain nombre de comorbidités classiquement associées au vieillissement : troubles métaboliques, risque cardiovasculaire,

ostéoporose, troubles neurocognitifs, atteinte rénale et hépatique, cancers

## **§.II. Problématiques générales et spécifiques identifiées**

**En France, la prise en charge des personnes âgées est pensée et structurée dans sa globalité. Et ce au delà des problèmes spécifiques de santé que chaque individu est susceptible de rencontrer.**

Les questions centrales liées au vieillissement concernent l'ensemble de la population générale, que les individus soient séropositifs ou séronégatifs :

- l'autonomie,
- le maintien à domicile,
- la coordination des interventions, des professionnels sanitaires, sociaux et médico sociaux,
- le parcours de soins,
- la question des aidants,
- et in fine, la très grande dépendance.....

L'ensemble de ces éléments sont des problématiques qui intéressent la majorité des personnes âgées qu'elles soient concernées ou non par une maladie chronique.

L'amélioration de l'espérance de vie des PVVIH (personnes vivant avec le VIH) et la chronicisation de cette infection (au même titre que le cancer, le diabète ou les maladies cardiovasculaires), **n'ont pas conduit à élaborer une politique de santé publique spécifiquement dédiée aux PVVIH vieillissants. Car in fine, les problématiques rencontrées sont les mêmes**: santé, autonomie, dépendance, parcours de soins, interventions à domicile.

Dans les faits, les difficultés récurrentes rencontrées chez les PVVIH vieillissants sont majoritairement liées à l'isolement, la précarité économique et accessoirement à l'accueil en EHPAD.

En effet, cette communauté peut se caractériser, par un isolement accru, du fait de :

- La non reconnaissance légale des couples homosexuel jusqu'à l'adoption du PACS (1999) et du mariage pour tous (2013),
- L'épidémie du VIH,
- Les diverses discriminations et réactions de rejet de la part des familles d'origine,
- La difficulté à concevoir ou à adopter un enfant,
- L'ensemble de ces déterminants contribuent à l'isolement et créent des difficultés notables lorsque les personnes deviennent dépendantes.

**AIDES, « Enquête VIH, Hépatites et vous », 2010 :**

- 72,3% des PVVIH de +de 50 ans se déclarent célibataires ou seules.
- 62,6% vivent seules.
- 27,8% avec un partenaire ou un conjoint.
- 61,1% ne peuvent compter sur des personnes pour un hébergement de quelques jours en cas

de besoin.

- 54,3% ne peuvent compter sur aucune matérielle en cas de difficultés.
- 88,7% ne peuvent pas toujours compter sur un tiers pour les amener chez le médecin
- 32,4% n'ont jamais quelqu'un à qui parler en cas de besoin
- 14,1% n'ont jamais personne pour leur manifester de l'amour et de l'affection.

Pareillement, la fragilité économique due à un parcours professionnel morcelé par la maladie paupérise cette population:

- faibles ressources,
- petites retraites,
- absence d'épargne
- difficulté d'accèsion à la propriété vu le cout de l'emprunt...

**Selon une enquête seronet.info et l'étude « VIH, Hépatites et vous » Aides 2010**

- 16,8% des PVVIH de + de 50 ans déclarent bénéficier d'une retraite à taux plein.
- 4,1% des répondants pensent pouvoir compter sur l'aide financière d'un proche
- 52,8% déclarent rencontrer de réelles difficultés financières pour faire face à leurs besoins.

En 2013, Michèle Delaunay, la ministre chargée des personnes âgées et de l'autonomie a confié à trois associations, une mission sur le vieillissement de la communauté homosexuelle et parmi elle celui des personnes séropositives:

- SOS Homophobie,
- Groupe SOS,
- Aides.

Aussi, a-t-il été demandé à ces équipes de réfléchir à des propositions opérationnelles afin de prendre en compte, trois sujets :

1. Le vieillissement de la communauté LGBT (lesbiennes, gay, bisexuelles et transsexuelles),
2. L'accueil en établissement et l'usage des services à la personne,
3. Vieillir et sida : le nombre de personnes de plus de 60 ans vivant avec le VIH allant croissant.

Ce que met en exergue ce rapport est la question de l'intégration en EPAHD. En effet, avec les questions liées aux dimensions affectives, sociales et économiques l'accueil de ce public peut être plus compliqué.

Ainsi, les personnes LGBT concernées par le VIH ne sont pas prévues dans les schémas d'accueil et dans la formation des auxiliaires de vie travaillant en Institut. Il peut, alors, en résulter des comportements inadaptés liés aux spécificités de ces publics :

- comme par exemple, une consommation accrue de substances psycho actives, des problèmes familiaux, des deuils, un isolement ou une dépendance à l'alcool.
- Ou encore, une gestion compliquée des interactions médicamenteuses pour les personnes transgenres.
- Enfin, les publics PVVIH peuvent également avoir des histoires de vie plus complexes. Cependant, la prise en charge en EHPAD reste globale et ne se focalise pas sur les spécificités de cette communauté. En plus de comportements discriminants des personnels hospitaliers, les demandes d'admission quel que soit le profil de la personne font généralement l'objet d'un passage en commission d'entrée.

En plus de comportements discriminants des personnels hospitaliers, les demandes d'admission quel que soit le profil de la personne font généralement l'objet d'un passage en commission d'entrée.

