



**Syracuse University**  
Aging Studies Institute

# Policy Brief

## HIV and Aging: Global Implications for Social Care of a Vulnerable Population

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## **Overview of an Aging Epidemic**

In the early 1980s when Human Immunodeficiency Virus (HIV), the cause of Acquired Immune Deficiency Syndrome (AIDS), was first identified, life expectancy following diagnosis was approximately two years (Halkitis, 2013). With the advent of highly-active antiretroviral therapy (HAART) in the mid-1990s, life expectancy for people with HIV (PWH) increased sharply. PWH receiving HAART treatment shortly after diagnosis can now expect to live as long as uninfected individuals (van Sighem, Gras, Reiss, Brinkman, & de Wolf, 2010). As a result the population with HIV is aging. It is estimated that in 2015, 50% of PWH in the U.S. were age 50 and older (U. S. Senate Special Committee on Aging, 2005). However, part of this growth is due to new infections as adults 50 and older account for 17% of annual HIV diagnoses in the U.S. (Centers for Disease Prevention and Control, 2016).

The ageing of the HIV population is being observed globally in high resource countries like Western Europe where HAART therapy is widely available (e.g., Kirwan et al., 2016). However, we are witnessing the same phenomenon in low resource settings like sub-Saharan Africa as access to HAART improves (Hontelez et al., 2012). It is estimated that 13% of HIV-infected adults in sub-Saharan Africa are age 50

and older, comprising 2 to 3 million individuals (Negin et al., 2015); 2 to 3 times the size of the entire U.S. population with HIV. Aging with HIV due to HAART is a success story, but this success brings with it a new set of challenges. Namely, short of a cure for HIV, how can we best address the burgeoning need for social care among this aging population? And how can we address the challenges to providing adequate social care for older PWH in both high and low resource settings?

### **Sources of Data**

Three parallel research efforts provide the evidence base to examine caregiving needs and social care resources among older PWH. High resource settings were assessed in the Research on Older Adults with HIV (ROAH) project studies conducted New York City. (Brennan, Karpiak, Shippy, & Cantor, 2009; Brennan, Karpiak, London, & Seidel, 2010). In order to extend the ROAH project to low resource settings in sub-Saharan Africa to obtain parallel data, we conducted two smaller scale studies in Uganda (Negin et al., 2015) and South Africa (MacPhail et al., 2016). Demographic and selected health characteristics of the three ROAH samples are provided in Table 1. These data provide a unique opportunity to examine and compare the social care needs and resources of older PWH in high and low resource settings.

**Table 1.** Demographic and Health Characteristics of the ROAH Project Samples

Variable	U.S./ New York City		Uganda		South Africa	
	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation
<b>Age</b>	55.5	4.9	61.0	7.8	58.3	6.1
<b>Years Since HIV Diagnosis</b>	12.6	5.3	9.0	5.0	8.0	5.4
<b>Gender</b>	<b>Number</b>	<b>%</b>	<b>Number</b>	<b>%</b>	<b>Number</b>	<b>%</b>
Male	640	70.0	42	41.6	30	27.8
Female	264	28.9	59	58.4	78	72.2
Transgender	10	1.1				
<b>Race/Ethnicity</b>						
Black	455	50.2	101	100.0	97	89.8
Hispanic	299	33.0				
Coloured <sup>a</sup>					8	7.4
Asian/Pacific Islander	5	0.6				
Native American	13	1.4				
White	116	12.8			3	2.8
Multiracial	18	2.0				
<b>Sexual Orientation</b>						
Heterosexual	577	66.5	101	100.0	108	100.0
Gay/Lesbian	206	23.7				
Bisexual	74	8.5				
Other	11	1.3				
<b>Lives Alone</b>	631	69.7	92	91.1	84	77.8
<b>Diagnosed with AIDS</b>	463	51.0	58	59.2	15	14.2
<b>On HAART</b>	777	85.0	99	98.0	106	98.0

Note. US/NYC ROAH (N = 914), Uganda ROAH (N = 101), South Africa ROAH (N = 108).

<sup>a</sup> Coloured is a racial designation used in South Africa for persons of mixed race having Black, White and/or Asian racial backgrounds.

