Counting carers

How to improve data collection and information on households affected by AIDS and reduce the poverty of carers, people living with HIV and vulnerable children

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HelpAge International
Leading global action on ageing

HelpAge International is a global network of not-for-profit organisations with a mission to work with and for disadvantaged older people worldwide to achieve a lasting improvement in the quality of their lives.

Counting carers: How to improve data collection and information on households affected by AIDS and reduce the poverty of carers, people living with HIV and vulnerable children

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Summary

Counting carers aims to guide governments, NGOs and others working to improve data collection and analysis efforts. It identifies the limits of existing data and suggests how this may be further analysed to produce better information and what future surveys might include.

It draws on research by HelpAge International into the availability of data on households affected by AIDS conducted in 2006. Reducing poverty by supporting caregivers, people living with HIV and vulnerable children requires that national data be collected and disaggregated by age, sex and socio-economic status (SES) particularly in high prevalence nations. Anecdotal reports and qualitative studies show that caregivers are overburdened with responsibilities and that older people and other economically disadvantaged persons provide care to people living with HIV and vulnerable children. However, indicators of health and wellbeing, and measures of income and support, are needed to develop and implement policies and assistance that are based on actual needs and at a level that reduces poverty and helps prevent poor health.

National household surveys collect nationally-representative data that usually fall into two categories: health surveys and economic surveys. Ideally these would be married in order to link essential economic and health data. For example, the Survey on Orphans and other Vulnerable Children in Rural and Urban High Density Zimbabwe 2004/2005 used standard household survey methodologies along with new indicators developed by UNICEF and UNAIDS to provide important insights into the situation of caregivers, vulnerable children and people living with HIV. However, because the data was not fully disaggregated and lacked additional indicators, many important questions remain unanswered.

The key gaps and challenges in data collection and analyses fall into three categories:

- limited analysis and disaggregation of key data by age, sex and household SES
- exclusion of key indicators in surveys, such as measures of care and support, income and expenditure data, and measures of use, access and satisfaction with public sector services
- infrequent data collection in high prevalence areas and lack of longitudinal data.

The analysis and presentation of existing data can and should be improved, in order to help understand the situation of households and reduce poverty. Suggestions include:

- disaggregating data in order to show the household composition, dependency ratios, SES, and the number of working adults in homes of vulnerable children and people living with HIV; and young and older person households by age and sex of the household head;
- assessing the most vulnerable children's health and wellbeing (such as rates of growth failure, schooling, etc.) by the age and economic status of household heads to determine whether children are fairing worse in older-headed households as a result of poverty;
- and collecting new prevalence data to quantify vulnerable households (i.e. child and older person households with vulnerable children and people living with HIV), identify vulnerable communities, and quantify vulnerable children and caregivers for people living with HIV.

Moving forward, future surveys should aim to collect the following data in order to construct the 'ideal' survey:

- household panel data with parental survivorship for all children, whether they are single (one parent has died) or double (both parents have died) orphans and whether they live with a surviving parent
- HIV prevalence data on all ages (18 months+)
- caregiving and income-earning activities
- care and support indicators for vulnerable children and people living with HIV
- external sources of support (all types)
- income and expenditure data
- indicators of access and satisfaction with public services
- community-level indicators, such as social capital
- additional indicators of health and wellbeing for all.

Ultimately, ongoing, longitudinal data is needed in order to understand how the household arrangements of AIDS-affected households are changing and the impact of caregiving on older persons, people living with HIV and vulnerable children.

Recommendations

- Existing data is further analysed to show household composition by age, sex and socio-economic status.
- Future surveys should measure qualitative data: caring roles and support received by households; income and expenditure; and use, access and satisfaction with HIV services.
- Ongoing longitudinal data is needed to understand how arrangements of AIDS affected families are changing and the impact of caregiving on older persons, people living with HIV and vulnerable children.

Counting carers

How to improve data collection and information on households affected by AIDS and reduce the poverty of carers, people living with HIV and vulnerable children

Counting carers aims to guide governments, NGOs and others working to improve data collection and analysis efforts. It identifies the limits of existing data and suggests how this may be further analysed to produce better information and what future surveys might include.