Dans la pratique, les refus possibles énoncés peuvent être liés :

- d'une part au **profil médical de la personne** : pathologies psychiatriques trop importantes.
- d'autre part lors de l'examen du dossier, la charge en cours du personnel soignant est évaluée pour estimer si la prise en charge du nouvel arrivant est gérable.
- Pareillement, **le profil social de la personne** peut être aussi pris en compte. Un public plus difficile, désociabilisé, avec des difficultés d'intégration peut faire l'objet d'un refus car il nécessitera un temps relationnel plus important.
- Enfin, l'identité de genre n'est pas clairement mentionnée dans le dossier par contre la séropositivité à l'infection VIH apparaît clairement comme une possibilité de discrimination mais difficilement identifiable. **Le volet financier de la prise en charge**



joue un rôle dans l'acceptation des dossiers. L'aide sociale à l'hébergement n'intervient que lorsque la personne est admise dans la structure.

- Autre point sensible, **la prise en charge des dépenses de soins dans le cas de molécules dites onéreuses** (molécules ARV pour les PVVIH). En cas d'une pharmacie à usage interne au sein de l'EHPAD, la prise en charge revient à l'établissement. Or certains établissements peuvent refuser des patients dont la prise en charge médicamenteuse serait trop coûteuse au regard du budget de l'EHPAD.

En 2011, 22% des EHPAD représentant 31% des places, disposaient d'une pharmacie à usage interne. **Toutefois certaines ARS allouent sur demande des établissements des crédits exceptionnels pour aider à cette prise en charge.**

Depuis quelques années, se sont développés **des modes d'accueil communautaires** comme la maison des Babayagas à Montreuil ou encore le projet « village – canal du midi ». **Ce type de projets communautaires peut être vu comme une rupture du pacte Républicain.** Inversement, les personnes et les associations auditionnées dans le cadre du rapport rendue à Mme Delaunay, font montre d'une demande réelle et récurrente de lieux d'accueil pour personnes LGBT.

### **§.III. Les réponses apportées en France**

En France, le système de protection sociale mis en place vise à protéger les individus des différents accidents et divers risques inhérents à l'existence :

- Ainsi, **l'inscription en affection longue durée (ALD) de l'infection par le VIH** permet une prise en charge à 100% des soins de santé afférents,
- L'inscription à la Maison Départemental des Personnes Handicapées (MDPH) lorsque la maladie chronique peut être invalidante permet de toucher diverses aides financières ; l'allocation adulte handicapé (**AAH**) garantit un revenu minimum visant à faire face aux dépenses de la vie courante. La prestation de compensation du handicap (**PCH**) peut prendre en charge en totalité ou en partie les dépenses liées au handicap.
- **L'APA** (allocation personnalisée d'autonomie) est destinée aux personnes âgées de 60 ans et plus en perte d'autonomie. L'APA aide à payer les dépenses nécessaires pour rester vivre à domicile malgré le manque d'autonomie, ou aide à payer une partie du tarif dépendance en EHPAD (établissement d'hébergement pour personnes âgées dépendantes). L'APA est versée par le conseil départemental.
- **L'accueil en EPHAD** est possible à partir de 60 ans lorsque la dépendance devient trop lourde et avec une aide financière du département si la personne connaît des difficultés financières.
- Enfin, **les dispositifs de services d'aide à domicile ont pour objectif de favoriser l'autonomie des personnes âgées** et leur permettre de continuer à vivre chez elles le

plus longtemps possible. Ces interventions concernent : l'entretien du logement et du linge, l'aide au lever, l'aide à la toilette, l'aide aux courses, la préparation des repas, la prise des repas, l'aide au coucher. Les aides à domicile peuvent également accompagner les personnes âgées lors de sorties, réaliser des activités de loisirs avec elles, et ainsi contribuer à maintenir leur vie sociale. Certains services d'aide à domicile peuvent également proposer les prestations suivantes : Télé-assistance, portage de repas à domicile, petits travaux de bricolage.

- Une enquête (« VIH, hépatites et vous ») réalisée par Aides en 2010 sur un échantillon de 2 356 personnes montrait que presque un tiers des PVVIH de +de 50 ans disaient avoir besoin d'aide pour réaliser les gestes de la vie quotidienne (ménage, courses, repas, toilette etc.). Pour ceux qui recevaient des aides à domicile (73%), 74% déclarait qu'elle répondait à leurs besoins.

Comme évoqué précédemment, en France la question du vieillissement est traitée dans sa globalité et surtout dans une approche indifférenciée des individus. Elle ne tient compte ni de l'orientation sexuelle, ni du genre et encore moins du statut sérologique des individus, elle s'adresse à toutes et à tous et concerne l'ensemble des seniors susceptibles d'avoir recours à l'ensemble des aides et des dispositifs et existants.

Toutefois de 2010 à 2014, « *le plan national de lutte contre le VIH/SIDA et les IST* » a défini **et a mis en place des actions visant à limiter, en amont, la précarité économique et la fragilité des seniors concernés par le VIH**. Ainsi, le volet prise en charge sociale et lutte contre les discriminations du plan, prévoyait de :

- Faciliter l'accès, l'insertion, le maintien et le retour dans l'emploi,
- Favoriser l'accession à la propriété,
- De sensibiliser les opérateurs des prestations handicap et invalidité aux spécificités des handicaps liés au VIH/SIDA et aux maladies chroniques,
- De favoriser via des formations, les approches respectueuses des choix d'orientation sexuelle en intervenant auprès des professionnels sanitaires et sociaux en contact avec la population des femmes et des hommes homo-bisexual(le)s.