## **Multimorbidity and the Burden of Disease**

The aging PWH population frequently experiences multiple comorbid conditions, or multimorbidity, in addition to HIV infection. HAART is very effective at controlling the HIV virus, and treatment adherent PWH largely attain undetectable HIV viral loads. However, the presence of HIV causes permanent changes to the immune system, similar to the immunosenescence observed in aging individuals in general, and is related to chronic inflammation (Fulop et al., 2017). These immunological changes are presumed to be responsible for multimorbidity in older PWH. Recent studies find that more than half of PWH die from non-AIDS related causes (Antiretroviral Therapy Cohort Collaboration, 2010).

In the ROAH studies, the highest average number of comorbidities in addition to HIV was reported by Ugandans (5.3), followed by the U.S. (3.3), while South Africans reported the fewest average number of comorbidities (1.2). The difference in the average number of comorbidities does not appear related to concurrent immune system functioning, as Ugandans were the least likely to report CD4 t-cell counts of less than 200 (8%), compared to South Africans (12%) or North Americans (17%). Instead, comorbidity appeared to parallel reported AIDS diagnoses. An AIDS diagnosis results from a CD4 counts of 200 or less, or from the presence of opportunistic infections like Kaposi's sarcoma, which indicate the collapse of the immune system. An individual retains an AIDS diagnosis even if CD4 counts rebound and/or opportunistic infections are successfully treated. Older PWH in Uganda and the

U.S. were the most likely to report an AIDS diagnosis (59% and 51%, respectively), whereas only 14% of older adults in South Africa had been diagnosed with AIDS.

In the U.S., the finding of 3 comorbidities on average among older PWH has been replicated in other studies (e.g., Balderson et al., 2013). A recent analysis of the relative burden of disease between older PWH and a non-HIV infected comparator group matched on age, gender, and race/ethnicity finds the former group much more likely to report multimorbidity than the latter (Ambroziak et al., in press). Some have attributed the high level of multimorbidity to accelerated aging. However, this hypothesis has not been supported in an examination of age of incidence of diseases experience by older PWH. Research finds that PWH are not developing diseases at earlier ages than non-HIV infected individuals, rather they are more likely to experience multiple comorbidities, a condition described as accentuated aging (Karpiak & Havlik, 2017). However, regardless of the underlying process, high levels of multimorbidity in populations whose average age is less than 60, portends a high demand for caregiving and other social care resources for aging PWH.

## **Behavioral Health and Psychosocial Issues**

### *Depression*

In the U.S. and Uganda ROAH samples, depression was the most frequently mentioned comorbidity (52%



and 42%, respectively), although no one in South Africa ROAH reported experiencing depression in the past year. However, when we assessed severe levels of depressive symptoms using the Center for Epidemiological Studies Depression Scale (CES-D; Andresen, Malmgren, Carter, & Patrick, 1994; Radloff, 1977), the highest proportions were observed in South Africa (43%) and Uganda (44%), as compared with 25% in the U.S. sample. The failure to self-report depression in the South Africa sample is likely due to societal stigma concerning mental illness in that country (Hugo, Boshoff, Traut, Zungu-Dirwayi, & Stein, 2003). High rates of depressive symptoms in older PWH are a cause for concern, particularly with regard to the impact on physical health in a population with a high burden of disease. Depression has been found to suppress the immune system and is associated with an increased inflammatory response (Kiecolt-Glaser & Glaser, 2002; Tiemeier, Van Tuijl, Hofman, Meijer, Kiliaan, & Breteler, 2002). Among PWH, depression may contribute to neuropsychological impairment or exacerbate cognitive deterioration associated with age-related changes neural functioning (Gibbie et al., 2006). Depression is associated with decrements in functional ability in PWH (O'Cleirigh, Skeer, Mayer, & Safren, 2009). And perhaps most significantly, depression has been implicated in numerous studies as one of the best predictors of HAART nonadherence (e.g., Ammassari et al., 2004; Boarts, Sledjeski, Bogart, & Delahanty, 2006; Horberg et al., 2008).

Grov and colleagues examined depression in the U.S. ROAH sample, and found that in addition to

poorer health-related quality of life, loneliness and HIV stigma significantly increased the odds of severe levels of depressive symptoms (Groh, Golub, Parsons, Brennan, & Karpiak, 2010). In the ROAH Uganda and South Africa samples, we observe a similar pattern of depressive symptoms being significantly correlated with not only levels of multimorbidity ( $r = .50$  and  $.31$ , respectively), but with greater loneliness ( $r = .41$  and  $.23$ , respectively) and HIV stigma ( $r = .41$  and  $.35$ , respectively). Thus, regardless of region, depression among older PWH appears to stem from many of the same issues, some of which may be amenable to intervention. Recently, we tested a telephone-based social support intervention for older PWH with depression that was administered in conjunction with standard mental health treatment. There were significant reductions in depressive symptoms over the six-month study period (Brennan-Ing et al., in press). In examining qualitative data from this intervention, many participants attributed their improvement to feeling supported and connected to others through the weekly phone calls with their care manager.