Methodology

This paper draws on research into the availability of data on households affected by HIV and AIDS conducted in 2006. HelpAge International has investigated what data and information is available and what information gaps still need to be filled. In order to do this, the following sources were examined:

- formal and grey (informally published) literature on children affected by HIV and AIDS
- literature on older persons, caregivers and households affected by HIV and AIDS
- national data sets and data from multilateral agencies relating to HIV and AIDS
- interviews with the organisations that collect national data about their current projects and future plans (such as Measure DHS, which collects Demographic Health Surveys; UNICEF, which collects Multiple Indicator Cluster Surveys; and representatives from the HIV/AIDS Survey Database and The African Household Survey Database).

Why improve data and information on households affected by HIV and AIDS?

HIV has far-reaching impacts on the livelihoods of families. HIV and AIDS can cause individuals and entire households to become vulnerable and poorer as families take on greater caregiving responsibilities, meet growing health care costs, and lose economic opportunities.

Older people in particular are increasingly taking responsibility for caring for children and adults living with HIV and AIDS. They do this without recognition or support from policy makers and service providers, because the data and information needed to provide effective responses to the increased vulnerability and poverty older people face as a result of HIV and AIDS is unavailable.

If effective responses are to be found to the HIV pandemic better information is needed on how AIDS impacts on different members of the household and what support is needed.

‘Our grandmother is so wonderful. She helps us in so many ways. She feeds us, dresses us and brings us up properly.’

Catherine, 15, Malawi.

Care giving roles of older women and men

‘Our grandmother is so wonderful. She helps us in so many ways. She feeds us, dresses us and brings us up properly. When we see her, we see our mother. If she were not here, we would have been scattered around other families and would not be treated in the same way. We are so grateful that she is still with us.’

Catherine, 15, the eldest of eight grandchildren being cared for by Irene, 80 years old, in Malawi.

Existing qualitative research describes how older people are bearing the caregiving burden for people living with HIV and orphans and other vulnerable children. Older people are frequently praised for providing care to adult children and grandchildren.

However, research shows that older people disproportionately experience chronic poverty and struggle to meet their own basic needs, especially when they lose the financial support of their adult children and take on responsibility for dependent children.

It is recognised that many older people, particularly older women, absorb the largest share of the care burden when AIDS affects their families and that they fulfil child care, income earning and other responsibilities without adequate support. However, caregivers are not recognized when resources are allocated in responses to the HIV pandemic. This is partly due to the fact that caregiving is still unpaid work and because existing data does not reveal the situation of older caregivers.

The benefits of better data

Fully disaggregating data helps to expose hidden trends, enables the identification of vulnerable populations, helps establish the scope of the problem and makes vulnerable groups more visible to policy makers. Even the simplest data on household SES, together with indicators of health status and children’s schooling, helps governments identify vulnerability. Further disaggregating data would also help governments better prioritise budget allocations, ensuring resources are targeted to those in the greatest need.

Collecting more and richer information on the experiences of vulnerable groups would help policy makers understand the scope of the response that is needed and create effective policies and programmes. For example, data that captures external support to households shows whether families and communities are coping and if government and other services reach families. In addition, data that shows the social and economic impact of HIV and AIDS helps target responses to those in need. The needs of older people vary but commonly include:

- social protection support in the form of regular, predictable, non-means tested, cash transfers such as pensions and child-care grants
- assistance tending fields, setting up small business or finding employment
- home-based care assistance and child-care support.

For example, in the Kalomo District of Zambia, data from donor-funded surveys was fully disaggregated to show the degree and causes of poverty in over one thousand poor households. In the Kalomo District Pilot Social Cash Transfer Scheme, the poorest 10 per cent of households that have high dependency ratios and no able-

bodied worker, receive social welfare assistance. This programme reaches 1,027 households, including older person caregivers. Through evaluation, programme implementers have learned that families use cash transfers to buy basic needs. They also save portions of the transfers and invest in seeds or animals for resale.

Indicators that measure the impact of policies across sub-populations help determine whether policies are implemented and effective, and whether governments are meeting goals and targets.