## 11. UNITED KINGDOM

**Title of the Programme:** Health, Wealth and Happiness

**Contact:**

Name: Clive Blowes

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**Programme is being implemented since:** 2012 (Pilot) & 2014 (National launch)

**Implemented by:** Civil society

**Scope of Submission:**

- Community-based services for people living with HIV 50+
- Psychosocial programmes for people living with HIV 50+
- Services and programmes for key populations living with HIV 50+ (including sex workers, men who have sex with men, transgender people, prisoners and people who use drugs)
- Training for health care providers about HIV in ageing populations (clinical diagnosis etc)

**Has the programme been evaluated / assessed ?** No

**Is the program part of the implementation of the National AIDS Strategy?** No

**Is the program part of the National Plan Broader than the National AIDS Strategy?** No

**Background**

In 2010, when little evidence existed, THT partnered with Age UK and The Joseph Rowntree Foundation and published a report, [A National Study of Ageing and HIV \(50 Plus\)](#), examining the needs and concerns of older people living with HIV (OPLWH) as they age. This showed that older people with HIV can be disadvantaged in a wide range of ways – from poorer health, to social care issues and housing problems and recognised the need for tailored support. Our project grew from this study to provide the support needed, acknowledging that over 50s are the fastest growing group of people living with HIV.

**Description**

The project was implemented in 2012 by THT. An innovative project t, it supports the financial, emotional and physical well being of over 50s living with HIV in Brighton, Bristol, London, Manchester and the West Midlands. It aims to increase resilience to manage key transitions in the lives of older people. It delivers:-

- Peer support to address isolation and loneliness

- Accredited Advice on benefits, housing, managing money, and planning for older age
- Counselling & Emotional support to develop coping strategies, deal with life transitions
- Opportunity to develop new skills and gain improved knowledge (e.g. IT skills, mindfulness)
- Partnership work with other organisations to provide a joined up and holistic support
- HIV training for mainstream organisations to improve their understanding of HIV and ageing to better equip them to deliver services
- Inform policy and practice through lobbying and campaigning using project evidence.

### **Results of the programme**

The pilot worked with 192 people in London. The national programme has supported over 730 people to date. The current programme covers five major cities in the UK.

### **Impact of the programme**

The project helps OPLWH to manage key transitions related to ageing/HIV. Through social inclusion activities, 328 OPLWH (to date) are now reconnecting with their communities, making new friends and developing peer networks. Through skills building activities, 288 OPLWH report learning new skills that will help them manage life changes, such as IT skills and relaxation techniques. Our advice, counselling and workshop activities have enabled 432 OPLWH to report reductions in anxiety and tension and increased levels of confidence for the future.

Our accredited advisors have supported 350 people with a variety of welfare and financial matters and achieved over £430k in financial benefits for OPLWH in Year 2 alone. The project's exceptional ability to engage and build the capacity of OPLWH can be demonstrated by our mobilising/upskilling OPLWH as peer mentors to support those less able. Highly successful partnerships have been developed - demonstrated by an 87% increase in sign-posting routes during our pilot. Our organisational training has enabled 82 organisations to have greater understanding to support OPLWH.

### **Financing and management**

The project is coordinated/managed by THT, with partners George House Trust in Manchester. Now in its third (final) year, it has been financed by the Big Lottery Fund, which is funded by the UK's National Lottery.

## **Lessons learned and recommendations**

The project is peer-led, ensuring that services delivered are what are needed. We rely on a large network of partner organisations to provide expertise and an holistic approach. A big challenge is reaching service users with no access to technology in a digital age who may only access their clinic twice a year. Changes in social care and welfare are impacting clients significantly both financially and in terms of access to care.

## **IX. MULTIPLE COUNTRIES**

### **12. EUROPE**

**Title of the programme:** Ageing with HIV, a lifecycle approach

**Contact:**

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**Programme is being implemented since:** December 2015

**Implemented by:** Civil society

**Scope of Submission:**

- Health-centre initiatives for people living with HIV 50+
- HIV-sensitive education programmes for children born with HIV and young people living with HIV
- Age-appropriate (and gender-responsive) sexual health education
- Training for health care providers about HIV in ageing populations (clinical diagnosis etc)
- Age-sensitive strategic information and monitoring systems
- Community led research gaps related to ageing with HIV
- Community mobilization

**Has the programme been evaluated / assessed ?** Yes

**Is the program part of the implementation of the National AIDS Strategy? No**

**Is the program part of the National Plan Broader than the National AIDS Strategy? No**

## **Background**

Although important progress has been made in the HIV treatment field in the last decade, there are still many gaps concerning research and appropriate responses in terms of health and social care focused on specific aspects such as age, gender and country origin, physical and psychological comorbidities.<sup>11</sup>

Current evidence shows not only that adolescents and younger people are more vulnerable to HIV than persons in older age groups invoking an obligation to take action and to take into account age-appropriate HIV related interventions aimed at reducing risk, vulnerability, morbidity, and mortality among this population<sup>12</sup>, but also that young people growing older with HIV face important challenges. Owing to the expansion of effective antiretroviral which is – albeit disproportionately - available worldwide, people are getting older and are ageing with HIV. Moreover people aged over 50 are a growing part of the epidemic and HIV responses need to be adapted to this important demographic trend<sup>13</sup>.