#### *Use of Alcohol and Other Drugs*

Substance use is another prominent behavioral health concern among PWH given its association with other mental health issues such as depression (Pence, Miller, Whetten, Eron, & Gaynes, 2006), as well as poor adherence to HAART (Chesney, 2000; Ware, Wyatt, & Tugenberg, 2005). In addition, the use of alcohol and other substances is associated with decreased HAART

efficacy (Michel et al., 2010). In the U.S. ROAH sample, lifetime use of alcohol (81%) and other substances (84%) was prevalent. Thirty-eight percent of the U.S. sample reported recently using alcohol, as did 30% of older PWH in Uganda. This compares to 17% of older PWH in South Africa. Current use of other substances was much higher in the U.S. sample (37%), but almost nonexistent in South African or Uganda (2% and 0%, respectively). In the U.S., the most frequently reported substances used were pain killers (38%) and marijuana (23%), which may indicate self-medication for the symptoms of HIV or other health comorbidities.

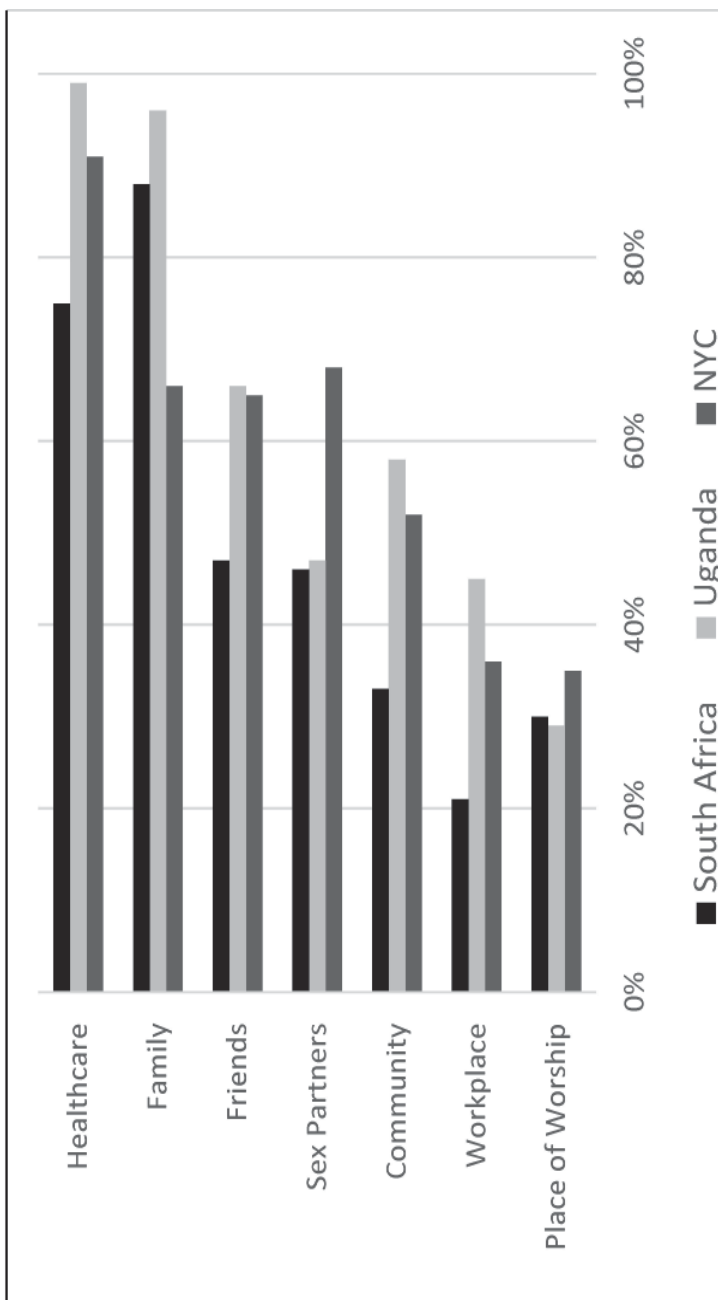
Given the well-documented negative effects of tobacco use on health and the high level of multimorbidity observed among older PWH, tobacco use among this population is also a cause for concern. In the U.S., 57% of the ROAH sample reported using tobacco, followed by 18% of older PWH in South Africa, and 6% of participants in Uganda. These data suggest that targeted smoking cessation programs for older PWH are warranted in order to help reduce the incidence of comorbidities such as cardiac disease and cancer in order to optimize health outcomes for these populations.