Improving data collection and analysis benefits governments in many additional ways. For example, with better information, governments can focus their response on the most vulnerable groups, rather than being overwhelmed by entire populations needing assistance. New policies or programmes can be piloted; policy makers can build support and capacity to reach more households until all vulnerable groups are reached. Governments can show bilateral and multilateral partners the issues that they are concerned about and ask for help based on better information.

For example, statistics are crucial in the designing and monitoring of Oportunidades poverty reduction program in Mexico. Cash transfers go to mothers, not fathers, because statistics show that mothers allocate more money to children's health and education. Also girls get larger grants in secondary school, to counter their higher dropout rate. Evaluation showed the program has a positive impact, leading to its extension to urban areas.

The act of improving data collection and analysis helps to fulfill the goals and targets that governments have agreed to, and data that shows support and assistance have reduced household vulnerability, enables governments to demonstrate they have met their obligations.

International commitments on HIV and AIDS, ageing, poverty and statistics

- The UN Declaration of Commitment on HIV/AIDS (2001) commits member states to 'review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, and particularly in their role as caregivers'.

- The Madrid International Plan of Action on Ageing (2002) commits all UN member states to improvement in the assessment of the impact of HIV and AIDS on those caring for infected or surviving family members, and to 'introduce policies to provide support, health care and loans to older caregivers to assist them in meeting the needs of children and grandchildren in accordance with the Millennium Declaration'.

- The Africa Union (AU) Policy Framework and Plan of Action on Ageing (2002) commits AU member states to 'protect the rights and needs of older people affected by HIV/AIDS, including the recognition that older people are the major providers of care for those who are sick and for orphaned grandchildren'.

- The Millennium Development Goals (2000) commit UN member states to halving, by 2015, the number of people living in extreme poverty and halting and reversing the spread of HIV.

- The Marrakech Action Plan for Statistics (2004) sets goals for improving statistical systems to measure poverty.

- The Political Declaration drafted at the UN High Level Meeting on AIDS in 2006

commits member states to address 'the vulnerabilities faced by children affected by and living with HIV, to provide support … to children and their families, women and the elderly, particularly in their role as caregivers'.

How data is collected at national level

Household surveys are the most common method of assessing the situation of households.[1] Survey data is used to monitor health, demographic and economic indicators, for policy and programme development, and for reporting on Millennium Development and other goals.

The HIV/AIDS Survey Indicator Database houses national household surveys with information on HIV and AIDS. The indicators provide insight into behaviours, attitudes and knowledge, and/or HIV prevalence. Currently, there are 183 surveys available in the database, which is at http://www.measuredhs.com/hivdata/start.cfm

Least and middle developed nations frequently rely upon surveys designed by agencies such as the World Bank, UNICEF and the World Health Organization rather than designing their own instruments. The funding for household surveys comes from a variety of sources including government budgets, bilateral and multilateral donors, and private donations. Usually, national statistics offices will administer and analyse survey data, maintaining ownership of the information.

Using standardised surveys provides the potential for drawing cross-national comparisons as well as alleviating countries of having to do complex survey design. However, these international surveys may not adequately collect information relevant to each context and countries may lack the capacity to gather additional information due to technical, financial and methodological factors. Moreover, household survey design may not sample all groups in a population. In some cases, the poorest people living in the most hard-to-reach rural regions are excluded from surveys. Nevertheless, countries often rely upon the collection of one household survey every few years to learn about their people.

National statistics offices generally follow templates to guide what information they publish. Reports usually provide information on demographic shifts in households; the size of the growing orphan population; HIV prevalence by age and sex; and the percentage of vulnerable families who lack assets and are living in poor quality housing.

Some data or findings may not be made public or used to inform policy making for a variety of reasons related to additional cost, the skill level and time capacity of the staff at national statistics offices and supporting agencies and the sensitivity of the data. Most frequently, statistics with one variable (univariate), for example age of head of household, and two variables (bivariate) are presented. But analyses with several variables (multivariate) are the most useful to gaining a deeper understanding of households. In a multivariate analysis the data collected in surveys is analysed in relation to other indicators in the survey and is included in analytical models. For example, rather than using data to show the number of poor families by sex of the household head, data can be used to show poor families by the age and sex of the household head, and the number of dependents in the household. This type of analysis can show the effect of a number of factors on a household's poverty and vulnerability.