In order to better understand the current specific needs of PLHIV/AIDS and how to contribute to the development of more focused responses for this population, EATG developed a project addressing the challenges and the unmet needs of PLHIV/AIDS in a life cycle perspective (for more info please see Annex 1: Project rationale and background).

## **Description**

The project is run by the European AIDS Treatment Group. The main objective is to identify the gaps in research, treatment, care and retention to care in 3 specific age groups and take the needed steps to address the needs identified. It involves 3 Working Groups: Training and Capacity Building, European Community Advisory Board and Policy Working Group, all 3 of which will implement and further the results of the project. It is divided in 3 phases according to the age groups: +50, children and young people (up to the age of 25) born with HIV (or infected in early age), and people between the age of 25-50 that are living with HIV for more than 10 years. Each phase consists of 2-3 webinars that address the preliminary issues already identified and are specific to the age group.

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<sup>11</sup> UNAIDS. The Gap Report 2014

<sup>12</sup> Idele, P.; Gillespie, A.; Porth, T.; Suzuki, C.; Mahy; Kasedde, S. & Luo, C.. 2014. Epidemiology of HIV and AIDS among Adolescents: Current Status, Inequities, and Data Gaps. *Acquir Immune Defic Syndr*, Volume 66, Supplement 2, 144-153

<sup>13</sup> UNAIDS. Report on the global AIDS epidemic focused on the issue HIV and ageing, 2013

Each phase concludes with a conference for about 75 participants. Participants are from the WHO European Region and links are made to researchers/clinicians and community groups in Europe and USA. (Annex 4) Among the objectives of the project are: To have increased awareness within the patients' community; researchers; healthcare providers and other key stakeholders of the clinical and psychosocial unmet needs of PLHIV/AIDS at different life age stages. To have advocacy needs identified in order to better respond to the varied needs of PLHIV/AIDS and for more focused responses according to different age stages. To be able to contribute to the future development of gold standards of care for PLHIV/AIDS through the production of policy recommendations based on the specific needs identified in each age band.

The project has its own website [www.ageingwithhiv.org](http://www.ageingwithhiv.org) that provides information and resources to all interested individuals. It also includes all the presentations from the conferences and the recordings of the webinars. Finally, community engagement is intensified through the facebook page of the project where members are invited to share content and where there are constant updates about the project and issues that seem to be important to the members. (Annexes 5 & 6)

### **Results of the programme**

The project was aimed as pan-european but reached global coverage. So far the first phase has been concluded and most results are related to that first phase.

- First phase: Webinar 1: 64 participants, Webinar 2: 52 participants, Conference: 96 participants registered to attend.
- Second phase: Webinar 1: 52 participants, Webinar 2: No of participants TBA, Webinar 3: No of participants TBA, 108 participants will attend the conference which will be held in January 2017
- Third phase: Webinar 1: No of participants TBA, Webinar 2: No of participants TBA, Webinar 3: No of participants TBA, Conference: TBA participants

Geographic Coverage of the conference: Europe (as it is defined by WHO) Please see Annex 4  
Website statistics: 15.046 views, 3.810 unique users, for more info please see Annex 5  
Facebook page: 598 likes, post reach 8 669: please see Annex 6

### **Impact of the programme**

The immediate impact of the project is measured by the participation in webinars and the

conference as well as the conference evaluations. Moreover we are monitoring the website and facebook page to measure engagement.

The project so far has managed to create a community of PLHIV +50 and we are confident the next phases will enlarge it engaging other age groups. The project has managed to : give voice to PLHIV, give access to resources and support, improve awareness, and will mobilize action in national/local level (although there is no provision for monitoring that action).

On behalf of EATG healthcare professionals trainings have already started to be implemented as well as funding allocation for future activities as they have been identified by the project so far (see Annex 2 – conference report).

### **Financing and management**

Each phase has an appointed project co-ordinator, a project manager and a Steering Committee/Advisory Group that support the co-ordinator in his/her tasks. All decision making relies with the Chairs and the Executive Director. The project is financed by ViiV Healthcare and Gilead Sciences Inc. to which they have no input to the content and/or development of the program.

### **Lessons learned and recommendations**

The success of the program brought clinicians, researchers, experts and PLHIV together to raise the profile and changing face of HIV, highlighting numerous quality of health factors, alongside the natural ageing challenges such as heart disease, diabetes, arthritic conditions and frailty. The program highlighted the division across health care provision, both within country and across the European region, and the need for multidimensional assessment and engagement in care pathways. It has also demonstrated where people with HIV are valued & essential in the development and delivery of programmes of care with this bottom up model of engagement. The program was designed and implemented by PLHIV, and has identified gaps both in science and policy affecting people ageing with HIV.

The biggest challenge has been to select the conference participants, since places are limited according to funding. Funding was secured to allow for 75 people to attend the conference (including speakers). There were 97 applications received from community members to attend the conference (excluding speakers and other professionals working within HIV and/or ageing). The demand to attend this event far outreached expectations but demonstrates the need and urgency for further work in this area.