### *Stigma*

Although HAART has rendered HIV into a disease that can be treated and managed, it remains a communicable disease and substantial fears and myths concerning HIV transmission persist. HIV stigma

extends beyond the disease itself and includes social taboos around common means of transmission, including same-sex behavior, having multiple sexual partners, and intravenous drug use. Some continue to view HIV infection as a personal failure, and those having HIV as being morally deficient or being punished for their sins (Brennan & Karpiak, 2009). These myths and stigma contribute to continued negative perceptions of those having HIV, leaving many with the virus reluctant to disclose their HIV status to others.

In the ROAH surveys, we asked participants about disclosing their HIV serostatus in a variety of social contexts, including health care settings, with family and friends, in the workplace, etc. (see Figure 1). The patterns across settings was remarkably similar, in that older PWH seemed most likely to disclose to health care providers (75% to nearly 100%), followed by families, and friends. Older PWH in Uganda and South Africa reported greater levels of disclosure to family compared to the U.S. sample, while disclosure to friends was greatest among the U.S. and Ugandan older PWH relative to their South African peers. In the U.S., over 60% disclosed to sex partners, compared to around 40% of respondents in South Africa or Uganda. The least likely settings for disclosing one's HIV status was in the workplace or in places of worship. These data support the notion that people with HIV seek to exert control over the disclosure process, and outside of health care providers, tend to do so with those they feel closer to versus more distant acquaintances. While disclosure of HIV status may result in the



**Figure 1.** Disclosure of HIV Status to at least One Person in Various Social Settings.

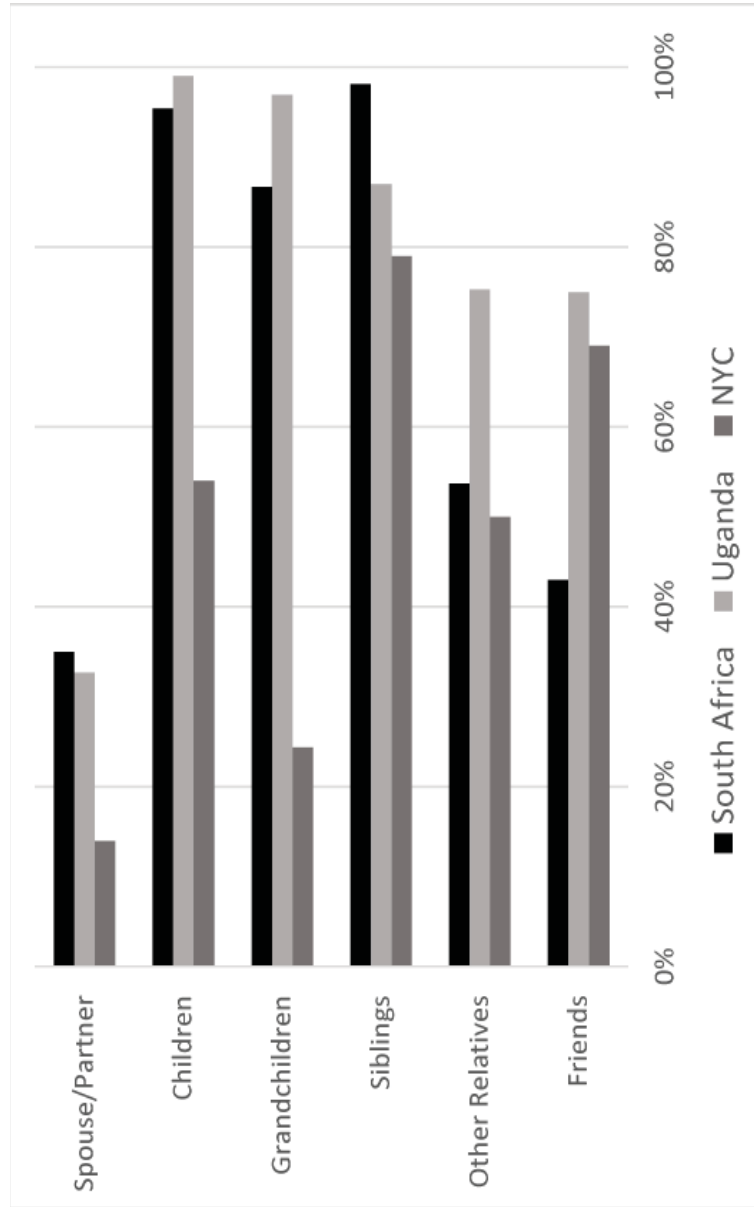
activation of social support resources, it can also lead to rejection, verbal or physical violence, and discrimination, such as loss of employment (Brennan & Karpiak, 2009).