Once government reports are released, often one year after data collection concludes, the raw data may be publicly available. The World Bank, UNICEF, UNAIDS, non-governmental organisations (NGOs), and academics may further analyse and publish studies using this data. Table 1 below indicates the major sources of nationally-representative household surveys and the information currently collected.

Table 1: Information currently collected by surveys

Survey (agency involved in design)	Health surveys					Economic surveys		
	Demographic Health Measured Health	Multiple Indicator Cluster (UNICEF)	AIDS Impact Survey	Behavioural Surveillance, Sexual Behaviour	World Health Survey (WHO)	Core Welfare Indicators Questionnaire (World Bank with UNDP and UNICEF)	Income Expenditure	Living Standard Measurement Survey
Orphans aged 0-14 can be identified	X	X	X					
Vulnerable children can be identified	S		X					
Measures of health and/or health behaviours	S	S	X		X			
Health problems and health care needs			X		X	S		
Health System responsiveness					X	X		X
HIV prevalence data	S							
Wealth Index	X	X	X	X	X	X	X	X
Income and Expenditure Data					E	X	X	X
GIS Data	S				X			
Basic information on care needs			X		X			
Caregiving in the home			X		X			

Key: X = data is there in full; S = some data is available or information is available in selected surveys; E = expenditure data only

The limits of current data

Despite current efforts, globally, there are important knowledge gaps in understanding the situation of AIDS-affected households and caregivers. The key gaps and challenges in data collection and analyses fall into three categories:

1. Limited analysis and disaggregation of key data

Not all existing data is analysed. Some of the critically important data from household surveys is not currently analysed. Therefore survey findings are based on averages and the realities facing vulnerable groups are not necessarily revealed. This leaves vulnerable groups invisible and socially excluded, living in poverty and without support.

The situation of families impacted by AIDS may vary widely and vulnerability is based on a range of factors. These factors include the household members' age; sex; health; marital status; household SES (which is based on adults' occupation or employment status, educational level and income); household size; external support; and other household and community level factors. Neither government statistic agencies in their reports, nor academics in research articles, have fully disaggregated data based on these factors.

Although several cross-country studies begin to describe where orphans live, lending some insight into who provides care, these analyses compare the world by regions, rather than fully describing the situation by country or smaller geographical areas. In addition, while studies describe the relationship of orphans to the household head, a complete description of the household composition is overlooked, despite the implications for economic vulnerability.

Another limitation is that some studies provide details on living arrangements for only a portion of youth in the survey, usually limited by age. Moreover, the highest prevalence nations are often not included in analyses. One study focuses on countries where the adult HIV prevalence rate is under 2 per cent, excluding nations where rates are 20-38 per cent. Consequently, within and across countries, the following is still unknown:

- the number of 'skipped-generation' households, where older persons live with children, but without the middle generation (and in these households, the economic status, and age and sex of the household head)
- the number of households where there are large caregiving burdens and only one or few adults to meet household needs
- the average household size and the percentage of older-person headed households where there are high caregiving burdens.

The collection of HIV prevalence data in household surveys is a recent and important advancement in quantifying the epidemic.[2] If this data was more fully used we could better understand affected households and show:

- household composition by SES in affected families
- dependency ratios by household SES and the age and sex of the household head in affected families
- the number of most vulnerable children and people living with HIV or AIDS by

SES of the household, and age and sex of the household head.

Another advancement in household surveys is the collection of geographical information. Households can be digitally enumerated by location so that maps can be drawn to illustrate characteristics of communities and regions. This data can be more fully used to identify vulnerable communities. Maps could illustrate the distribution of overburdened and vulnerable households, vastly improving advocacy efforts and everyone's understanding of the problem.

2. Exclusion of key indicators in surveys

Data collected is limited. The type of data available on affected households is very limited. Without key information on the experiences of vulnerable families, it is difficult to design appropriate policy and programme responses.