The lessons learned: Community is essential for retention to care, treatment and research (scientific and social) as it can identify the gaps and highlights the needs of the people before researchers/clinicians, increasing the efficacy and efficiency while keeping it cost-effective and relevant.

Among the conference outcomes we have identified:

- Promote equal partnerships in care between clinicians and PLHIV
- Equality of PLHIV in care with clinicians to improve ageing, co-morbidities, quality of life and a person centred approach in all areas.
- Specific needs for further research, policy and training developments, please see Annex 2 Conference report.

### **13. SUB-SAHARAN AFRICA**

**(Cameroon, Ghana, Kenya, Malawi, Nigeria, Rwanda, Tanzania, Uganda, Zimbabwe)**

**Title of the programme:** Action to Promote the Legal Empowerment of Women in the Context of HIV

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**Programme is being implemented since:** 2010

**Implemented by:** Civil society

**Scope of Submission:**

- Gender-responsive programmes, in particular for women living with HIV 50+
- Securing women's property and inheritance rights in the context of HIV

**Has the programme been evaluated / assessed ?** Yes

**Is the program part of the implementation of the National AIDS Strategy? N/A**

**Is the program part of the National Plan Broader than the National AIDS Strategy? N/A**

## **Background**

Globally, in 2015 there were an estimated 17.8 million women living with HIV (15 and older), constituting 51 per cent of all adults living with HIV.<sup>14</sup> In 2015, of the total estimated 1.9 million new HIV infections globally, 900,000 or 47 per cent were among women; in sub-Saharan Africa women comprised 56% of new infections.<sup>15</sup> As in many parts of the world, women in sub-Saharan Africa do not enjoy the same rights, privileges, opportunities and access to resources or services as men. Discriminatory laws and customary and traditional practices often limit or deny women's rights to property and inheritance. These inequalities place women at heightened risk of HIV infection, constrain their ability to seek care, support and treatment and undermine their ability to cope with the consequences of illness and to care for themselves and their families.

Women living with HIV are particularly vulnerable to property and inheritance rights violations because of the widespread stigma associated with HIV. They are often stripped of their assets and forcibly evicted from their lands and homes. For some, the dispossession interferes with or precludes their ability to access HIV treatment, care and support. These issues are exacerbated for widows, who are often blamed for the AIDS-related deaths of their husbands.

## **Description**

UN Women's programme, "Action to Promote the Legal Empowerment of Women in the Context of HIV and AIDS", implemented with support from the Foreign Affairs, Trade and Development Canada aimed at the following:

- Increasing the number of legal frameworks and processes that effectively promote and protect women's property and inheritance rights in the context of HIV and AIDS.
- Strengthening the enabling environment for promoting and protecting women's property and inheritance rights at the community level.
- Working with local groups and NGOs to help women living with HIV and AIDS to better claim and advocate for their property and inheritance rights.

From 2010 to 2013, UN Women has awarded \$2.2 million in small grants (of up to \$75,000) to twenty legal service organizations, community-based/grassroots networks, and organizations of women living with HIV in Cameroon, Ghana, Kenya, Malawi, Nigeria, Rwanda, Tanzania,

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<sup>14</sup> UNAIDS estimates, 2016.

<sup>15</sup> Ibid.

Uganda, and Zimbabwe. A second grant was provided to ten organizations who had excelled in implementation.

### **Results of the programme**

The programme achievements included:

- Enhanced knowledge and awareness of more than 3,700 duty bearers at national and local levels and of 29,000 community members on the need to protect women's property and inheritance rights in the context of HIV and AIDS;
- Enhanced knowledge and skills of 900 new and existing community justice and legal service providers, including traditional rulers and law enforcement actors, to support women's access to property and inheritance rights in the context of HIV;
- Increased legal literacy and rights awareness of more than 16,200 women living with or affected by HIV and AIDS through community sensitization, information dissemination and radio programmes;
- Approximately 1,270 property and inheritance-related cases reported to or handled by community paralegals or community dispute resolution mechanisms as a result of increased availability and accessibility of legal services for women living with HIV at community level;
- Improved security of tenure for more than 700 women in Tanzania and Zimbabwe. In Tanzania, more than 400 plots have been awarded to women in six villages. In Zimbabwe, 312 women living with HIV obtained land allocations;
- Over 470 grassroots women and 5,100 children at risk of disinheritance registered and obtained the necessary legal documents, such as birth certificates, death certificates, and identification cards, to secure their property rights through local registration drives organized in Kenya.

\*\*More details about the programme, grantees, beneficiaries, and achievements can be found at the micro- website: [www.genderandaids.org/wpir](http://www.genderandaids.org/wpir)

### **Impact of the programme**

Overall, as a result of the programme implementation, 130,774 people living or affected by HIV in the nine sub-Saharan countries have increased access to information about women's legal, property and inheritance rights. 85% of these beneficiaries were women. There is an increased number of community-level legal frameworks and processes that effectively promote and protect women's property and inheritance rights in the context of HIV and AIDS. Eight grantees made progress towards changing the national-level legal frameworks and legal procedures regarding women's property and inheritance rights in Cameroon, Ghana, Kenya, Nigeria and Zimbabwe.

Five grantee projects directly challenged customary laws, or tried in their activities to enforce legislation protecting women.