### **Social Supports and Social Care Resources**

In order to face the challenges of aging, many older adults rely on support from family and friends for assistance with day-to-day tasks, emotional and informational support and advice, and caregiving when the need arises (Cantor & Brennan, 2000). According to the AARP, if formal paid help replaced the informal caregiving received from family and friends, the cost in the U.S. would be \$470 billion annually (Reinhard, Feinberg, Choula, & Houser, 2015). Cantor's Hierarchical Compensatory Model of Social Support posits that in times of need, people prefer to access help from close family (i.e., spouses/partners, children), followed by friends, neighbors, and lastly government and community-based forms of assistance in a hierarchical manner (Cantor & Brennan, 2000). People will turn to more distant sources of support when family caregivers are not available or are unable to provide the type of assistance required. Social networks of older PWH in the U.S. have been characterized as fragile, friend-centered and unable to provide the level of caregiving assistance that will be required given the high burden of disease observed in this population (Shippy & Karpiak, 2005a; 2005b). Is this true across all resource settings?

In examining the social support networks across the three ROAH sites, few of these older adults have a spouse or partner available to assist them in times of need (see Figure 2). In the U.S. sample only about 1 in 6 reported having a partner/spouse. In Uganda and South Africa, the proportions were approximately 30% to 35%, but these individuals were almost exclusively men. Given differences in fertility rates and sexual orientation across settings, it was not surprising to find that older PWH in the sub-Saharan Africa samples were much more likely to report having children and grandchildren in their social networks. However, many of these older PWH were caring for their grandchildren (South Africa 40%, Uganda 55%), and more than 80% were either primarily responsible or shared responsibility for their grandchild's care. The proportions reporting siblings or other relatives in their networks were fairly comparable across the three samples, and friends were prominent in the networks of older PWH in Uganda and the U.S.

The ability of social network members to provide caregiving assistance may be limited by these individuals' own health problems, including HIV, and this may temper the seeming advantage that older PWH in South Africa and Uganda have with regard to children and grandchildren. While only 12% of older PWH in the U.S. sample reported having a family member with HIV, this proportion rose to nearly half of those from Uganda and South Africa (46% and 51%, respectively). And while many older PWH in our qualitative studies have said they will rely on friends for caregiving support, 75% of the U.S. sample reported



**Figure 2.** Social Network Composition of Older Adults with HIV.



having a friend with HIV, followed by 68% of South Africans and 36% of Ugandans. Thus, while these social bonds with other PWH may provide a source of assistance, they may in turn create caregiving demands for older PWH who have caregiving needs of their own.

**Help from Family and Friends.**

Older PWH in the three samples were asked about the types of help and support that they receive from both family members and friends (see Table 2). The differences in support patterns of the three

**Table 2.** *Patterns of Assistance from Family and Friends among Older Adults with HIV*

<u>Type of Assistance</u>	<u>Family</u>			<u>Friends</u>		
	<u>South Africa</u> %	<u>Uganda</u> %	<u>U.S./NYC</u> %	<u>South Africa</u> %	<u>Uganda</u> %	<u>U.S./NYC</u> %
Shop/Run Errands	80	53	38	100	57	37
Keep House/Prepare Meals	67	57	32	100	34	24
Take/Drive Places	98	41	30	100	53	32
Communications	96	58	27	100	59	18
Manage Money	100	30	24	100	27	17
Give Advice	99	64	48	100	45	54
Talk when Feeling Low	98	69	63	98	61	68
Talk about Personal Matters	99	65	59	99	41	65

*Note.* South Africa N = 108; Uganda N = 101; U.S./NYC N = 914.