Although household surveys provide information on a range of topics, they still lack important indicators, such as the burdens caregivers face, the problems household members encounter and whether families receive assistance. With indicators of health and wellbeing, and measures of income and support, we can target policies and assistance based on actual needs and at a level that reduces poverty and its associated consequences.

For example, while the World Health Survey contains indicators on caregiving for the chronically ill, there is no information on economic support; and the most vulnerable children cannot be identified. Demographic Health Surveys have orphan and HIV prevalence data, but lack caregiving and key economic information. The economic surveys (CWIQ) collect information on who benefits from social and economic policies, but lack a mechanism to identify vulnerable children and households affected by AIDS.

In the health surveys (e.g. DHS, MICS) SES is measured by wealth indices rather than income and expenditure data. Wealth indices are a function of asset ownership and housing characteristics and may not provide insight into the resources needed to get by on a daily basis. In contrast, income and expenditure data directly reveal the resources that households have and use.[3] Ideally, household income and expenditure data would be collected in order to understand household finances and identify vulnerable families. In addition, data on caloric consumption can also be collected and used to estimate food insecurity and vulnerability. These types of information are essential for establishing the minimal supports families need to survive, avoid health problems and keep children in school.

In 2004, new AIDS-related care and support indicators were developed through a collaborative effort on the part of UNICEF, UNAIDS and other organisations. To date, these indicators have been used in a limited number of countries, but additional surveys are in the planning stages.[4] The Survey on Orphans and other Vulnerable Children in Rural and Urban High Density Zimbabwe 2004/2005 used these indicators and standard household survey methodologies to assess affected households. This survey provided key insights, including the following facts:

- 40 per cent of children are categorised as 'Most Vulnerable Children'.
- 10 per cent of households have a chronically ill member.
- 60 per cent of households do not receive support to care for orphans and

vulnerable children.

- 20 per cent to care for people living with HIV.

The survey also provides data on child growth failure, health care access, schooling, psychosocial wellbeing and basic needs, as well as information about the child's relationship to the household head. However, because data is not fully disaggregated and lacks additional indicators, there are still outstanding questions relating to households, with the most vulnerable children and people living with HIV such as:

- How many adults are there in these households and what ages are they?
- How many older person households are there without other adults?
- Who provides care? (health, basic needs, bathing, toileting, emotional, etc.)
- Who earns income? How much? How often?
- What is the SES of affected households?
- What is the geographical distribution of vulnerability?
- Which households receive support? Is support adequate? What are the health and educational outcomes of children in supported households?

The above limitations inhibit a richer analysis of the situation of affected households. Ideally, appropriate questions from all these surveys would be combined to construct an instrument that provides the data required to understand the impact of the HIV pandemic. Such an 'ideal' survey would include the data listed in Table 2 opposite.

Table 2: An 'ideal' survey

What type of data should be collected?	What will it tell us?
Household panel: for each person captures age, sex, highest level of education attained, whether currently in school, work status, occupation	Determine household demographics and SES
For all children, whether mother and father are alive; if they live in the same household; if they have contact with the child, and if living elsewhere, why	Identify1 orphanhood and vulnerable status; reason for parent living away
HIV prevalence data on all ages (18 months+)	Identify affected households and vulnerable children
Details on income-earning activities: number of hours worked per week	Determine work burden, irregular work and unemployment
Details on caregiving; number of caregiving hours per week; types of caregiving activities	Determine who provides care; caregiving burden
Indicators of external support for vulnerable children and people living with HIV including cash, in kind, services and other types of support; who provides what type of support; whether support is adequate and what needs are unmet	Determine the type and adequacy of support; identify unsupported households
Income and expenditure data. Total monthly income from all sources by source and total monthly expenses, especially itemised for care-giving expenses	Determine SES; Identify poverty and resources needed to meet basic needs; and burden of care
Housing characteristics and asset ownership	Determine SES; compare to income and expenditure data to help validate
Indicators of access and satisfaction with public services; details on the types of services that household members use; what services they do not use and why; satisfaction with quality of and access to services; knowledge of existing services;	Determine quality and reach of public sector services; and exclusion from public services
Community-level indicators, such as the types of services that are available, measures of social capital	Determine community assets and community vulnerability
Indicators of wellbeing for all, including caloric consumption, mobility of older caregivers; emotional health of the most vulnerable children	Determine wellbeing or vulnerability of household