A greater understanding achieved among the general – especially male – population of the immediate needs of women in the context of HIV/AIDS and how to address those problems in favour of disadvantaged women. An evidence base has been increased concerning legal empowerment for the targeted women, especially regarding procedures and training for the dimensions of empowerment. The programme was evaluated.

The final evaluation can be downloaded from  
<http://gate.unwomen.org/Evaluation/Details?evaluationId=4755>

### **Financing and management**

UN Women's programme, "Action to Promote the Legal Empowerment of Women in the Context of HIV and AIDS" has been implemented with support from the Foreign Affairs, Trade and Development Canada. UN Women has awarded \$2.2 million in small grants (of up to \$75,000) to twenty legal service organizations, community-based/grassroots networks, and organizations of women living with HIV in Cameroon, Ghana, Kenya, Malawi, Nigeria, Rwanda, Tanzania, Uganda, and Zimbabwe. A second grant was provided to ten organizations who had excelled in implementation.

### **Lessons learned and recommendations**

Key lessons learnt:

- As a body of evidence increases, so does the need for new definitions (e.g. empowerment) and approaches: when the grantee projects started, the focus was on legal empowerment. Over time, the grantees noted that there were many dimensions to empowerment, including economic and social empowerment.
- The process of law reform takes a very long time, and it takes resources to support legal reform.
- Women were not the only target group of the programme; men and children also benefitted.

Recommendations:

- To replicate the programme experience through the new longer-term programme (minimum 5 years), covering more countries in the region.

- In the interest of sustainability, future programme/s should aim at advocating and helping the governments to identify costs and setting up of national spending categories for paralegal services for women living with HIV.
- Ensure the future programme strategies cover all aspects of empowerment (legal, political, social and economic).
- Small grant portfolios in future programme/s should be diversified to provide separate funding for grantees willing to lobby and advocate for national-level changes in laws.

## Overview of Submissions for the 39th PCB Thematic Segment: HIV and Ageing

### I. AFRICAN STATES

#	Country	Title of the programme and submitting organisation	Subject of the Case Study	Comments/ links to background note
1.	<b>Benin</b>	<p>Camp de retraite des jeunes adolescents nés avec le VIH pour le renforcement de l'éducation à la vie</p> <p><a href="#">Hôpital d'Instruction des Armées</a></p>	<p>L'Unité de Prise en charge de l'enfant exposé ou infecté par le VIH (UPEIV) du Service de Pédiatrie de l'Hôpital d'Instruction des Armées de Cotonou au Bénin a été créée en Février 2000 dans la période où le Bénin s'est résolument engagé dans le programme de Prévention de la Transmission Mère-Enfant et de la mise à l'agenda du PNLS du renforcement de la prise en charge pédiatrique.</p> <p>Cette unité dans ses défis à lancer le projet « vivre, survivre et vieillir » avec le VIH en Mai 2007 après une revue de ses acquis qui montrait que l'introduction des sciences sociales et humaines en accompagnement de la clinique faisait réduire drastiquement la morbidité et la mortalité, voyant des perspectives meilleures de vie à ces enfants.</p> <p>Ainsi la vision « vieillir » a vu une déclinaison de différentes stratégies dont l'une consistait à faire des camps de retraite en vue d'engager une vie responsable de ces adultes de demain. L'annonce du statut replonge l'enfant au centre de ses préoccupations de santé et de vie. Le partage d'expérience avec les pairs reste un véritable challenge.</p> <p>Pour documenter cette problématique que nous décrivons ici les défis et bénéfices d'un camp de retraite d'adolescents infectés.</p>	<ul style="list-style-type: none"> <li>• Enfants nés avec le VIH</li> </ul>

2.	<b>South Africa</b>	Putting the `Great White Hope' out to pasture  <a href="#">David Patient Ross</a>	Living and Ageing with HIV	<ul style="list-style-type: none"> <li>● HIV and Ageing</li> <li>● People living with HIV over 50</li> </ul>
3.	<b>Uganda</b>	3. 1 Improving the quality of life of older persons and the people under their care, especially orphans and vulnerable children through livelihood support, advocacy and institutional development  <a href="#">Uganda Network of AIDS Service Organizations (UNASO)</a>	- Help Age International and Uganda Reach the Aged Association (URAA) identified the need to establish HIV Prevention, Care and Treatment advocacy group in 2008 to mitigate the impact of HIV&AIDs among older persons in the country.	<ul style="list-style-type: none"> <li>● People living with HIV over 50</li> <li>● People over 50 at risk of HIV</li> <li>● Advocacy</li> </ul>
		3.2 Ugandan Grandmothers Gathering <a href="#">Stephen Lewis Foundation</a>	<p>-In recent years, the number of grandmothers holding families and communities together has become too big to ignore, and some recognition of their commitment, sacrifice and challenges has begun to impress itself upon the international donor and development communities. Grandmothers are standing up and speaking out.</p> <p>-In October 2015 – just after the International Day of Older Persons, celebrated on October 1 st – almost 500 grandmothers from across Uganda came together for the first ever National Grandmothers' Gathering, to raise national awareness of the issues they face and advocate for recognised rights and increased support.</p>	<ul style="list-style-type: none"> <li>● Women</li> <li>● People living with HIV over 50</li> <li>● People over 50 at risk of HIV</li> <li>● Advocacy</li> </ul>