ROAH samples reflect the composition of their social networks, as well as differences in cultural and social norms. These data show that older South African PWH are the most likely to report instrumental assistance (i.e., shop/run errands, keep house/prepare meals, take/drive places, facilitate communications, and manage money) and emotional support (i.e., advice, talking when feeling low or about personal matters) from both family and friends compared to the other two ROAH samples. Older PWH in Uganda receive the next highest levels of support, but are more likely to receive emotional support from family rather than friends. In the U.S. sample, friends were relied upon more than family for emotional support. We should also note that in the U.S. where friends dominate the social networks of older PWH, the amount of help received from friends does not compensate for the lack of family support. This is in line with other studies of older U.S. adults that find the bulk of instrumental support is typically provided by family (Cantor & Brennan, 2000).

#### *Are Older PWH Receiving Sufficient Social Support?*

Older PWH in the ROAH studies were asked about their perceptions of instrumental and emotional support availability and adequacy. Past research has found positive perceptions of social support are associated with better psychological functioning and adaptation (Cohen & Wills, 1985). With regard to instrumental support, less than half of older PWH reported that such help was available all of the time (Uganda 40%,

South African 38%, U.S. 30%). Two-thirds of older PWH in South Africa reported receiving all the instrumental help they need in the past year, compared to 42% of the U.S. sample and 32% of older Ugandans. When asked about emotional support availability, 64% of older Ugandan PWH said such support was available all of the time, in comparison to 47% of the U.S. sample and only 9% of South Africans. However, older South African PWH were the most likely to report receiving all the emotional support they needed in the past year, followed by 45% of older Ugandans and 33% of older PWH in the U.S. These findings show that even among the sub-Saharan African PWH having family-centered social networks that provide considerable levels of support, sizeable proportions feel that the help they need is either not available or inadequate. In comparison, older PWH in the U.S. receive less assistance from their social networks, and less than half report that the support they need is either available or adequate. Although we did not ask about service utilization in the two sub-Saharan African samples, we find that older adults with HIV in the U.S. use three times as many non-HIV/AIDS services on average compared to older adults in general (Brennan-Ing, Seidel, London, Cahill, & Karpiak, 2014). This is consistent with Cantor's Hierarchical Compensatory Model, namely, these older adults with high levels of need for assistance are increasingly accessing formal community-based services because their informal networks of family and friends are unable to meet these needs.

## **Policy Implications**

Given our ability to successfully manage HIV through HAART, providing care and support for the aging PWH population will be the emerging issue in this epidemic in the 21st century. Providing adequate care and support for older PWH faces different challenges in high and low resource settings.

In many high resource settings, government and community-based services for older adults are being stretched following decades of no-growth or reduced funding for health and social service programs that have occurred in the context of an expanding, aging population. Funding for this service sector is not keeping pace with demand, leading to a reduction of available services and the failure to provide services to all of those in need. In this context, it is imperative to explore ways of leveraging existing resources in largely siloed service sectors so that HIV providers can refer their clients to senior services, and vice versa. For this type of networked service structure to be feasible, it is important that we enhance the cultural competence of senior service providers around issues of: HIV infection; lesbian, gay, bisexual and transgender issues; sexual health, and intravenous drug use concerns. For HIV providers, training and gaining competence working with older adults and an understanding of the ageing process is needed. Providers in high resource settings should also utilize existing paradigms for working with older adults, such as geriatric care models, which will allow them to care more effectively for clients with multiple comorbid conditions (Siegler & Singh, 2016).

In low resource settings, such as sub-Saharan Africa, the situation is less complex, but perhaps even more dire. Government and community services are often sorely lacking, and in some instances nonexistent. Services may be concentrated in large urban areas which create access issues for older PWH who do not live close by and must travel long distances to access formal social supports. Many services that are provided in low-resource settings are through faith-based or international organizations. Given the limited resources in these areas, how do we build an adequate service system to meet the needs of an aging population of PWH? To do so will require a concerted and dedicated international effort with investment on the part of high resource nations.

Aging with HIV is creating new challenges for the social care systems of countries in both high and low resource settings. As Dr. Linda Fried, Dean of Columbia University's Mailman School of Public Health, summarized at a conference on HIV and aging in 2010 (AIDS Institute, 2010):

*Public health must end the division of issues into silos of aging, HIV, and other chronic diseases. Providers should take a multi-disciplinary approach to chronic HIV infection, design a new integrated approach to health care and public health, and re-think expectations about health at every age.*

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