The indicators that governments should systematically tabulate:

- indicators which will reveal the situation of caregivers and inform effective responses
- number of affected households (whether household contains person living with HIV or AIDS and/or most vulnerable children), disaggregated by age and sex of household head and household SES
- household composition in affected household (number of children, adults, older persons and dependency ratio); disaggregated by age and sex of household head and household SES
- extent of caregiving burden by household (number of people cared for, type of care and number of hours providing care); disaggregated by age and sex of household head and household SES
- economic activities in affected households (type and frequency of work and number of hours working); disaggregated by age and sex of household head and household SES
- receipt, type, and frequency of external support in affected households (medical, emotional, material and social support) with chronically ill persons and/or vulnerable children; disaggregated by age and sex of household head; household SES; and location of household
- adequacy of external support in affected households; disaggregated by age and sex of household head, household SES and location of household
- self-reported support needs in affected households; disaggregated by age and sex of household head, household SES and location of household
- use of and satisfaction with public services in affected households; disaggregated by age and sex of household head, household SES and location of household
- type, capacity and number of community services and use of services by affected households; disaggregated by age and sex of household head, household SES and location of household
- rate of child growth failure, being out of school, etc. for most vulnerable children; disaggregated by age and sex of household head and household SES
- plot vulnerability spatially.

3. Infrequent data collection

Longitudinal data is collected infrequently. Currently, data is not collected often enough to capture the dynamic nature of the HIV pandemic, in which illness, deaths and mobility change circumstances frequently. With more frequent data collection, policy makers can anticipate and follow trends, averting vulnerability and disaster.

Administered in five-year intervals, national household surveys are scheduled too infrequently to capture the dynamic nature of the HIV pandemic. Much of our existing knowledge is from data collected between 1998-2001, which is inarguably outdated in the highest prevalence nations. New rounds of data collection are underway, but in the meanwhile, policy makers and service providers must rely upon outdated information.

Beyond national surveys, data collection on AIDS and caregiving is sparse. Currently, existing insights into older people and other caregivers in AIDS-affected families are limited to qualitative work from parts of Cambodia, Thailand and Tanzania and a survey from several districts of Botswana. While these studies do provide some rich detail on affected households, findings cannot be generalised outside or even throughout the country of study, nor can they be solely relied upon for policy planning. Nevertheless, smaller surveys and qualitative studies are critical to understanding how to provide adequate and appropriate support. Moreover, participatory methods, where older person and other caregivers are directly included in designing research objectives and data collection, are needed.

The dearth of data at district and local levels most likely stems from the several issues, such as the lack of resources allocated to monitoring, evaluation and research activities. There is also a lack of statistical literacy among many stakeholders and service providers, including NGOs and community-based organisations. NGOs and others that focus on service delivery may easily overlook the importance of data collection at the local level.

Recommendations

Governments, in partnership with researchers and the development community, must strive to collect, analyse and disseminate timely and robust data in order to design programmes and policies that respond to the needs of people affected by AIDS. Improving data collection and analysis is essential to the process of meeting international targets for responding to the HIV pandemic, reducing poverty, improving health and economic development and fulfilling human rights.

Data collection and analysis can and should be improved in order to understand the situation in households and be used as a tool for poverty reduction. In order to reach goals outlined in the UN Declaration of Commitment on HIV/AIDS, the Madrid International Plan of Action on Ageing, the Africa Union Plan of Action on Ageing (2002), the Millennium Development Declaration, The Political Declaration drafted at the UNGASS and the Marrakech Action Plan for Statistics (which sets goals for improving statistics to measure poverty) the following recommendations are provided:

- **Existing data is further analysed to show household composition by age, sex and socio-economic status**

Improving data analyses by disaggregating data and using newly collected prevalence data will quantify the number of vulnerable households and identify vulnerable communities.