## II. ASIAN STATES

4.	<b>India</b>	<p>Vihaan Care and Support Programme for People Living with HIV and AIDS.</p> <p><a href="#">India HIV/AIDS Alliance</a></p>	<p>-Alliance India's <u>Vihaan</u> (meaning dawn) care and support program was established under the fourth phase of India's National AIDS Control Programme (NACP), complementing the National ART programme. Vihaan established Care &amp; Support Centres (CSCs), which were linked to the government's ART centres across India, serve as a comprehensive unit for treatment support for retention, adherence, positive living, referral and linkages to services.</p>	<ul style="list-style-type: none"> <li>• People living with HIV</li> <li>• People living with HIV over 50</li> <li>• Children born with HIV</li> <li>• People over 50 at risk of HIV</li> <li>• Men who have sex with men</li> <li>• People who inject drugs</li> <li>• Sex workers</li> <li>• Transgender</li> <li>• Women &amp; Girls</li> <li>• Young people</li> </ul>
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5.	<b>Thailand</b>	<p>5.1) Living Longer with HIV in Asia Pacific</p> <p><a href="#">Asia Pacific Network of PLHIV APN+</a></p>	<p>-This research was undertaken to identify the issues facing PLHIV who are living longer with HIV and primarily those growing older. The intention was to identify the key issues to inform policy and programmes to address the aging PLHIV population in Asia and the Pacific.</p> <p>-This is the ONLY research of its kind undertaken to date, with the research conducted by PLHIV with PLHIV, and under the auspices of the University of Malaya, thus ensuring the validity of the research for a technical, procedural and ethical point of view. It is the only research that examines aging other than in developed countries where the issues can be quite different because of the resource context.</p>	<ul style="list-style-type: none"> <li>• People living with HIV over 50</li> <li>• Children born with HIV</li> <li>• Men who have sex with men</li> <li>• People who inject drugs</li> <li>• Sex workers</li> <li>• Transgender</li> <li>• Women</li> </ul>
		<p>5.2) Seniors fulfill their dream while knowing their rights - Building capacity for promoting older people's rights and income security in Thailand,</p> <p><a href="#">Foundation for Older Persons' Development</a></p>	<p>The project Building capacity for promoting older people's rights and income security in Thailand, in cooperation with the Older People's Group (OPA) in Banthi District, Lamphun Province, organized a volunteer team named "Older People's Rights Promotion Volunteer Team of Banthi".</p> <p>The team's purpose is to promote knowledge about older people's rights and to encourage, monitor, and protect those rights. The volunteer team also works with relevant government agencies in the 10 pilot villages to raise their awareness about the rights to older people</p>	<ul style="list-style-type: none"> <li>• People living with HIV over 50</li> <li>• People over 50 at risk of HIV</li> </ul>

### III. EASTERN EUROPEAN STATES

6.	<b>Poland</b>	<p>“My short Story”</p> <p><a href="#">Wojciech J. Tomczyński</a>  <a href="#">Chairman of Polish Network of PLWHA</a>  <a href="#">"Sieć Plus"</a></p>	<p>Personal Story of a 70 year old man - Getting infected, the turmoil soon after and, later, the light at the end of the tunnel - living 30 years with HIV</p>	<ul style="list-style-type: none"> <li>● People living with HIV</li> <li>● People living with HIV over 50</li> </ul>
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### IV. Latin American and Caribbean States

7.	<b>Brazil</b>	<p>Elderly people living with HIV programme in the Treatment and Training Reference Centre (CRT) of São Paulo state, Brazil</p> <p><a href="#">Centro de Referência em Tratamento (CRT)</a></p>	<p>-In spite of advances in antiretroviral treatment, adverse events and toxicities play a role with regard to dyslipidemia, insulin resistance, demineralization and renal impairment. (Warriner et al, Infect Dis Clin N Am 28 (2014) 457–476). In this context, the elderly people living with HIV programme was created in 2011 as part of the Treatment and Training Reference Centre (CRT) in São Paulo state, located in São Paulo city.</p>	<ul style="list-style-type: none"> <li>● People living with HIV over 50</li> </ul>
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## V. Western European and Other States

8.	<b>Canada</b>	8.1) National Coordinating Committee on HIV and Aging (NCC)  <a href="#">Realize (formerly the Canadian Working Group on HIV and Rehabilitation)</a>	- The NCC attempts to identify common ground and improve access to services that meet the needs of older adults living with and vulnerable to HIV by bringing together stakeholders from different sectors and professional backgrounds, and older adults living with HIV.	<ul style="list-style-type: none"> <li>• People living with HIV over 50</li> <li>• People over 50 at risk of HIV</li> <li>• Advocacy</li> </ul>
		8.2) HIV & Older Adults: Working Together Across Canada <a href="#">Realize (formerly the Canadian Working Group on HIV and Rehabilitation)</a>	- The content introduces learners to the care and support needs and lived experiences of older adults living with and vulnerable to HIV using a blended learning approach.	<ul style="list-style-type: none"> <li>• Awareness-raising</li> <li>• Policy change</li> <li>• Service providers in HIV organizations and agencies serving older adults</li> </ul>
		8.3) Planning for the Long Term: A Psychoeducational Workshop Series for People Aging with HIV  <a href="#">ACT – AIDS Committee of Toronto</a>	Planning for the Long Term (PLT) was created in response to the increasing numbers of people aging with HIV and the concerns these service users were raising with ACT.  <u>PLT seeks to achieve the following:</u>  (a) decreased social isolation among people aging with HIV, including long-term survivors, through group support that connects people to one another; and  (b) increased knowledge about topics related to HIV and aging across physical, emotional, and financial health categories.	<ul style="list-style-type: none"> <li>• People living with HIV over 50</li> <li>• Men who have sex with men</li> <li>• Women</li> </ul>