- **Future surveys should measure qualitative data: caring roles and support received by households; income and expenditure; and use, access and satisfaction with HIV services**

Developing indicators is a dynamic process that should aim to anticipate, identify and follow trends and vulnerability. For hard to reach, populations qualitative data may provide rich insights. Previously overlooked populations should be targeted and participatory methods should be used.[5]

- **Ongoing longitudinal data is needed to understand how arrangements of AIDS affected families are changing and the impact of caregiving on older persons, people living with HIV and vulnerable children.**

'Good statistics are not just a concern of the international community. Timely and reliable information is needed by governments, businesses, the press, and citizens to make informed decisions'.

The Marrakech Action Plan for Statistics

These actions would provide much needed insight into the social and economic impact of the HIV pandemic in affected households. A more sophisticated understanding would help set agendas and define priorities, foster the further engagement of additional stakeholders, strengthen advocacy efforts, inform evidence-based policy and programme development and facilitate programme and policy evaluation. Ultimately, this information could help create public policies that support families in the most efficient way and prevent negative coping strategies that impact health, survival and economic development.

The responsibility for national data collection mainly falls on governments. However, more and deeper partnerships should be formed among governments, international agencies, bilateral donors, NGOs, academics, activists and other stakeholders, given the formidable task of collecting adequate and accurate information. In addition, service providers, including NGOs, also have a responsibility to assist and undertake data collection at the local level. Evidence-based policymaking that reduces poverty and meets the needs of HIV-affected households, requires improved data collection, analysis and dissemination.

Endnotes

1. For an excellent book describing the power and flexibility of household surveys, including the design, implementation and analyses of surveys, see *Household sample surveys in developing and transition countries,* New York: Department of Economic and Social Affairs Statistics Division, United Nations, 2005.

at http://unstats.un.org/unsd/hhsurveys/pdf/Household_surveys.pdf

2. HIV testing response rates are around 80 per cent. By 2006, prevalence data was available for Botswana, Burkina Faso, Cameroon, Dominican Republic, Gambia, Kenya, Mali, South Africa, Tanzania, Uganda and Zambia.

3. Household income includes salaries, cash transfers, pensions, grants and other donations or income.

4. Additional surveys are in process in the Democratic Republic of the Congo, Cote d'Ivoire, Rwanda, Swaziland, Uganda and Zimbabwe.

5. For more information on participatory research methods see Heslop, M., *Participatory research with older people: a sourcebook*, London: HelpAge International, 2002.

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News and analysis highlighting ageing as a mainstream development issue. Published twice a year for policy makers, programme planners and researchers concerned with development and poverty reduction.
Ageways
Exchanges practical information on ageing and development, particularly good practice developed in the HelpAge International network. Published twice a year for project staff, carers and older people's groups.

Other publications

Making cash count: Lessons from cash transfer schemes in east and southern Africa for supporting the most vulnerable children and households (2005)
This study was conducted as part of a UNICEF-commissioned review of social-protection measures reaching the increasing numbers of vulnerable children in east and southern Africa.

Coping with love: Older people and HIV/AIDS in Thailand (2005)
This report presents the findings of research carried out in northern Thailand. It highlights the issues faced by older people affected by HIV/AIDS, the contributions they are making to their households, and the lack of services and support available to them.

The cost of love: Older people and the fight against AIDS in Tanzania (2004)
This report presents the key issues facing older women and men affected by HIV/AIDS in Tanzania, including their role in providing care and support to their sons and daughters living with HIV/AIDS and to their grandchildren. It draws on participatory research with older people, community leaders, government officials and young people in five regions of Tanzania.

Building blocks: Africa-wide briefing notes: supporting older carers (2004)
These briefing notes are based on discussions at a HelpAge International and International HIV/AIDS Alliance workshop in Kenya on the situation of older carers of orphans and vulnerable children. They explain why programmes designed to support orphans and vulnerable children need to pay more attention to the needs of the older people who care for them.

Forgotten families: Older people as carers of orphans and vulnerable children (2004)
This report by HelpAge International and the International HIV/AIDS Alliance is motivated by a shared understanding of the role of older carers in supporting orphans and vulnerable children, and a recognition of the economic and social importance of this relationship in combating poverty and HIV/AIDS.

All these publications are available from:

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