9.	<b>Finland</b>	<p>Equal retirement project <a href="#">SETA</a></p> <p><u>A video Submission in Finnish</u> <b>'Yhdenvertainen vanhuus- Haluaisin pystyä kertomaan - Risto'</b></p>	<p>Equal Retirement</p> <p><i>- Seta Equal retirement II project (2015-2016) to promote equality for older people and makes gender and sexual orientation diversity visible. The aim is to develop a network of volunteers, which is equivalent to the elderly service the information needs in the field. Network are welcome to rainbow seniors and others interested in the subject. The project is part of RAY's Vivid age -programme (2012-2017), which is implemented in cooperation with the Confederation of Care for the Elderly.</i></p> <p><b>Transcription of Video Submitted</b></p> <p>"I have lived a really happy childhood. Our mother told us as children that none of us was an unwanted child - we were all hoped for and expected. In 1950s' I first time woke up with the feeling that something was not right, and I was somehow broken. I had the first love affair at school, but it was very secret. At some stage I read from books that it is normal. From SETA ("Sexual equality" -an national human rights NGO) I have received support and learned that we are many, and we can all be different, yet we are all accepted. I'd like to be able to one day tell everyone what I am, and what is the "real Risto".</p> <p>My homosexuality alone is one thing I am afraid to tell to anyone, because not everyone would understand it. If they also knew that I was HIV positive, it would be even a greater risk to increase the stigma. HIV medication is a strong part of my life, and I have to take them every</p>	<ul style="list-style-type: none"> <li>• HIV-infected people and their families</li> <li>• Peer support</li> <li>• Advocacy</li> </ul>
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			<p>day. The day I am unable to control my own medication I need help. I hope someone is there to help me. I have lived the time when in the hospital I was totally isolated due to my HIV positivity. When I recently was in a car accident I was surprised how I was not isolated, I was in a room where there were others, just normal patients. When I was recovering among “normal people” I felt wonderful, being treated as anyone else.</p> <p>Stigma no longer forced people to protect themselves unnecessarily from HIV. Let’s see how it is when I will be put into a home for the elderly, and perhaps people around me will not have the same knowledge and understanding. I regret nothing. I have found in myself the wonderful side of being a homosexual, and I have fully accepted it. It is wonderful. The issue of growing old is a fact. We no longer die of AIDS, but because of growing old and ageing normally. With my friends we have talked that it would be wonderful if we had a safe haven, and elderly home, where they could treat us accordingly, even at a stage when we have lesser understanding of things. I wish there was an elderly home that could take into consideration homosexuality and understand it is not an illness, it just is.”</p>	
10.	<b>France</b>	<p>VIH et VIEILLISSEMENT <a href="#">Ministry of Social Affairs and Health</a> <a href="#">France.In France</a></p>	<p>-les personnes âgées vivant avec le VIH sont prises en charge dans le cadre du système mis en place pour les maladies chroniques et le vieillissement.</p>	<ul style="list-style-type: none"> <li>● People living with HIV over 50</li> </ul>

11.	<b>United Kingdom</b>	Health, Wealth and Happiness <a href="#">Terrence Higgins Trust (THT)</a>	<p>- In 2010, when little evidence existed, THT partnered with Age UK and The Joseph Rowntree Foundation and published a report, A National Study of Ageing and HIV (50 Plus), examining the needs and concerns of older people living with HIV (OPLWH) as they age. This showed that older people with HIV can be disadvantaged in a wide range of ways – from poorer health, to social care issues and housing problems and recognised the need for tailored support.</p> <p>-Our project grew from this study to provide the support needed, acknowledging that over 50s are the fastest growing group of people living with HIV.</p>	<ul style="list-style-type: none"> <li>● People living with HIV over 50</li> </ul>
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## VI. MULTIPLE COUNTRIES

12.	<b>Europe</b>	Ageing with HIV, a lifecycle approach <a href="#">European AIDS Treatment Group</a>	<p>-In order to better understand the current specific needs of PLHIV/AIDS and how to contribute to the development of more focused responses for this population, EATG developed a project addressing the challenges and the unmet needs of PLHIV/AIDS in a life cycle perspective.</p>	<ul style="list-style-type: none"> <li>● People living with HIV over 50</li> <li>● Children born with HIV</li> <li>● People over 50 at risk of HIV</li> <li>● Men who have sex with men</li> <li>● People who inject drugs</li> <li>● Transgender</li> <li>● Women &amp; Girls</li> <li>● Young people</li> </ul>
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13.	<b>Sub-Saharan Africa</b> <i>Cameroon Ghana Kenya Malawi, Nigeria Rwanda Tanzania Uganda Zimbabwe</i>	Action to Promote the Legal Empowerment of Women in the Context of HIV  <a href="#">UN Women</a>	Promote and protect women's property and inheritance rights in the context of HIV and AIDS.	<ul style="list-style-type: none"><li>• Women</li><li>• People living with HIV over 50</li></ul>
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